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Legal Capacity
in International Human Rights Law

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Chapter 1: Introduction

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

Thomas Hammarberg, Commissioner for Human Rights of the Council of Europe, 2012

1. Outline

This introductory chapter sets out the historical and philosophical context in which the research leading to this book has been conducted and how the research developed. It lays out the purpose and significance of the work, the problems that it seeks to address and a roadmap through the various chapters. The scope and delimitations of the study are then established and the chapter ends by offering definitions of the terms 'legal capacity' and 'mental disability' which appear multiple times throughout the book.

The book sets out an analysis of how the law is used as a means to remove decision-making rights from people with mental disabilities, and how international law can be used to repatriate people's rights. Since Roman times, the law has allowed judicial officers to label people as 'insane' and incapable to make rational decisions. Their decision-making rights are handed over to someone else, henceforth a 'guardian', and a range of their rights – to decide where to live, to freedom of expression, to marry, to vote – are removed.

Article 12 of the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD) establishes a 'right to recognition everywhere as persons before the law', a construct through which the law can recognise and validate the decisions and transactions that a person makes. The Convention recognises that laws should respect people's will and preferences, and to provide access to supports where needed.

This book critiques the ways in which international human rights mechanisms are adjusting their jurisprudence to take this newly-articulated right into account. This is law that matters. In liberal democracies we value our ability to author our own lives. Without the legal authority to do this, people remain in the margins of societies, and that has been the case for people with mental disabilities for several centuries.

2. Context

The legal device of guardianship has its roots in three Roman law doctrines.[1] First, guardianship was a mechanism to benefit other people, not the person under guardianship: if an 'insane person' was to inherit property, a guardian was to be appointed, and if there was none, the person's relatives had to take charge of his property.[2] Second, insane people were equated with children, based on the assumption that both were incapable of making decisions: a person who had not reached the age of puberty could not inherit; his nearest agnate was to obtain guardianship.[3] And third, it is bad to defraud a person under guardianship. A wrongdoer was instructed to pay back double the amount and was to be viewed as "infamous" (infamia). This means that the censor – the officer responsible for public morals – would render informal damage to the wrongdoer's reputation, a serious punishment, as the person

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[1] For a summary of a connection, see Charles P. Sherman, "Debt of the Modern Law of Guardianship to Roman Law", Michigan Law Review, Vol. 12, 1 January 1913.

[2] Law VII of Table V of the VII Tables: 'When no guardian has been appointed for an insane person, or a spendthrift, his nearest agnates, or if there are none, his other relatives, must take charge of his property.'

[3] Law VI of Table V of the VII Tables: 'When the head of a family dies intestate, and leaves a proper heir who has not reached the age of puberty, his nearest agnate shall obtain the guardianship.'

would be disqualified for certain rights in public and in private law such as being a witness in a trial.[4]

Viewed through the lens of contemporary international human rights law, these three tenants of Roman law are unhelpfully embedded in many legal systems. Perhaps a more generous reading is to translate the doctrines into something altogether more positive. People with mental disabilities may need the rest of society to do something different – but not necessarily put people under guardianship. We recognise that people whose capacities or functioning are somehow impaired are particularly vulnerable to abuse – but we need not equate them to children. And there is something particularly pugnacious about ill-treating a person more vulnerable than the wrong-doer – even if nowadays a jail term may seem more appropriate than declaring someone as infamous.

This book is not an examination of Roman law and does not seek to trace the aetiology of contemporary laws and policies. Understanding the historical root of the problem can, however, help explain the commitment that legal systems have to categorising a certain group of people as 'incompetent'.

What is wrong with such legal systems? First, the process of placing someone under guardianship and keeping them in that category seems to violate principles which are now established under international human rights law. The opinion of one doctor is needed, sometimes not even an independent doctor or a doctor with a particular medical background being required. The person whose legal capacity is being questioned is not always invited to attend court or is otherwise heard. No counter evidence is presented, and the medical evidence is not probed. The person need not be informed of the proceedings or the court's decision. Second, the consequences of placing someone under guardianship are often severe, unjust and unnecessary. As a result of being placed under guardianship, the law assumes that the person is completely incompetent in all areas,[5] and that the guardian will take all decisions in the

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[4] A. H. J. Greenidge, *Infamia, its Place in Roman Public and Private Law,* 1894.

[5] This is what is known as plenary or total guardianship. Some jurisdictions – such as Spain, Hungary and Argentina – have a system whereby a judge can decide to restrict

person's best interests, so the guardian can decide to place the person in a far-away institution, can block court proceedings if the person wants to review their guardianship status, can block a complaint against himself, without the performance of the guardian being regularly assessed.

People under guardianship are prohibited from working – their signatures are invalid (they are, after all, invalids) or are placed in sheltered workshops where their skills are not developed and they do not earn a proper income. Even the right to vote is removed, plunging the person under guardianship into political invisibility and making it more difficult to make progress on more substantive rights if a politician can look at someone and think that they are a political nothing.

Guardianship strips people of their autonomy and other rights, without any legal or moral justification, in a process lacking fair trial rights or other safeguards, with the result that a person is at elevated risk of exploitation, violence and abuse, with all routes to access to justice blocked.

Formally, my argument proceeds as follows. Evidence suggests that plenary guardianship affects many thousands of people, restricts rights, rather than prevents abuses and is never needed, as there are always alternatives. It could be said that such a regime is so disproportionate to its aims and so arbitrarily applied, that it lacks the character of law. Society should therefore change the system into something more just, in line with human rights law and principles.[6]

The Universal Declaration of Human Rights establishes that rights must be underpinned by the rule of law.[7] It is my contention throughout the book that guardianship regimes are unjust in fundamental terms of the rule of law. Put another way, legal constructs that remove rights from people identified by

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legal capacity in certain areas of the person's legal remit: such as financial decisions, medical decisions or the right to vote.

[6] These ideas were first presented in my speech 'Guardianship litigation: resisting casual positivism' to the 2nd World Congress on Adult Guardianship, Melbourne, Australia, 15 October 2012.

[7] Universal Declaration of Human Rights, 1948, Preamble, 'Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law.'

others as incapable have the appearance of solid laws, but the logic of their architecture starts to look shaky when examined closely, as this book seeks to demonstrate.

Examining the texture of legal capacity laws reveals more at play than just protecting people with disabilities, the stated aim of modern guardianship laws. These laws have advanced since Roman times when it the stated aim was the other way around: protecting the family's wealth from the insane person. There are local interests involved, family disputes, corruption in the medical profession, inadequacy of social benefits systems, laziness of lawyers, disablism, sanism: prejudices of families as well as professionals. The result is that the person with a mental disability becomes 'the other', the abnormal ruled on by the normal hegemony. This book takes as a starting point that there is no such thing as the other. The nineteenth century French poet Jean Nicholas Arthur Rimbaud wrote, 'Je est un autre'.[8] Labelling people as 'other' makes us vulnerable to being so labelled ourselves.

Ultimately the contention of this book is that the consequences of being labelled as incompetent are so far-reaching and severe that the legal construction which allows the majority to label the minority in this way must change. Guardianship strips away all of their decision-making rights of persons labelled as incompetent. It removes people's personhood and part of that which makes them human: their authority to take decisions and forge their own way through life, their right to participate in their own lives but also in their/our democracies. There are alternatives to systems of guardianship, and many of these alternatives are outlined in chapter 2.

A system of commands that is so top down, so disproportionate to its (often non-stated) aims and so brutal in its effect cannot reasonably be said to be oriented to the public good. As such, from the standpoint of the rule of law, societies should reject such a system as unjust and not adequate enough to form part of the rule of law. This book aims to contribute to the global understanding of the development of a new legal framework within which

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[8] 'Je est un autre', Jean Rimbaud, Letter to Georges Izambard, 13 May 1871.

people labelled with mental disabilities can enjoy the rights to equality and justice on an equal basis with others.

3. Background to the research

Allow me to slip, for this section, into the first person. When she could not find a child-minder to look after me during the long summer holidays, my mother took me to her workplace. This was an inconvenience to her because she practiced as a psychiatrist and worked in Brentry Hospital, an institution where people with intellectual disabilities lived.

Founded in 1898 as a 'Certified Inebriate Reformatory', Brentry rebranded in 1922 as an institution for adults with intellectual disabilities. Its new purpose was to 'to occupy the patients as much as possible'.[9] As a child I would try to do that too: I spent entire days in the occupational therapy department playing computer games with the 'patients' (they were not actually ill). There was a lot of hanging around: games in those days took at least ten minutes to load with a cassette. That was nothing to the amount of time the residents had to hang around being occupied 'as much as possible'. My mother sometimes took me around the wards. One ward was called Shakespeare ward and I remember seeing people sat in chairs lined up against a wall, rocking back and forth. 'Is that because they have disability?' I remember asking.

'No, that's because they have nothing to do', said my mother, 'because they live in an institution'. She spent much of her time reducing sedatives and other medications prescribed by other doctors, and diagnosing medical issues that general practitioners had overlooked.[10] She got people to do activities and over time evacuated people into the community. Thanks to her and many other people's efforts, the institution closed in 2000,[11] and its ex-patients were

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[9] J. Jancar, 'The History of Mental Handicap in Bristol and Bath', *Psychiatric Bulletin* 1987, 11:261-264, p.262.

[10] Many doctors attribute the symptoms of a person with intellectual disability to their intellectual disability (for example a person behaving in a more agitated way is thought to be explained by their autism, not for example a stomach ulcer). This means illnesses go undiagnosed and untreated, impacting on the person's right to health.

[11] First published in 'Interview with Oliver Lewis', *Human Rights Brief*, Volume 19, Issue 2 (Winter 2012), p. 30.

provided with housing and community based supports. They developed skills to make their own decisions and staff provided them with the supports they needed.

Little did I appreciate it as a child, but what I was seeing was the link between legal capacity and the right to live in the community, between being given the authority to author our own lives and deciding where and with whom to live and what sort of supports we need to do that. This is one of the central themes of this book.

Fast forward a couple of decades, and after qualifying as a barrister in the UK, I joined the Mental Disability Advocacy Centre at its inception in Hungary in 2002. We decided to get a sense of what the key issues are across central and eastern Europe so during that year I travelled to the ten countries that were scheduled to accede to the European Union. We carried out site visits to community centres (where they existed) mental health institutions, children's institutions and euphemistically-named 'social care homes', which could be mega-institutions of 700 beds where the concepts of socialisation, care and home were mostly completely absent. In each country we then facilitated a two-day training session on the European Convention on Human Rights (ECHR) as it applied to people with mental health issues and intellectual disabilities. Participants at these seminars included human rights lawyers where we could find them, mental health service user organisations, people from intellectual disability organisations, people who worked in ombudsperson offices and some mental health professionals. In many of these countries our seminars were, according to the participants, the first ever fora that discussed the problems of people with mental health problems or intellectual disabilities in human rights terms.

To help us with the content of the seminars, in May 2002 British lawyer Oliver Thorold and I wrote a training pack on the ECHR Rights which dealt sought to provide participants with the basics of how the Convention interfaced with mental disability law issues. There were two appendices: the standards of the European Committee for the Prevention of Torture, and the UN's 1991 Mental Illness Principles. We wrote about various provisions of the Convention providing for the rights to life, to freedom from ill-treatment, to liberty, to privacy and correspondence: all of these areas were firmly attached to a particular Convention provision. The final section of the training pack dealt with guardianship. It was two a mere pages long and began as follows:

> *The lives of thousands of people in the central and eastern Europe are affected in a fundamental way by the system of guardianship. Regulated by Civil Codes largely unchanged since Soviet times, guardianship attracts a low priority for legislators pressed by the international community to reform more visible areas of the legal system. Guardianship remains largely unmonitored whilst people under guardianship are locked away and forgotten: their very status preventing them from complaining. Human rights abuses may pervade the entire system: from judicial enquiry into incapacity, appointment of guardian, guardian's powers, oversight of the guardian and review of necessity of guardianship.*

The section introduced the possibility these legal measures of protection could actually be human rights violations in themselves, as well as create a string of other violations. Few other people had framed guardianship in this way and we got some strange looks from participants during the seminars: isn't guardianship a good thing? The guardianship chapter did not refer to ECHR cases because we could not find any. At that time the UN Convention on the Rights of Persons with Disabilities was no more than a sparkle in the international legal community's eye,[12] and I had barely heard about this initiative and had no idea that the resultant text would have anything to say about guardianship. What we did have at that time was a Council of Europe Recommendation from 1999, a seemingly-progressive document which hardly anyone had heard of. We dutifully promoted in our training seminars (and it is analysed in Chapter 2 of this book).[13]

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[12] The UN General Assembly adopted Resolution 56/186 calling for a disability convention on 19 December 2001.

[13] This is section is adapted from my unpublished paper 'How can strategic litigation play a role in nudging States towards legal capacity utopia?' delivered on 13 November 2009 at the American University, Washington DC.

4. Purpose of the book

The primary research questions of this book are:

> *1. What are the human rights consequences of guardianship laws?*
>
> *2. To what extent does international human rights law recognise the right to legal capacity of people with mental disabilities?*

These research questions speak to both theoretical and operational issues of international human rights law. There is a need for both an analytical evidence-base of why guardianship regimes are bad, and a robust defence of alternatives to guardianship being a right. Without these, international law will have difficulty in demanding (pushing) or persuading (pulling) domestic governments and the judiciary to move from a legal system where substituted decision-making (guardianship) is the default, to one which provides support for people to author their own lives (which can safely be characterised as necessary in order to comply with recent developments in international human rights law).

A number of different sources have been used to answer the first question. Much of the material drawn on in this book comes from first-hand testimony. The book does not present empirical research conducted by the author but instead a legal analysis of existing material has been carried out. Many of the 'stories' about people's lives come from court cases which are analysed in chapters 3, 5 and 6. The book uses standard legal analysis to compare provisions of international law against the requirements of the UN Convention on the Rights of Persons with Disabilities, the CRPD.

It is the CRPD - in particular Article 12 - which forms the lens through which the second question is answered. The CRPD is the high-water mark of international law in this field, albeit one which policy-makers, judges and academics are still struggling to interpret. The CRPD and its interpretation by the UN Committee on the Rights of Persons with Disabilities, as well as the

European standards, all provide normative constraints on how things should be done, and they form the sources of this book's critique.

The CRPD sets out three essential elements of the right to legal capacity. First, that everyone with any sort or severity of disability, including a mental health issue however defined, has a right to legal capacity. This is located in Article 12(2) of the CRPD and means that the law must respect a person's right to decide. Second, the CRPD is not naïve and does not say anywhere that everyone has the mental capacity (or ability or talents) to decide on all areas of their life at all times in their life. It does, however, place a new obligation in Article 12(3) on States to provide supports which are necessary should a person with a disability require such assistance in order to exercise their legal capacity. Forms of support vary, depending on the individual's capabilities and needs, and are touched on in chapter 2 of the book. And thirdly, by lifting the shackles of legal constraint, the CRPD does not intend a free-for-all. In Article 12(4) and Article 16 it sets out a detailed range of safeguards to prevent all forms of exploitation, violence and abuse. The line between autonomy and abuse may be operationally fuzzy, but the norm is clearer now than before the CRPD was adopted. These elements are what any analyst is going to look for in a new legal capacity law, and will be dealt with throughout this book.

In deploying a theoretical analysis of international human rights law, the book seeks to offer some practical advice to those who are in positions of power to effectuate positive changes in people's lives and thus to improve the human condition. This is especially the case in chapters 2 with respect to international and domestic policy-makers, chapters 5 and 6 with respect to judges and lawyers, chapter 8 with respect to healthcare professionals and chapter 9 with respect to inspectors of hospitals and care homes.

The chapters of the book are located within the context of rather fast-moving developments in international law. The case-law of the European Court of Human Rights in the last decade has established, for example, that it is unlawful to remove the right to vote from people under guardianship en masse,[14] that it is contrary to human rights for a legal system to permit a

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[14] *Kiss v. Hungary*. See Chapter 5.

guardian to authorise the detention of someone in a psychiatric hospital,[15] and that it is impermissible to have a guardianship system which removes someone from their home and transfers them against their will to an institution where they have to spend several years.[16]

During the same time period, the treaty body established by the UN Convention on the Rights of Persons with Disabilities has started working, and has been producing its interpretations of the treaty by way of fourteen concluding observations and two general comments (at the time this book was finished in March 2015).[17] The Agency for Fundamental Rights of the European Union has been concerned also with the ways in which the UN Convention is being implemented,[18] as has the Council of Europe, whose Commissioner for Human Rights has said that governments need to abolish laws which incapacitate people, and must review their legislation to bring it in line with the UN Convention.[19] As well as these policy developments, some academics are trying to figure out what a new system could look like,[20] and policy-makers in several jurisdictions are carrying out pilot projects of supported decision-making, to replace systems where people's decisions are substituted by someone else's.[21]

This is a book comprising nine chapters including the introduction and conclusion, six of which have been published either in law journals or as book chapters. The intended audiences of these publications have been policy-makers, lawyers, civil society activists, and healthcare professionals to enable them to understand the international law binding on their countries and therefore their practice. The works have sought to clarify the legal obligations

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[15] *Shtukaturov v. Russia*. See Chapter 5.

[16] *Stanev v. Bulgaria*. See Chapter 6.

[17] These are examined in Chapter 2.

[18] EU Agency for Fundamental Rights, 'Legal capacity of persons with intellectual disabilities and persons with mental health problems', Vienna, July 2013. See Chapter 2.

[19] Thomas Hammarberg (2012) Issue Paper: 'Who Gets to Decide? Right to legal capacity for persons with psychosocial disabilities and intellectual disabilities'. Strasbourg. See Chapter 2.

[20] For example, Bach, M. and Kerzner, L. (2010) *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*.

[21] See for example, Margaret Wallace, 'Evaluation of the Supported Decision Making Project of the Office of the Public Advocate of South Australia', November 2012, available on the Public Advocate's website. Other pilot projects are taking place in countries as diverse as Bulgaria, Columbia and Zambia.

that these professionals are supposed to work within and provide analysis and tools to assist them in their work.

5. Scope and delimitations

The body of the book analyses the development of international human rights law and the treatment of legal capacity by human rights mechanisms and associated other fields, such as medical law and ethics and the global anti-torture framework. Legal capacity is a subject which can be examined from various perspectives including psychiatry, cognitive psychology, neuroscience, anthropology, social policy, economics and political science. The book does not venture into any of those areas. Instead, it digs deeper into international human rights law, with a view that the overall work and each of its parts would be a more interesting and useful contribution, rather than writing a collection of inevitably inexpert overviews.

Legal capacity is a subject that extends into many areas of law and life. It is relevant for inheritance matters, and for determining culpability in criminal law. Capacity to consent to euthanasia is a topic of societal importance in several jurisdictions, the Netherlands in particular. Private international law is relevant too in handling cross-border arrangements under the Hague Convention. These are all topics as fascinating as they are worthy of study but they all fall outside the scope of this book.

The book looks at the lived reality of people with disabilities from various countries and examines how international law deals with these realities. It does not set out an analysis of any particular country's laws or policies and nor does it report the results of any qualitative study about the lives of people under guardianship at the grassroots. Where the book lays out the human effect on guardianship, the facts are taken from reported judgments and reports from entities such as non-governmental organisations.

Current regimes of guardianship and their consequences will be examined in the book when they arise in case-law and under examination of States by UN mechanisms. The book makes the case that the legal and social devaluation of people deemed insane or incompetent (some laws use more polite words) are unjust and unnecessarily pervade many aspects of a person's life. A blueprint for utopic implementation of the right to legal capacity is beyond the scope of the book, as is any analysis of pilot projects taking place in various jurisdictions.

The book seeks to accomplish a critique of the present. It is hoped that the already-published chapters are a small contribution that assist and inspire others build a more just future.

Roadmap

The book is divided into three blocks. Chapter 1 serves as an introduction and is folowed by Block 1 (chapters 2, 3 and 4). These chapters examine the substantive content of the right to legal capacity and how it is situated within the architecture of international human rights law. Block two (chapters 5 and 6) examines the role of the judiciary and analyses the key jurisprudence on the right to legal capacity. Finally, block three (chapters 7 and 8) delves into two areas that are impacted by legal capacity: medical law and ethics, and the international framework on torture prevention.

Block one

Legal capacity has undergone a steady evolution in international human rights law, so much so that some commentators characterise the evolution as a revolution.[22] Chapters 2, 3 and 4 set out how historically international legal standards have dealt with legal capacity and explain the radically different vision of legal capacity in the UN Convention on the Rights of Persons with Disabilities (CRPD).

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[22] Gerard Quinn, "Rethinking Personhood: New Directions in Legal Capacity Law and Policy", delivered at a seminar at the University of British Columbia, Vancouver, Canada, 29 April 2011.

Chapter 2 sets out how legal capacity has emerged within international human rights law. It summarises the history of legal capacity and associated concepts, plotting the development from a status-based approach (is there a mental disorder?), through an outcomes approach (how good is the decision?) to a functional approach (how good is the decision-making process?). It suggests that even the functional approach – lauded by a Recommendation of the Committee of Ministers of the Council of Europe in 1999 – could come under critique when compared with the requirements of the CRPD.

The chapter sets out a complete panoply of utterances on legal capacity by international human rights bodies. It goes though in detail the approach to legal capacity articulated in Article 12 of the CRPD and. The CRPD is now the global legal capacity hub and its relevant provisions are examined in detail. The chapter explains how substituted decision-making systems of guardianship are incompatibe with the CRPD. It analyses how the text encourages law reform to create systems based on autonomous decision-making plus supports that a person may need in order to forge their way through life. It argues that the most significant threat in international law to the roll-out of CRPD-compliant laws, namely the interpretative declarations and reservations which nine States have entered on Article 12 of the CRPD. The chapter argues that many of these reservations may be unlawful according to established public international law.

Chapter 3 is a chapter from the book “Mental Disablity and the European Convention on Human Rights”, published in the Martinus Nijhof series which I co-authored with Peter Bartlett and Oliver Thorold in 2007.[23] It analyses Article 6 (right to a fair trial) and Article 8 (right to respect for privacy, home, family and correspondence) of the European Convention on Human Rights and argues that guardianship regimes may well fall foul of these provisions and should be taken more seriously by domestic courts and the European Court of Human Rights alike. The chapter quotes the then UN Secretary General in 2003 who said that the purpose of guardianship is to protect

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[23] With Peter Bartlett and Oliver Thorold, “Legal Capacity, Guardianship and Supported Decision-Making”, Peter Bartlett, Oliver Lewis and Oliver Thorold, *Mental Disability and the European Convention on the Rights of Persons with Disabilities*, Martinus Nijhof Publishing, 2007, pp. 149-177.

people, and that societies must "prevent improper recourse to, and use of, guardianship arrangements".[24] In the post-CRPD world, a UN Secretary General would likely not seek to legitimise guardianship regimes (as Chapter 5 demonstrates).

Fast-forwarding to the post-CRPD era, Chapter 4 was published in a book about rights and mental health in 2010.[25] It zooms out to look at why the CRPD exists, how it progresses the human rights project, and how it is relevant to mental health laws. It suggests that the CRPD embodies the expressive role of human rights by encouraging actors to rethink assumptions, evaluate positions and shift existing concepts or paradigms. It reviews the independent mechanisms at international and domestic levels and how the participation of people with disabilities themselves is guaranteed.

Block two

Chapters 5 and 6 examine the ways in which courts have grappled with the right to legal capacity. Chapter 5 is a journal article published in 2011 in the peer-reviewed journal European Human Rights Law Review,[26] and is the first analysis in the post-CRPD era of how courts have dealt with the challenge of implementing the right to legal capacity. It drills down into how it is that cases get to courts in the first place, and lays out some of the benefits of strategic litigation as an advocacy technique to highlight the otherwise largely invisible plight of people with mental disabilities.

Looking at the existing case-law and the targets of any future legal challenges, the chapter suggests three clusters of litigation to bulldozing the barriers to the life-world. First, chipping away at the guardianship edifice includes cases which seek to demonstrate the incompatibility with international law of

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[24] UN Secretary General, "Progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities - Report of the Secretary-General" [A/58/181], 24 July 2003

[25] "The Expressive, Educational and Proactive Roles of Human Rights: An Analysis of the United Nations Convention on the Rights of Persons with Disabilities", in Bernadette McSherry and Penelope Waller (eds), *Rethinking Rights-Based Mental Health Laws*, 2010, Hart Publishing, Oxford, pp. 97-128.

[26] Oliver Lewis, "Advancing Legal Capacity Jurisprudence", *European Human Rights Law Review*, 2011, 6, 700-714.

plenary guardianship regimes which have a series of fault-lines (such as appointment of the guardian behind the person's back, insufficiently clear statutory basis for filing an application to restrict legal capacity, low quality of evidence required to restrict legal capacity, guardianship in proceedings where the person has received no or inadequate notification, appointment of guardian who has a conflict of interest, ineffective appeal mechanism to challenge the guardianship, ineffective procedure for the adult to challenge appointment of the guardian, and lack of procedure for applying to regain full legal capacity.

The second cluster contains those cases which seek to decouple legal capacity from subsequent losses of human rights such as the right to marry, to vote, to decide on finances and so on. The third cluster of cases encourage the State to set up alternatives to guardianship, and it is this cluster which globally is under-litigated simply because the alternatives of guardianship are comparatively new and the present focus is on policy-making rather than litigation.

The chapter sets out those provisions of the European Convention on Human Rights which can be deployed in the above clusters of litigation. It then analyses the existing (in 2011) case-law in these areas. These are the right to fair trial under Article 6 of the ECHR and the right to privacy under Article 8.

Chapter 6 was written a year later. It was commissioned by the *Human Rights Brief*, a journal of Washington School of Law at American University, Washington DC.[27] It is an extended case-summary of the European Court of Human Rights judgment of *Stanev v. Bulgaria*, a case which I was involved in bringing. *Stanev* is one of the most important disability cases for a generation. It is the first case in which the Court found a violation of the right to liberty (Article 5 of the ECHR) of someone who had been placed under guardianship and transferred to a residential institution against his will, and the first disability case in which the Court found a violation of the absolute right to be free from degrading treatment (Article 3 of the ECHR). Chapter 5 arged that

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[27] "*Stanev v. Bulgaria*: On the Pathway to Freedom", *Human Rights Brief*, Vol. 19, Issue 2, 2012.

Article 8 of the ECHR would be an important provision for the Court to use in any case which challenges guardianship regimes. This is exactly the provision which the Court failed to look into, and which the two dissenting opinions in *Stanev* point out. Commentators' disappointment with the *Stanev* bench on the Article 8 point led to some research on how the Court has thus far integrated the CRPD into its judgments.

Block three

Chapters 7 and 8 examine two domains of law where legal capacity has real-life implications. Chapter 7 is a book chapter co-authored with Aart Hendriks in which we attempt to layer medical law and ethics onto disability.[28] It sets out the relevant legal and ethical theory, and explores the rights, principles and issues most prominent for the interrelationship between disability on the one hand and medical law and ethics on the other. The chapter discusses the various meanings of the term "disability" (all of which are problematic in their own ways), and the way this concept was finally defined in the CRPD. It outlines the problems flowing from human rights standards for the right to health in theory, and for healthcare professionals in practice. It offers some policy and practice suggestions for these bodies.

Chapter 8 is a co-authored paper published in the *International Journal of Human Rights* in 2012.[29] It is the first paper in a special edition on torture and disability that I co-edited. The chapter returns to a central theme of this book explored particularly in chapters 2, 5 and 6, namely the nexus between legal capacity and institutionalisation. It reviews the existing knowledge base on human rights situation inside institutions, and focuses on the forms of abuse and neglect which constitute violations of human rights. The chapter specifies as a problem that torture prevention mechanisms established by international law have tended to focus on prisons and police stations to the detriment of people in psychiatric and social care institutions. The implications of this, the

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[28] Aart Hendriks and Oliver Lewis, "Disability" in *Routledge Handbook of Medical Law and Ethics*, eds. Bartha Maria Knoppers and Yann Joly, 2014.

[29] With Dorottya Karsay, "Disability, Torture and Ill-treatment: Taking Stock and Ending Abuses", *International Journal of Human Rights*, Vol. 16, No. 6, August 2012, 816–830.

chapter points out, are not only that people with mental disabilities exposed to torture and ill-treatment carried out with impunity, but the monitoring bodies established at the domestic level are sent the unfortunate message by their international superior body that the rights of a person in a mental health institution matters less than the rights of a person in a prison. Whether

Finally, the conclusions are in Chapter 9. There is universal agreement, at least at the inter-governmental level, both about how legal capacity sits at the core of the 'paradigm shift' which the CRPD seeks to usher in. There is also agreement about the need for action at legislative, policy and service delivery levels. Despite this, the content of Article 12 of the CRPD is a matter of significant contention both in interpretation and thus in roll-out. The conclusion pulls together the learning from the book and offers some thoughts for the primary stakeholders in legal capacity laws around the world. It also points out the limitations of the study and offers thoughts around a future research agenda.

The chapter sets out the limitations of the research, and some pointers for future research. It also extrapolates some policy implications for governments, human rights litigators, international human rights mechanisms and mental health professionals. The chapter ends by suggesting that a way to narrow the gap between human rights rhetoric and lived reality is to encourage critical conversations: between diplomats, between lawyers and judges, between parliamentarians, and between civil society and governments. Open discussions can help put flesh on high-level principles. Ultimately, the conclusion chapter suggests notwithstanding the fact that the human rights framework does not set out operational detail, its value is in establishing a global vision of respect for diversity, the obligation to recognise autonomy and to provide access to support. Crucially, the human rights framework gives people a way to raise their concerns when things go wrong.

6. Definition of Terms

Two terms crop up multiple times in this book and would benefit from a definition: ‘legal capacity’ and ‘mental disability’.

Legal capacity

This phrase appears four times in Article 12 of the UN Convention on the Rights of Persons with Disabilities and in no other provisions. Article 12 establishes the obligation on States Parties inter alia to ensure that each person with disabilities has the right to legal capacity, and that people have access to supports to exercise it. The Convention offers no definition of legal capacity or supports. My definition is that legal capacity is ‘a construct which enables law to recognise and validate the decisions and transactions that a person makes’.[30]

Mental disability

The UN Convention on the Rights of Persons with Disabilities offers a definition of ‘persons with disabilities’ in Article 1. The convention says that they, ‘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.’ The Convention defines none of these terms further.

‘Mental disability’ in this book is not how the the word ‘mental’ is used by the Convetion. Rather, it is rather ugly umbrella term to mean people with intellectual, developmental, cognitive, and/or psychosocial disabilities. The chapters of the book are not concerned with the precise medical diagnoses which people are labelled with, but rather the human rights of those labels, and the interaction of society with those labels. Without buying into the medical approach, I offer this definition:[31]

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[30] See chapter 5 at p. 700.

[31] This definition is used by the non-governmental organisation, which I direct, the Mental Disability Advocacy Center.

People with intellectual disabilities generally have greater difficulty than most people with intellectual and adaptive functioning due to a long-term condition that is present at birth or before the age of eighteen. Developmental disability includes intellectual disability, and also people identified as having developmental challenges including cerebral palsy, autism spectrum disorder and fetal alcohol spectrum disorder. Cognitive disability refers to difficulties with learning and processing information and can be associated with acquired brain injury, stroke, dementias including Alzheimer's disease.

People with psychosocial disabilities[32] are those who experience mental health issues or mental illness, and/or who identify as mental health consumers, users of mental health services, survivors of psychiatry, or mad.

These are not mutually exclusive groups. Many people with intellectual, developmental or cognitive disabilities also identify or are identified as having psychosocial disabilities.

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[32] This term does not appear in the UN Convention on the Rights of Persons with Disabilities, but is used in documents produced by the UN Committee on the Rights of Persons with Disabilities.

BLOCK ONE

Chapter 2: The Development in International Law of Legal Capacity of People with Mental Disabilities

1. Introduction

Legal capacity, in broad terms, is the law's recognition of the decisions that a person makes. Without legal recognition, a person's decisions have no legal effect or validity. The impact of denying a person their legal capacity therefore has the potential to effect a wide range of areas of legal life – deciding where and with whom to live, property ownership and financial affairs, voting and political office, marriage and parenthood, employment and training, and all sorts of ordinarily routine contractual exchanges such as making a bank deposit or paying a telephone bill. Removing a person's legal capacity may also affect that person's authority to access justice to challenge wrongs, or even have a say in the decisions that are being made on that person's behalf.

The purpose of this extended chapter is to set out how legal capacity has evolved under international law, and has become established as a human right.[33] The scope of this chapter excludes jurisprudence under the European

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[33] I wrote much of this chapter – particularly sections 4 and 5 – for a report which was commissioned by the European Union Agency for Fundamental Rights (FRA), to myself and Professor Anna Lawson of the University of Leeds, UK. We submitted our report to FRA in June 2011 and it comprised four sections, two of which I drafted and two which Professor Lawson drafted. I was the main author of the part of the report on which this chapter is built. FRA eventually published parts of the report that we submitted in its July 2013 report 'Legal capacity of persons with intellectual disabilities and persons with mental health problems' but much of our material was edited out. I have

Convention on Human Rights as that is covered elsewhere.[34] Also excluded are the Inter-American and African regional human rights systems, for reasons of manageability and because it is the global and European systems which the most material to examine.

Specifically, in section 2, this chapter examines the approach to legal capacity taken by the international community through the prism of the high-water mark, namely the UN Convention on the Rights of Persons with Disabilities (CRPD). The chapter explains some of history of legal capacity and associated concepts. The chapter examines Article 12 of the CRPD in detail, as this is where the Convention sets out its provisions on legal capacity. It examines the controversies of substituted decision-making systems of guardianship (where one person's decision is substituted for another person's) versus supported decision-making, and asks whether systems of substitution can survive in the post-CRPD era. The UN Committee on the Rights of Persons with Disabilities, the committee established under the CRPD with a view to assist States-Parties with the correct implementation of the CRPD, is clearly calling for States to abandon systems of substitution and replace them with systems based on autonomous decision-making, making no distinction for people with various types of disabilities (intellectual disabilities or mental health issues) or the intensity of the impairment. This is set out in section 3(A). The Committee outlines a concept of supported decision-making, a cluster of different things which States are obliged to provide people who need such supports to have their will and preferences respected and acted upon. The clarity of the Committee's recommendations comes under significant scrutiny, as the Committee is one of the key actors to set out guidance for States on how to go about implementing Article 12 of the CRPD. In particular, the fourteen sets of concluding observations that the CRPD Committee has issued thus far are analysed through the lens of legal capacity, as is its first General Comment, which focuses on legal capacity.

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significantly added to the scope and depth of the report, including the analysis of the CRPD Committee, the reservations and interpretative declarations, and the European Union. The law is, to the best of my knowledge, correct as at 1 October 2014.

[34] Analysis of this jurisprudence is provided in chapters 3, 5 and 6 of this book.

Statements relating to legal capacity from the UN Human Rights Committee and the Committee on Economic, Social and Cultural Rights are examined in sections 3(B) and (C) respectively. Perhaps the greatest legal threat to the implementation of Article 12 of the CRPD are the reservations which nine States have entered on Article 12 of the CRPD when ratifying the Convention. Section 3(D) of the chapter examines whether these reservations are unlawful under established public international law.

Section 4 of the chapter sets out the major political statements which have touched on the right to legal capacity for people with disabilities from Council of Europe bodies. This includes the 1999 Recommendation of the Committee of Ministers of the Council of Europe, which represents a high-water mark of the pre-CRPD era. The Council of Europe Commissioner for Human Rights has published several statements on legal capacity, and these are analysed. Section 5 reviews the rather limited attention that the institutions of the European Union have given to legal capacity: on the one hand necessarily limited due to the few competences the EU has in this field, but on the other hand perhaps because the Commission has taken an overly narrow approach to its competencies and at the same time over-promised the actions it can take, as set out in the EU Disability Strategy 2010-2020. The EU Agency for Fundamental Rights was established to monitor EU institutions, and its work on legal capacity is examined in this section too. Section 6 sets out a conclusion which is critical of the overly purist approach of the CRPD Committee, and the normative and human risks of setting too high a water-mark for implementation.

2. Conceptual Issues

A. Context and Underlying Principles

Historically there have been two dominant approaches to legal capacity.[35] The first, a status-based approach, takes a medical diagnosis of a psychiatric or

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[35] For more on the approaches, see Dhanda, A. (2007) ‘Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future’, 34 *Syracuse J*

cognitive impairment as the basis for removing legal capacity entirely. The second, an outcome-based approach, is based on assessments of the quality of the result of a person's decision and scrutiny of the decision-making process. The approach works backwards from the outcome of the particular decision and, based on outcomes regarded as irrational, inappropriate or otherwise deemed not in the best interests of the person concerned, assumes an underlying inability to make 'good' decisions, judged from the perspective of other people. It thus seeks to prevent what others regard as bad, irrational or incompetent decision outcomes being given effect and seeks to protect the adult in question – and society at large – from the consequences of such decisions.

Parliaments and international policy-makers have, as this chapter sets out, largely rejected these approaches over the last few decades as they have made efforts to recognise the rights of people whose abilities and judgment calls may differ from others. A milestone towards rejecting these approaches in the European region was the adoption in 1999 by the Committee of Ministers of the Council of Europe of Recommendation No. R(99)4 on 'principles concerning the legal protection of incapable adults'.[36] This document rejected the former approaches and heralded a third approach that can be labelled the functional approach. In this approach, decision-making ability is assessed along two planes: point in time and type of decision.

With regard to point in time, the functional approach recognises that a person's ability to make decisions can fluctuate throughout life, with many factors having an impact (for example, temporary brain injury following a road traffic accident, drinking too much alcohol, being in a phase of mania. Another example of how capacity can fluctuate is in degenerative disease related to ageing (for example Alzheimer's disease) or unrelated to ageing (for example Parkinson's disease), which pose significant challenges to policy-makers to put in place mechanisms for a person to plan for a future point at

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Int'l L & Com, 429, and Keys, M (2009) 'Legal Capacity Law Reform in Europe: An Urgent Challenge', in Quinn, G. and Waddington, L. (eds) *European Yearbook of Disability Law*, Intersentia.

[36] Committee of Ministers of the Council of Europe (1999), Recommendation No. R(99)4E on principles concerning the legal protection of incapable adults, adopted on 23 February 1999.

which they may be unable to make autonomous decisions. A person's decision-making ability also depends on the type of decision to be made. A person may be able to understand and manage information relating to a decision about whether to fill a decayed tooth but may not be able to understand or manage information relating to a decision about whether to undergo heart surgery or continue with medication. A person may be able to understand how to buy a loaf of bread, but not how to buy an apartment. The fact that a person needs assistance with some things but not others is, of course, not specific to mental disability, or indeed any type of disability.

A person's ability to make a particular type of decision may not, therefore, influence their ability in other areas. They may, for example, need assistance in healthcare decisions but not need any support in daily living decisions (how to go shopping, which friends to meet etc). Further, a person who currently lacks the ability to make certain types of decision unassisted may over time develop the capacity to do so as they (re)gain the ability to appreciate and understand the possible consequences of those decisions. This might depend on all sorts of factors such as the existence of a circle of friends and trusted individuals, the quality of social support services, the cycle of a mental health problem and the effectiveness of treatment and rehabilitation.

The functional approach differs from the status-based and outcome-based approaches because, unlike them, it does not label a person as wholly incapacitated or incompetent. It recognises the need to establish safeguards to minimise the number of people subject to their decisions being taken by others (known as 'substituted decision-making'); the length of time for which a person is subject to such a measure; and the potential for abuse. Generally, the emphasis is on ensuring that the least restrictive arrangement is put in place.

Domestic laws may not fall neatly into any one of these approaches, and trace elements of paternalism can be found in the functional approach too. As a result of centuries of laws based on paternalism and protectionism (rather than autonomy and support), law oftentimes removes the authority to make particular decisions or whole categories of decisions (e.g. finances or health) from a person with mental disabilities and grants the power to make these decisions to a substitute decision-maker, often termed a 'guardian'.[37] Guardianship laws assume that the person with disabilities (or society or both) should be protected from the consequences of their bad decisions and the law therefore prevents them from making those decisions by declaring such decisions 'null and void' concerned. Protection against bad consequences are far broader than that allowed in Article 16 of the CRPD, which specifies that people with disabilities should be protected against exploitation, violence and abuse. The likely reason for this is that the CRPD rejects the notion that people with disabilities need to be protected from their own decisions: the very first principle of the Convention is '[r]espect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'.[38]

The status, outcome and functional approaches all rely on the convergence of medicine and law. A psychiatric opinion enables a judge to deprive a person of the authority to make legally-effective decisions, usually having as a consequence that authority is granted to another person with or without the consent of the person concerned. This has led the functional approach to come under increasing scrutiny for at least three reasons, which will be explained in turn.

First, the functional approach embraces the notion of protection (of society, against the person's decisions deemed bad decisions by others, as noted above), but fails adequately to protect relevant individuals from exploitation, violence and abuse. As noted, Article 16 of the CRPD details the steps that States must take in order to protect people with disabilities from these phenomena. In some instances the guardianship system is mis-used with the very intention of exploiting the 'protected' person. This is evidenced by several

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[37] As noted in chapter 1 of this book, Roman law had two types of guardian: tutors and curators. These terms still exist in some Latin-speaking countries, such as Romania.

[38] The CRPD's principles are examined in more detail in chapter 4 of this book.

reports examining the effectiveness of safeguards,[39] and by cases decided by domestic courts and by the European Court of Human Rights.[40]

Second, the functional approach assumes that legal capacity equates to legal independence. This equation is based on the assumption that in order to maintain one's legal capacity, one has to make decisions independently, without any communicational or other supports from other people or through an adapted decision-making process in which, for instance, standard means of presenting information are altered so as to reflect the particular circumstances of the individual in question. Furthermore, the assessment of functional capacity is telescoped into the notion of legal capacity, and its main criterion is the ability of the individual to act as an atomistic being. That is to say, the assessment looks into the person's decision-making ability alone, a falsehood given that most human beings make decisions in cooperation with others, and decisions are often influenced by and dependent on culture, values and social networks.

Third, the functional approach fails to augment a person's ability over time so that substituted decision-making becomes unnecessary. The guardian generally makes decisions based on the 'best interests' approach, without making decisions which build a person's ability over time to make supported or legally independent decisions. Canadian disability rights scholar Michael Bach suggests adapting Amartya Sen's capability approach and using it as a basis for policy development on legal capacity.[41] Bach posits that equality in decision-making requires States to ensure that each person has access to the support they may need to maximise their particular abilities in expressing their will and intent, and to understand and appreciate the nature and

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[39] See Mental Disability Advocacy Center (2008) *Guardianship and Human Rights in Bulgaria*, *Guardianship and Human Rights in Czech Republic*, and *Guardianship and Human Rights in Hungary*.

[40] The judgment of the European Court of Human Rights in the case of *Stanev v. Bulgaria* (Application No. 36760/06, admissibility decision of June 29, 2010, judgment 17 January 2012) is a good example: see chapter 6 of this book. Also, see *Shtukaturov v. Russia*, Application No. 44009/05, judgment on the merits 27 March 2008, judgment on just satisfaction 4 March 2010; *Salontaji-Drobnjak v. Serbia*, Application No. 36500/05, judgment 13 October 2009, both discussed in chapter 5 of this book.

[41] See, for example, Sen, A (1993) 'Capability and Well-Being' in Nussbaum, M. and Sen, A. (eds) *The Quality of Life*, Oxford Clarendon Press; and Sen, A. (2009) *The Idea of Justice*, Harvard University Press.

consequences of a particular decision.[42] Such supports may take a variety of forms. For some people it might take the form of information in plain or easy-to-read language. For others it might take the form of a support person communicating a person's decisions to others (e.g. a bank clerk) when those others are not able to understand the supported person's way of communicating. In the healthcare field, supports include technologies and people to help the person understand the relevant information, providing information in various formats, and allowing the person to make an advance directives to set out future intent. Models of supported decision-making are heterogeneous and many are already in operation: an analysis is beyond the scope of this chapter, and book.[43]

B. Scoping out supported decision-making

Several authors are busy building the philosophical, legal and practical implications of supported decision-making. Michael Bach zeros in on how supports can take place via a network model which encompasses three types of support to which everyone who needs them should have access: (a) Assistance in decision making takes three forms (including communication support perhaps using assistive technologies), interpretation of the person's communication (b) helping the person to express their will and preferences and assert an opinion and (c) helping to communicate the 'personal identity – a person's hopes, expectations, life plan'.[44]

Bach suggests that the CRPD opens up supported decision-making as a 'new alternative in the range of legally authorized decision making statuses',[45] a

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[42] Bach, M. and Kerzner, L. (2010) *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*, at http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner.

[43] Fiona Morrissey, 'The United Nations Convention on the Rights of Persons with Disabilities: A New Approach to Decision-Making in Mental Health Law', *European Journal of Health Law* 19 (2012) 423-440

[44] Michael Bach, 'Supported Decision Making under Article 12 of the UN Convention on the Rights of Persons with Disabilities: Questions and Challenges', presentation to Conference on Legal Capacity and Supported Decision Making, Parents' Committee of Inclusion Ireland, 3 November, 2007.

[45] Ibid, p. 17. Bach fleshes this out in the context of Ontario, with Lana Kerzner in 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity', available at http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner-partII-sectionIII.

useful addition to the status of legally independent decision-making (the status which houses most people in the world) and substituted decision-making such as guardianship which the international norms are moving away from, as this chapter explains in sections 3 and 4 below. Bach would retain a status/category beyond supported decision-making called facilitated decision-making for people whose will and preferences are unknown (and currently unknowable through all the best supports, technologies and effort) receive more intensive supports while their legal capacity remains intact. This formulation has sparked introspection by legal academics in several parts of the world, with one US professor analysing the guardianship laws in various States in that country and concluding that through 'respecting the individual's right and ability to make decisions, supported decision making significantly limits the stigmatization and marginalization caused by guardianship, and more fully integrates individuals with psychosocial disabilities into social, political and economic life'.[46]

Some commentators champion a system in which these 'hard cases' are rolled into the supported decision-making category.[47] Some propose one hundred per cent support for people in a coma, a proposition that is 'stretching fictions beyond the point of credulity', according to Quinn.[48] A minority of academic commentators propose that guardianship systems can survive post-CRPD.[49] It has been pointed out that '[e]ven articles that provide extensive discussions of the benefits and potential drawbacks of supported or co-decision-making provide little or no empirical support for their claims',[50] a slightly misplaced critique, given that authors in the field are collectively trying to map out a plan

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[46] Leslie Salzman, 'Guardianship for Persons with Mental Illness - A Legal and Appropriate Alternative?' 4 St. Louis U. J. Health L. & Pol'y 279 2010-2011, at p. 328.

[47] See Tina Minkowitz (2006–2007) 'The United Nations Convention on the Rights of Persons with Disabilities and the Right to Be Free from Nonconsensual Psychiatric Interventions'. *Syracuse Journal of International Law and Commerce* 34: 405; and Eilionoir Flynn and Anna Arstein-Kerslake (2014) 'Legislating personhood: realising the right to support in exercising legal capacity' *International Journal of Law in Context*, 10, pp 81-104.

[48] Gerard Quinn, 'Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD', HPOD Conference, Harvard Law School, 20 February 2010.

[49] Mary Keys, 'Legal Capacity Law Reform in Europe: An Urgent Challenge' in Gerard Quinn and Lisa Waddington (eds), *European Yearbook of Disability Law*: Volume 1 (Intersentia, Hart Publishing 2009) 71.

[50] Nina A. Kohn, Jeremy A. Blumenthal, Amy T. Campbell, 'Supported Decision-Making: A Viable Alternative to Guardianship?', *Penn State Law Review*, Vol. 117:4, 1111-1157 at 1129.

for the future, and the widely-shared acceptance that this is a new field, so there is inevitably going to be a lack of data in developed and low-income countries.[51]

The next section of this chapter sets out how the CRPD frames legal capacity. Some authors claim that the CRPD is 'instrumental to personhood'[52] while others use the CRPD to form a "conception of personhood that is divorced from cognition".[53]

Over the past five years there has been a growing – albeit tiny – academic literature on what supported decision-making should mean in theory and how it can be rolled out in practice. I would argue that much of this has been prompted by civil society organisations, including the nongovernmental organisation which I direct: in 2006-8 the Mental Disability Advocacy Center carried out desk-based and empirical research into guardianship systems and used a human rights based approach in framing the analysis.[54] We established that many of these systems did not meet basic norms of international law, and we used the maybe somewhat provocative term 'civil death' to describe the status of a person under guardianship in the jurisdictions in question and to emphasise the need to bring about change.[55] The reports pointed out for the first time that there was a fundamental problem in how the law stripped away people's rights.[56] This analysis led to officials from the World Health Organization and others[57] to call on governments to reform their legal

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[51] Soumitra Pathare, Laura S. Shields, 'Supported Decision-Making for Persons with Mental Illness: A Review', *Public Health Reviews*, Vol. 34, No 2.

[52] Quinn (2010) op cit.

[53] Eilionoir Flynn and Anna Arstein-Kerslake (2014), op cit.

[54] Mental Disability Advocacy Center, 'Guardianship and Human Rights in Russia: Analysis of Guardianship Law and Policy'. MDAC published similar reports with respect to Bulgaria, Czech Republic Georgia, , Hungry, Kyrgyzstan, Russia and Serbia.

[55] Michael L. Perlin, '"Striking for the Guardians and Protectors of the Mind": The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law', *Penn State Law Review*, Vol. 117:4, 1159 at p. 1162.

[56] 'In parts of Eastern Europe, mentally ill kept under wraps', article in the *International Herald Tribune*, 22 December 2008: '"We call it civil death," said Victoria Lee of the MDAC. "Once you are under guardianship, that's it. You basically become a non-person."'

[57] I was one of the authors.

capacity laws, within a wider analysis of how to reverse the inequalities of people with mental health issues around the world.[58]

Legal capacity was not identified as a topic which needed reforming in the study commissioned by the UN which promoted diplomats to consider negotiating a disability treaty.[59] That said, co-author of that study Gerard Quinn has been active since 2010 writing about legal capacity. He observes how the text contains a 'constructive ambiguity' with regard to how legal capacity should be played out.[60] The ambiguity is not necessarily a bad thing: it was necessary to enable negotiating States to agree on the text of the treaty: better to have a Convention with some ambiguous parts than to have no Convention at all.

While some authors have unpacked how legal capacity almost repatriates the human into disability rights field,[61] others have zeroed in on how Article 12 contributes to the advancement of moral philosophy by giving an account of the theory of justice. Recognising that 'some people with cognitive disability may always be dependent on others for the support necessary to make decisions and exercise legal capacity',[62] Anna Arstein-Kerslake argues for an inclusive approach to moral philosophy whereby we construct a sort of cognitive prosthesis to decision-making Building on the work of philosophers Anita Silvers and Leslie Pickering Francis, Arstein-Kerslake suggests prosthesis model of supported decision-making which attributes the results of

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[58] Natalie Drew, Michelle Funk, Stephen Tang, Jagannath Lamichhane, Elena Chávez, Sylvester Katontoka, Soumitra Pathare, Oliver Lewis, Lawrence Gostin, Benedetto Saraceno, 'Human rights violations of people with mental and psychosocial disabilities: an unresolved global crisis', *The Lancet*, Published online, 17 October 2011, DOI:10.1016/S0140-6736(11)61458-X

[59] Gerard Quinn and Theresia Degener , *The current use and future potential of United Nations human rights instruments in the context of disability*, UN, 2002.

[60] Gerard Quinn, 'Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD', HPOD Conference, Harvard Law School, 20 February 2010. More on the ambiguity in section 3(A) on the CRPD Committee's interpretation, in section 3(D) on reservations, and in section 6, the conclusions.

[61] Quinn, G., and A. Arstein-Kerslake (2012) 'Restoring the 'Human' in 'Human Rights': Personhood and Doctrinal Innovation in the UN Disability Convention' in *The Cambridge Companion to Human Rights Law*, C. Gearty and C. Douzinas (eds), 36–55, Cambridge University Press.

[62] Anna Arstein-Kerslake (2014): 'An empowering dependency: exploring support for the exercise of legal capacity', *Scandinavian Journal of Disability Research*, 1-16.

decisions to the person with disabilities in the same way that a gold medal is not awarded to a prosthetic leg but the paralympian who won the race.[63]

C. Article 12 CRPD: The nature of the obligation

Legal capacity is dealt with in Article 12 of the CRPD, which reads as follows:

> ***Article 12, CRPD***
>
> ***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 recognise 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*

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[63] Arstein-Kerslake (op cit, p. 7) citing Silvers, Anita, and Leslie Pickering Francis. 2009. Thinking about the Good: Reconfiguring Liberal Metaphysics (or not) for People with Cognitive Disabilities' *Metaphilosophy* 40 (3–4): 465–498 at p. 486.

> *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.*

The CRPD Committee has pointed out that many people have historically, and in several countries still are, denied legal capacity – such as people from ethnic minorities, women – but people with disabilities 'remain the group whose legal capacity is most commonly denied in legal systems worldwide',[64] and of these, people with psychosocial disabilities and intellectual disabilities are 'disproportionately' so.[65]

To reverse this, Article 12(1) sets out that people with disabilities have a right - to recognition as 'persons before the law'. This is a passive recognition which establishes identity before the law, but does not speak to agency to exercise legal capacity. The CRPD Committee gives examples of this as "having a birth certificate, seeking medical assistance, registering to be on the electoral role [sic] or applying for a passport" [66]

Article 12(2) requires States to 'recognise' that persons with disabilities 'enjoy legal capacity on an equal basis with others in all aspects of life'. By deploying the word 'enjoy', this paragraph confers agency upon those who are identified as rights holders in Article 12(1). The CRPD Committee goes further and says that Article 12(5) confers a 'right to recognition as a legal agent',[67] in that it sets out rights to inheritance (harking back to Roman law considerations), and other financial issues. The interpretations by UN treaty bodies are legally binding on States.

Of note, Article 12(2) provides that the exercise of legal capacity applies 'in all spheres of life', not merely in relation to the financial issues set referred to in paragraph 5. 'All areas of life' by definition cuts across all other CRPD

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[64] CRPD Committee General Comment No. 1 (2014) on Article 12: Equal recognition before the law, 19 May 2014. (Hereinafter 'CRPD GC1'), para. 8.

[65] CRPD GC1, para. 9.

[66] CRPD GC1, para. 14.

[67] CRPD GC1, para. 12.

provisions, which must include Articles 13 (accessing courts and non-judicial mechanisms), 25 (healthcare decisions), 23 (deciding about family and relationships), 29 (deciding whom to vote for, and deciding which organisations and political parties to join), 24 (deciding on educational options), 19 (decisions about where and with whom to live, and deciding on which community support services to access), 26 (choosing habitation and rehabilitation services) 27 (employment decisions), 33 (deciding to participate in monitoring CRPD implementation) and 4(3) (deciding whether and how to participate in the development and implementation of legislation and policies affecting people with disabilities).

Article 12(3) sets out that States must 'take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.' The inclusion of the word 'may' indicates that the default position for people with disabilities is the same as for anyone else, namely that autonomy and self-determination are to be protected. Support should not be imposed. In a departure from the functional approach, the measures that States must put in place relate to the exercise – rather than the removal – of legal capacity. In essence the Convention starts from abilities rather than deficits.

As noted in the previous section, the type of support that people may require in exercising their legal capacity will vary from person to person. A person with a degenerative disease of ageing (e.g. Alzheimer's disease) or a degenerative disease unrelated to ageing (e.g. Parkinson's disease) may wish to put in place planning documents anticipating future incapacity. Such planning documents may include instructional directives (specifying in a document actions which the person wants or does not want to take place) or proxy directives (specifying a person who will take decisions on behalf of the adult). For a person with a brain injury the support may take the form of assistive communication technology. Advances in neuroscience are opening up innovative ways to enable a person to communicate their will and preferences where none was previously detectable.

For a person with an intellectual disability, the support may be a form of what has become known as supported decision-making. Rather than being a clear-cut model, supported decision-making represents a cluster of various approaches and systems. It might take the form of circles of support that includes life planning and identification of a network of trusted people.[68] Or the support may be very different. For a person with mental health problems support may be more of a one-to-one approach such as the personal ombudsman system in one part of Sweden.[69] Creativity seems to be key in identifying the form and style of support which best suits people's needs, as well as in ensuring that the people who are carrying out the support are equipped with the skills in providing information to the particular adult so that they can make decisions and that these can be communicated to other parties.[70]

Article 12(4) of the CRPD sets out safeguards that need to be put in place. One such safeguard is an adult protection system. This should exist not in order to protect against 'bad' decisions (however assessed), but in order to comply with Article 16 of the CRPD. This provision, as noted above, lays down State obligations to guard against all forms of exploitation, violence and abuse.

Another safeguard that needs to be put in place is one which ensures that support persons communicate and interpret decisions rather than impose their own view on the adult. There is some debate, however, as to whether this is tacit acknowledgement of the legitimacy of substituted decision-making or whether the safeguards have reference solely to supported decision-making systems.[71] Some are of the view that Article 12(4) applies to 'substitute decision-making', whilst acknowledging that the number of people subject to such a system and the amount of coercion and abuse within it, should be minimised. An alternative interpretation is that Article 12(4) applies to 'supported decision-making' only and should not be understood to imply the

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[68] See, for example Circles Network, a UK charity, at http://www.circlesnetwork.org.uk.

[69] See the Personal Ombuds scheme in Skåne, Sweden, at http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php.

[70] The need for training of professionals and staff working with people with disabilities is set out in the General Obligations of the CRPD in Article 4(1)(i). By extension, training should also be provided for support people who may not be professionals or paid staff, as such.

[71] Dhanda, A. (2007) op cit.

need for substitute decision-making.[72] It is difficult, however, to envisage how a person with disabilities requiring more intensive supports and with nobody in their lives who understands their form of communication or intentions, or a person in a coma who has not established a prior planning/advance directive document, can be supported to make decisions.

3. United Nations

The previous section outlined the nature of the right, and set out the obligations on States to implement Article 12 of the CRPD. This section outlines statements of UN bodies in relation to legal capacity of people with mental disabilities. Prior to the adoption of the CRPD there are several examples of how UN bodies saw the function of guardianship to protect. A 1971 resolution of the UN General Assembly stated that a person with intellectual disabilities has, 'a right to a qualified guardian when this is required to protect his personal well-being and interests'.[73] In 2003 the UN Secretary General said that, '[t]he function of guardianship is to protect the individual from any danger which his or her mental conditions may cause',[74] Prior to the CRPD, the default at the international policy level statement about anything to do with legal capacity was substituted decision-making, and it was thought that the best way to achieve this was to deprive someone totally or restrict someone partially of their legal capacity. Since the adoption of the CRPD the pendulum has swung significantly, so that there is now much more emphasis on forms of supported decision-making, which the Office of the UN High Commissioner for Human Rights (OHCHR) has described as 'the

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[72] See UN Office of the High Commissioner for Human Rights (OHCHR), *Thematic study of the Office of the United Nations High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities*, A/HRC/10/48 (2009), paras. 44-47.· See also UN Committee on the Rights of Persons with Disabilities (2009) *Guidelines on Treaty Specific Document to be Submitted by States Parties under Article 35(1) of the UN Convention on the Rights of Persons with Disabilities*, Geneva, which instructs States to report on '[t]he existence of safeguards against abuse of supported decision-making models' and does not mention substituted decision-making.

[73] UN General Assembly (1971) *Declaration on the Rights of Mentally Retarded Persons*, Article 5.

[74] United Nations Secretary-General (2003), *Progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities*, 24 July 2003, A/58/181.

process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters'.[75] The view of the OHCHR is that Article 12 should impact upon criminal and civil law, pointing out that laws should be repealed which allow for disqualification from running for political positions, participating in juries or as witnesses and the OHCHR also recommends revising criminal laws to ensure that they are disability-neutral.[76]

The OHCHR's view is that legal capacity law review and reform is necessary to provide, amongst other items, 'legal recognition of the right of persons with disabilities to self-determination'.[77] This sense of reclaiming autonomy was picked up by Manfred Nowak, the then UN Special Rapporteur on Torture who in 2008 wrote a report which explicitly referred to the link between deprivation of legal capacity and the torture and ill-treatment of people with disabilities.[78] In this report, Nowak directly links legal capacity with the possibility of being subjected to torture, explaining that people with disabilities often find themselves in a position where they are stripped of power and placed under the total control of another person, a situation in which the likelihood of torture and other forms of ill-treatment is increased. The powerlessness may be related to a person's particular disability, but, Nowak notes, 'it is often circumstances external to the individual that render them "powerless". A prime example of such an external circumstance is a system in which one's ability to make decisions recognised by law and to have legal standing is taken away and given to others'.[79] Nowak goes on to make the point that deprivation of legal capacity is one form of State acquiescence with regard to violence against people with disabilities.[80]

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[75] United Nations Office of the High Commissioner for Human Rights (OHCHR) (2009), *Thematic study of the Office of the United Nations High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities*, A/HRC/10/48 (2009), para. 45.

[76] Ibid, para. 47.

[77] Ibid, para. 45.

[78] Nowak, M. (2008) *Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment,* A/63/175, 28 July 2008.

[79] Ibid, para. 50

[80] Ibid, para. 69.

A. Committee on the Rights of Persons with Disabilities

The UN Committee on the Rights of Persons with Disabilities (CRPD Committee) decided during its first session to hold a day of general discussion to take place annually. The purpose of this form of event is 'to foster a deeper understanding of the contents and implications of the Convention as they relate to specific articles or topics'.[81] The CRPD Committee decided to hold its first day of general discussion on Article 12 of the CRPD, because it had identified the provision as being 'one of the cardinal rights and principles of the Convention'.[82] The event took place in October 2009, and the outcome was that the Committee referenced how a general comment would be helpful (it took them over four years to write it).[83]

Unrelated to the day of general discussion, the CRPD Committee in the same year published its 'reporting guidelines'. The purpose of this document is to provide assistance as to the format with which States must report 'on measures taken to give effect to its obligations under the [CRPD] and on the progress made in that regard', as required two years after ratification and thereafter every four years. [84] The document contains non-mandatory guidance to States on how they should report on Article 12 implementation.[85] The guidelines ask States to report on measures taken to ensure that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life, any support available to persons with disabilities to exercise their legal capacity and manage their financial affairs, whether there are safeguards against abuse of supported decision-making models, and what sort of awareness-raising and education campaigns exist in relation to equal recognition of all persons with disabilities before the law. Curiously, States

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[81] UN Committee on the Rights of Persons with Disabilities (2009a) *Outline of the Day of General Discussion on Article 12 of the CRPD – The right to equal recognition before the law*, 2nd session, 19 -23 October 2009.

[82] Ibid.

[83] I attended this day. The Committee produced no outcome documents. See http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGD2009.aspx for the background documents, including one from my NGO, the Mental Disability Advocacy Center.

[84] Article 35(1) and (2) of the CRPD.

[85] UN Committee on the Rights of Persons with Disabilities (2009) *Guidelines on Treaty Specific Document to be Submitted by States Parties under Article 35(1) of the UN Convention on the Rights of Persons with Disabilities*, Geneva, UN.

need only report on '[w]hether legislation does or does not exist which restricts the full legal capacity on the basis of disability' and about any 'actions being taken towards conformity with article 12 of the Convention', but the CRPD Committee has not asked about the nature and form of such laws which restrict full legal capacity, who and how many people are subject to them, nor the safeguards which are present in such systems to guard against abuse. It seems that the CRPD Committee has focused on gathering information from States about what should be, and has partially neglected to seek information about what is.

The Committee has bemoaned the 'general failure to understand that the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making.'[86] It instructs States to 'abolish'[87] substituted decision-making regimes which defines as a situation in which:

> *legal capacity is removed from a person, even if this is in respect of a single decision;*
>
> *a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; and*
>
> *any decision made by a substitute decision-maker is based on what is believed to be in the objective "best interests" of the person concerned, as opposed to being based on the person's own will and preferences.*[88]

The obvious question is what about cases where it is not possible to establish the 'will' of a person? The Committee sheds no light on this, despite being requested to do so by several bodies that sent submissions after the draft general comment was published, and before the deadline for submissions. The most striking comment came from the government of Denmark, which was heavily critical of the CRPD Committee's absolutist stance:

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[86] CRPD GC1, para. 3.
[87] CRPD GC1.
[88] CRPD GC1 para. 27.

> *If substitute care and treatment decisions are not made for these individuals, they will run the risk of being exploited, neglected, or even left to die. To assume that no one would ever require someone else to make a decision on their behalf would against this background not only be flagrantly wrong but ultimately irresponsible.*[89]

To date, the CRPD Committee has examined fourteen States' compliance with the CRPD.[90] It has recommended that each government 'replace' substituted decision-making with supported decision-making for persons with disabilities. It has demanded that States provide 'recognition [of] all persons' legal capacity and [their] right to exercise it'.[91]

The high-level obligations on States with regard to guardianship are clear. They must

> *adopt measures to repeal the laws, policies and practices which permit guardianship and trusteeship for adults and take legislative action to replace regimes of substituted decision-making by supported decision making, which respects the person's autonomy, will and preferences, in the exercise of one's legal capacity in accordance with article 12 of the Convention.*[92]

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[89] 'Response from the Government of Denmark with regards to Draft General Comment on Article 12 of the Convention – Equal Recognition before the Law', (undated), p. 1. See also, from the same country: the 'Danish Institute for Human Rights questions the reasoning of the Committee for not envisaging any situations where it may be necessary to use some forms of substituted decision-making,' Letter to the CRPD Committee from the Danish Institute for Human Rights, 21 February 2014, p. 2. The Australian Human Rights Commission requested that the general comment 'refer to situations where it is difficult or impossible to determine the will and preference of the person with a disability', 28 February 2014, p. 3. And the Finnish Human Rights Center was of the opinion that, 'there are situations in which [...] support is not sufficient. The Convention cannot, and by the pure text and the general understanding of it, does not totally ban the possibility of substitute decision-making in some, be it limited and clearly specified, cases', letter to the Committee, 21 February 2014, p. 2.

[90] These are Tunisia and Peru in April 2011, Spain in September 2011, Argentina, China and Hungary in September 2012, Paraguay in April 2013. Austria, Australia and El Salvador in September 2013, Paraguay in 2013 and Azerbaijan, Costa Rica and Sweden in May 2014. For the purposes of simplicity in citing these reports the format 'CRPDon [Country] will be used.

[91] CRPD on China, para. 22.

[92] Ibid.

To monitor progress in implementing such a repeal of laws, the Committee also recommends States to establish an 'independent review mechanism' to restore the rights of those stripped of their legal capacity.[93]

The CRPD Committee has begun to flesh out some guiding principles about what supported decision-making should look like in practice. It should be available for everyone, including with high support needs.[94] It 'is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity'[95] should 'respect the person's autonomy, will and preferences'[96] rather than be made on the person's 'best interests'.[97] It should 'never amount to substitute decision-making'.[98] It is not good enough to establish supports without abolishing substituted regimes.[99] A person with alternative communication modes should not be denied supports (although the Committee offers no practical guidance as to how a person's will should be understood if no-one can understand the person's communication).[100] The measure should recognise 'all persons' legal capacity and right to exercise it; accommodations and access to support where necessary to exercise legal capacity; [and] arrangements for the promotion and establishment of supported decision-making'.[101] The nature of the duty is to '[e]stablish, recognize and provide'[102] supports at 'nominal or no cost'.[103] The Committee offers no hints as to how someone should adjudicate who needs supports and what sorts of those supports should be. The Committee is bereft of guidance beyond saying that 'mental capacity assessments' (undefined) should not be used, and that States need to develop 'new, non-discriminatory indicators of support needs'.[104] The Committee points out how mental capacity 'is highly controversial' and cannot be measured objectively, but rather is 'contingent on

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[93] CRPD on Paraguay, para. 30.
[94] CRPD GC1, para. 29(a).
[95] CRPD GC1, para. 17.
[96] CRPD on Peru, para. 25; on Austria, para 28; on China, para. 21; and on Azerbaijan, para. 27.
[97] CRPD GC1, para. 29(b).
[98] CRPD GC1, para. 17.
[99] CRPD GC1, para. 28.
[100] CRPD GC1, para. 29(c).
[101] CRPD on China, para. 22.
[102] CRPD GC1, para. 50(c).
[103] CRPD GC1, para. 29(e).
[104] CRPD GC1, para. 29(i).

social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity'.[105]

The CRPD does not frame access to supports in Article 12(3) as a right, but an obligation on the State. The Committee seems to reiterate this by clarifying that States have 'an obligation to facilitate the creation of support, particularly for people who are isolated and may not have access to naturally occurring support in the community'.[106] There is considerable theoretical confusion about the nature of the obligation to provide supports. The Committee says that the obligation is 'for the fulfillment of the civil and political right to equal recognition before the law',[107] and therefore progressive realization does not apply: upon ratification States need from one moment to the next to ensure access to supports for all. This seems far-fetched, and may come back to haunt the Committee as they see that no country is able to execute such a societal shift. A wiser response would perhaps have been to say that it is a hybrid right and that there needs to be gradual roll-out of access to supports: States would then have been asked to report on progress year on year and give evidence of the increase of availability.[108]

The CRPD Committee praised Austria for a pilot program to replace the guardianship system and the Committee urged the government to 'do more' to make sure that people get are not placed under guardianship and get access to supported decision-making.[109] The advice to 'do more' is non-specific and Austria will comply if it provides access to one more person to supported decision-making.

With regard to consent to medical interventions, the Committee has commented how the ordinary rules of medical law are suspended for people deprived of legal capacity. It interprets article 14 of the CRPD as 'the right to be free from involuntary detention in a mental health facility and not to be forced to undergo mental health treatment'[110] With regard to Hungary, the

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[105] CRPD GC1, para. 14.
[106] CRPD GC1, para. 29.
[107] CRPD GC1, para. 30.
[108] This line of critique will be expanded in the conclusions of this chapter, section 6 below.
[109] CRPD on Austria, para. 28.
[110] CRPD GC1, para. 31.

Committee recommended that the government, ‘adopt measures to ensure that health care services, including all mental health care services, are based on the free and informed consent of the person concerned’.[111] Commenting on the law in Australia, the Committee found that people’s legal capacity could be restricted not just by detaining them in a psychiatric hospital, but by placing them on community treatment orders, where a person with a diagnosis of a mental health issue can be legally obliged to take psychiatric medication in the community.[112] Further, it noted in Spain that law reform needs to happen to ensure that, ‘informed consent of all persons with disabilities is secured on all matters relating to medical treatment, especially the withdrawal of treatment, nutrition or other life support’.[113] In its 2014 observations, it has tightened its wording that governments should guarantee the ‘right to free and informed consent to receive medical treatment’,[114] and that the right should be about the authority ’to give and withdraw informed consent for medical treatment.’[115] It noted in Argentina that abortions can be sanctioned by the woman’s guardian, a situation it admonished.[116]

The CRPD Committee has provided some limited guidance about how States should arrange domestic laws to regulate the losses of rights consequent on denial or restriction of legal capacity. This includes ‘the right to free and informed consent to medical treatment, the right of access to justice, and the rights to vote, to marry and to choose their place of residence’,[117] as well as the right to work,[118] ‘the right to have a home and found a family’,[119] to adopt children,[120] and to be considered as creditworthy by banks.[121]

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[111] CRPD on Hungary, para. 28. The Committee made similar recommendations in its reports on Austria, para. 31, on Spain, para. 36, on Argentina, para. 42, and and Costa Rica, para. 22.

[112] CRPD on Australia, para. 34.

[113] CRPD on Spain, para. 30.

[114] CRPD on Costa Rica (para. 22) and on

[115] CRPD on Sweden, para. 34.

[116] CRPD on Argentina, para. 31.

[117] CRPD on Paraguay, para. 30; on Austria, para. 28; on Azerbaijan, para. 26 on Costa Rica, para. 22; and on Sweden, para. 34.

[118] CRPD on Sweden, para. 34.

[119] CRPD on Costa Rica, para. 21.

[120] CRPD on Azerbaijan, para. 27.

[121] CRPD on Costa Rica, para. 23-4.

Of particular interest with regard to the global jurisprudence on the link between legal capacity and segregation from the community,[122] the Committee has said strongly that:

> *The segregation of persons with disabilities in institutions continues to be a pervasive and insidious problem that violates a number of the rights guaranteed under the Convention. The problem is exacerbated by the widespread denial of legal capacity to persons with disabilities, which allows others to consent to their placement in institutional settings.*[123]

It has recommended to the Paraguay government to abolish civil commitment in psychiatric hospitals 'in order to ensure that persons with disabilities who are subject to those procedures are able to fully exercise their legal capacity'.[124] This decoupling of legal capacity and institutionalisation is a point acknowledged and addressed by the European Court of Human Rights in its judgment on the *Stanev v. Bulgaria* case.[125] It has further expressed encouragement to States to '[d]evelop a wide range of community-based services and supports that respond to needs expressed by persons with disabilities, and [which] respect the person's autonomy, choices, dignity and privacy, including peer support and other alternatives to the medical model of mental health'.[126]

The CRPD Committee has given consistent guidance about training of stakeholders in the legal capacity field, in particular civil servants, judges, legal professionals and social workers, 'on the recognition of the legal capacity of persons with disabilities and on mechanisms of supported decision-making',[127] adding that this training should be done in 'consultation and cooperation' with people with disabilities and their NGOs, echoing the sentiment laid out in Article 4(3) of the Convention, which sets out participation of people with disabilities in policy-making. The Committee has

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[122] A theme explored particularly in chapter 6 of this book.

[123] CRPD GC1, para. 46.

[124] CRPD on Paraguay, para. 36.

[125] Again, this is analysed in chapter 6 of this book.

[126] CRPD China, para. 23.

[127] CRPD GC1 at para. 39, and CRPD Committee on Hungary, para 26; on Spain, para. 34; on Austria, para. 28; and on Tunisia, para. 23.

been specific in its recommendations to some countries – for example Argentina – that the country should organise training for judges 'on the human rights model of disability' in order 'to encourage them to adopt the supported decision-making system instead of granting guardianships or trusteeships'.[128]

The Committee has picked up on some of the civil law consequences of depriving a person of legal capacity. It recommended to the Peruvian government to amend the Act for Foreigners, which prohibits people with intellectual and psycho-social disabilities from citizenship.[129] Striking at the heart of Article 12(1) of the CRPD which sets out recognition before the law, the CRPD Committee had the opportunity to comment on the phenomenon in Peru whereby 'a number of persons with disabilities, especially those living in rural areas and in long-term institutional settings, do not have identity cards and, sometimes, have no name'.[130] As well as giving these identity cards, the government was told to collect accurate data on undocumented people with disabilities.[131] In El Salvador the law prohibits people with restricted legal capacity from working as notaries, something which the Committee noted 'that the Public Notaries Act limits possibilities for "blind", "mute" and "deaf" persons and those who "are not in full command of their mental faculties" to work as notaries', and asked the government to change this system,[132] adding that reasonable accommodations should be provided to people with disabilities in the workplace, a requirement spelled out in Article 27 of the Convention, on the right to work.

B. Human Rights Committee

One would expect the CRPD Committee to be the most active UN treaty body issuing pronouncements on the legal capacity of people with mental disabilities. But given the stretch of legal capacity into other areas of law, one would expect other treaty bodies also to have dealt with some aspects of the

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[128] CRPD on Argentina, para. 20.
[129] CRPD on Peru, para. 6.
[130] Ibid, para. 22.
[131] Ibid, para. 23.
[132] CRPD on El Salvador, para. 27.

right to legal capacity. The reality is that this subject has largely been absent from the purview of UN human rights treaty bodies other than the CRPD Committee. This section examines the performance of the UN Human Rights Committee, which is the treaty body established under the International Covenant on Civil and Political Rights (ICCPR). It has dealt with legal capacity with regard to three countries.

First, in relation to the Czech Republic in 2007, it noted that the Czech government should ensure that 'all persons without full legal capacity are placed under guardianship that genuinely represents and defends the wishes and interest of those persons'.[133] Second, in its concluding observations on the Russian Federation in 2009, it took the opportunity to lay out its most comprehensive analysis of legal capacity to date.[134] In this document, the UN Human Rights Committee expressed concern about the lack of adequate safeguards in the guardianship system, the disproportionate nature of restrictions on human rights caused by deprivation of legal capacity, and the number of persons who are subjected to this measure. It placed particular emphasis on the fact that people deprived of legal capacity in Russia do not have legal remedies to challenge violations of their rights, including ill-treatment or abuse by guardians or staff of mental health and social care institutions. The practice of depriving a person of legal capacity on the basis of the mere existence of a psychiatric diagnosis was criticised. Of particular interest is the fact that the UN Human Rights Committee recommended that the Russian government should amend its law and policy so that any measures restricting a person's legal capacity on account of a disability should be necessary, proportionate and based on the person's individual circumstances. It also recommended that such measures should be accompanied by effective procedural safeguards including prompt access to an effective judicial review of guardianship. And third, with regard to Lithuania three years later in 2012.[135] Similarly, the Committee commented on the lack

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[133] UN Human Rights Committee, *Concluding Observations: Czech Republic*, 90th session, 9-27 July 2007, CCPR/C/CZE/CO/2, para 14.

[134] UN Human Rights Committee, *Concluding Observations: Russian Federation*, 97th session, 12-30 October 2009, CCPR/C/RUS/CO/6, para 19.

[135] UN Human Rights Committee, *Concluding Observations: Lithuania,* 105th session, 9-27 July 2012, CCPR/C/LTU/CO/3, para. 14.

of legal representation in court proceedings where legal capacity was at stake, and the denial of people under guardianship to initiate restoration proceedings. It was also concerned that abortion and sterilisation could be authorised by guardians without reference to the will and preferences of the person concerned.

C. Committee on Economic, Social and Cultural Rights

The UN Human Rights Committee's sister treaty body is the UN Committee on Economic, Social and Cultural Rights (ICESCR Committee). Its mother treaty (the International Covenant on Economic, Social and Cultural Rights) establishes in Article 2(2) an obligation on each State Party 'to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or *other status'* [emphasis added]. In 2009 the ICESCR Committee issued a general comment on non-discrimination, which significantly advanced the interface of legal capacity and discrimination.[136] The general comment includes guidance as to what is meant by 'other status'. It explains that:

> *[t]he nature of discrimination varies according to context and evolves over time. A flexible approach to the ground of 'other status' is thus needed to capture other forms of differential treatment that cannot be reasonably and objectively justified and are of a comparable nature to the expressly recognised grounds in Article 2(2).*[137]

The general comment sets out a non-exhaustive list of various other grounds of discrimination which 'could include the denial of a person's legal capacity because he or she is in prison, or is involuntarily interned in a psychiatric

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[136] UN Committee on Economic, Social and Cultural Rights (2009), *General Comment No. 20: Non-Discrimination in Economic, Social and Cultural Rights*.

[137] Ibid, para. 27.

institution, or the intersection of two prohibited grounds of discrimination, eg where access to a social service is denied on the basis of sex and disability'.[138]

The ICESCR Committee has also addressed the issue of a person's functionality which, as noted above in the discussion of the functional approach, is a key issue in the right to legal capacity. In its general comment 14 (2000) on the right to health, the ICESCR Committee recommends that States roll out 'physical as well as psychological rehabilitative measures aimed at maintaining the functionality and autonomy of older persons'.[139] In the light of the CRPD which was adopted six years after general comment 14, it is reasonable to read into the statement an inclusion of social supports which are aimed at maintaining the functioning and autonomy of everyone with disabilities, whether elderly or not.

Five years prior to the non-discrimination general comment, in 1995 the ICESCR Committee adopted a general comment specifically on older people, recommending that States, 'make efforts to promote research on the biological, mental and social aspects of ageing and ways of maintaining functional capacities and preventing and delaying the start of chronic illnesses and disabilities'.[140] For States amending legal capacity laws so as to ensure that people with degenerative diseases (whether age-related or not) can execute planning documents which express their preferences and to which reference might be made at a time when they are no longer able to communicate them, this is sound advice.

D. Reservations and Interpretative Declarations

Several States have entered a reservation or declaration in relation to Article 12 upon signing or ratifying the CRPD. The reason this issue is presented in this chapter is because reservations represent the greatest threat to the global interpretation of Article 12 of the CRPD, and disability rights scholars

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[138] Ibid.

[139] UN Committee on Economic, Social and Cultural Rights (2000) *General Comment No. 14: The right to the highest attainable standard of health.*

[140] UN Committee on Economic, Social and Cultural Rights (1995) *General Comment 6: The economic, social and cultural rights of older persons*, para. 42.

interested in law in action, unpicking the reservations and critique their legality seems an essential element of any review of the law in this area.

The Vienna Convention on the Law of Treaties defines a reservation as a 'unilateral statement, however phrased or named, made by a State, when signing, ratifying, accepting, approving or acceding to a treaty, whereby it purports to exclude or to modify the legal effect of certain provisions of the treaty in their application to that State'.[141] Modifying the legal effect of Article 12 poses a serious risk to universal implementation of the right to legal capacity across States Parties, and it is therefore worth examining what these statements say and what they might mean.

There are nine significant declarations or reservations that potentially impact on the implementation of Article 12 of the CRPD. They are, in chronological order of the date when the State ratified the Convention: El Salvador (December 2007), Egypt (April 2008), Australia (July 2008), Canada (March 2010), Estonia (May 2012), Poland (September 2012), Norway (June 2013), Kuwait (August 2013), Singapore (August 2013), and Venezuela (September 2013).[142]

El Salvador was among the first countries to sign the Convention, and when it did so it entered a reservation, which it confirmed upon ratification. The reservation sets out El Salvador's commitment to implementing the Convention, but only 'to the extent that its provisions do not prejudice or violate the provisions of any of the precepts, principles and norms enshrined in the Constitution of the Republic of El Salvador, particularly in its enumeration of principles.'

This formulation, which essentially states that El Savadorian law trumps binding international law, has come under fire from several States. In September 2008, Austria entered an objection to El Salvador's reservation, stating that its 'general and vague wording [...] raises doubts as to the degree

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[141] Vienna Convention on the Law of Treaties, 1969, Done at Vienna on 23 May 1969. Entered into force on 27 January 1980. United Nations, Treaty Series, vol. 1155, p. 331.

[142] The wording of the reservations and declarations can be found on the UN's treaty website: www.treaties.un.org. The reservations are not otherwise listed and have no reference numbers.

of commitment assumed by El Salvador in becoming a party to the Convention and is therefore incompatible with international law'. The Netherlands and Sweden entered similar objections in January 2009, Portugal in September 2009, the Czech Republic in November 2009, Germany in January 2010 and Slovakia in September 2010. The CRPD Committee examined El Salvador's compliance with the CRPD in October 2013. Given all the fuss at the diplomatic level, the Committee's commentary on the reservation is surprisingly brief. The Committee simply states that it is 'concerned' about the reservation,[143] and urges the government to 'expedite the process of withdrawing [it]'.[144]

Australia's declaration on Article 12 confirms its 'understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards'. When the CRPD Committee examined Australia's compliance with the CRPD in 2013 it noted that it was 'concerned about the existence of [Australia's] interpretative declarations',[145] and urged the government to 'review' the declarations 'in order to review them'.[146]

Similarly to Australia's statement, Canada's 'declaration and reservation' explains that 'Article 12 permits supported and substitute decision-making arrangements in appropriate circumstances and in accordance with the law.' The Canadian statement then sets out a sort of legal insurance policy in the format of 'if he says y, we will say z':

To the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Canada reserves the right to continue their use in appropriate circumstances and subject to appropriate and effective safeguards.

Canada submitted its interpretation upon ratification in March 2010. The CRPD Committee began its examination of State reports under Article 36 of

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[143] CRPD on El Salvador, para. 5.

[144] Ibid, para. 6.

[145] CRPD on Australia, para. 8

[146] Ibid, para. 9.

the CRPD in April 2011. As will be shown below, the CRPD has been consistently forthright since that time of its interpretation that Article 12 demands a replacement of substitute decision-making regimes. Thus we can assume that Canada's interpretation sprung into effect at that time. Some authors are calling for Canada to withdraw its interpretation.[147]

Egypt's 'interpretative declaration' is different from Canada's and Australia's in that it separates out the two elements of the right to legal capacity: namely the capacity to have rights (for example a person's capacity to have the right to vote) versus the capacity to act or perform (continuing the example, actually voting in an election). Egypt confirms its interpretation of Article 12 allows the Egyptian law to prevail, whereby 'persons with disabilities enjoy the capacity to acquire rights and assume legal responsibility ('ahliyyat al-wujub') but not the capacity to perform ('ahliyyat al-'ada')'. The idea that existing domestic law shall prevail is also present in Kuwait's interpretive declaration whereby '[t]he enjoyment of legal capacity shall be subject to the conditions applicable under Kuwaiti law.' Singapore is even more defiant in its reservation, saying that its existing law provides 'an appropriate and effective safeguard, oversight and supervision by competent, independent and impartial authorities or judicial bodies of measures relating to the exercise of legal capacity, upon applications made before them or which they initiate themselves in appropriate cases.' Singapore therefore reserves the right to continue to apply its current legislative framework in lieu of the regular review referred to in Article 12(4) of the Convention.

In Europe, the supremacy of domestic law has also been expressed by two countries. Estonia's reservation interprets Article 12 as a provision which does 'not forbid to restrict a person's active legal capacity, when such need arises from the person's ability to understand and direct his or her actions. In restricting the rights of the persons with restricted active legal capacity the Republic of Estonia acts according to its domestic laws.' In the meantime, Poland's interpretative declaration sets out how the country will implement Article 12 so as to allow 'incapacitation [...] in the manner set forth in the

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[147] Nicholas Caivano (2014) 'Conceptualizing Capacity: Interpreting Canada's Qualified Ratification of Article 12 of the UN Disability Rights Convention', 4:1 online: *UWO J Leg Stud* 3.

domestic law' where 'a person suffering from a mental illness, mental disability or other mental disorder is unable to control his or her conduct.' Essentially, all of these interpretations fly in the face of that set forth by the CRPD Committee. Similar to the situation in relation to Australia and El Salvador, the CRPD Committee recommends that the European countries withdraw their reservations and declarations which the Committee considers to be incorrect in law.

In Latin America, Venezuela's declaration is meaningless as it says that Article 12(2) (which sets out the right to legal capacity for everyone in all areas of life) 'mean[s] that in the case of conflict between that paragraph and any provisions in Venezuelan legislation, the provisions that guarantee the greatest legal protection to persons with disabilities, while ensuring their well-being and integral development, without discrimination, shall apply.' This is vacuous as international law is a floor, not a ceiling: if the CRPD's standards are higher than domestic law, then domestic law needs to be amended, and if Venezuela's laws provide more rights than that set out in domestic law, that is a wonderful thing for the people of Venezuela. Of note, Mexico entered a similar reservation when it ratified the CRPD in December 2007 which it withdrew in January 2012.

Norway's declaration is the most sophisticated of all:

> *Norway recognises that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Norway also recognises its obligations to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. Furthermore, Norway declares its understanding that the Convention allows for the withdrawal of legal capacity or support in exercising legal capacity, and/or compulsory guardianship, in cases where such measures are necessary, as a last resort and subject to safeguards.*

A question for the international community is: what status do these declarations have? The definition of a reservation was set out at the beginning of this section, and indeed the CRPD itself sets out that States may enter reservations, with a warning (restating a principle already established in public international law) that, reservations 'incompatible with the object and purpose of the present Convention shall not be permitted'.[148] The UN Human Rights Committee has said that '[i]t is not always easy to distinguish a reservation from a declaration as to a States's understanding of the interpretation of a provision, or from a statement of policy. Regard will be had to the intention of the State, rather than the form of the instrument.'[149] The Vienna Convention on the Law of Treaties helpfully points out that a reservation need not be called a reservation for the international community to treat it as such. 'Declarations' may therefore be treated as reservations if they contain the elements of a reservation, namely that they consist of:

> a unilateral statement
>
> however phrased or named
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> made by a State, when signing, ratifying, accepting, approving or acceding to a treaty
>
> which purports to exclude or to modify the legal effect of certain provisions of the treaty in their application to that State.

In its declaration upon ratification, the Norwegian government unilaterally and expressly seeks to exclude or modify the effect of provisions set out in Article 12 of the CRPD. This then meets the Vienna Convention's definition of a reservation. It then needs to be established whether the reservation is lawful. The Vienna Convention sets out that it is unlawful for a State to enter a reservation if that reservation 'is prohibited by that treaty' [150] or 'is incompatible with the object and purpose of the treaty'.[151] The stated purpose of the CRPD is set out in Article 1 of the treaty, and it is 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their

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[148] Article 46 of the CRPD.

[149] UN Human Rights Committee General Comment No. 24 (52) on issues relating to reservations made upon ratification or accession to the Covenant or the Optional Protocols thereto, or in relation to declarations under article 41 of the Covenant, U.N. Doc. CCPR/C/21/Rev.1/Add.6 (1994).

[150] Article 19(a) of the Vienna Convention on the Law on Treaties 1969, op cit.

[151] Ibid, Article 19(c). This is also the wording contained in Article 46 of the CRPD.

inherent dignity.' Article 12 is generally considered to be at the core of the paradigm shift from the medical (charity) model to the social (human rights) model of disability. It is difficult to see how entering a reservation like Norway's on Article 12 does not strike at the very heart of the purpose of the Convention.[152] At the time of writing, no State had objected to Norway's reservation, despite calls from civil society to the Norwegian government to withdraw it.[153]

4. Council of Europe

This chapter has thus far set out the nature of the Article 12 CRPD obligation, examined the interpretation of the CRPD committee and two main UN treaty bodies and has cast doubt on the legality of some reservations entered by some States which have the potential to pull apart the treads of the CRPD tapestry. The chapter changes now zooms into Europe, and the first part of the regional focus examines standards of the Council of Europe. This section is divided into three subsections: (a) statements by the Committee of Ministers, the main political body of the Council of Europe, (b) the Parliamentary Assembly made up of national parliamentarians and (c) the independent office of the Commissioner for Human Rights.

A. Committee of Ministers

As already noted in section 2(A), above, one of the most important documents safeguarding the rights of people deprived or restricted of legal capacity is Recommendation No. R(99)4 of the Committee of Ministers to member states 'on principles concerning the legal protection of incapable adults'.[154] The Recommendation speaks 'to the protection of adults who, by reason of an impairment or insufficiency of their personal faculties, are incapable of

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[152] Mental Disability Advocacy Center, 'Legal Opinion on Norway's Declaration/Reservation to the UN Convention on the Rights of Persons with Disabilities', 28 November 2013.

[153] Ibid.

[154] Committee of Ministers of the Council of Europe (1999), Recommendation No. R(99)4E on principles concerning the legal protection of incapable adults, adopted on 23 February 1999.

making, in an autonomous way, decisions concerning any or all of their personal or economic affairs, or understanding, expressing or acting upon such decisions, and who consequently cannot protect their interests'.[155] It adopts a functional approach to legal capacity, as explained in section 2(A), above. Notwithstanding its recognition that 'different degrees of incapacity may exist and that incapacity may vary from time to time', [156] the Recommendation rests upon the not unproblematic premise that at any point in time, an adult is either capable or incapable: on or off like a light-switch.

That said, Recommendation No. R(99)4 is a high water-mark in international law. It is the first instrument to grapple with, and set out a radically different legal approach to rights, rejecting the status based and outcome approaches of older texts. It contains some important principles, such as that of flexibility, including measures of protection needing to include 'those which do not restrict the legal capacity of the person concerned',[157] and to 'include those which are limited to one specific act without requiring the appointment of a representative or a representative with continuing powers'.[158]

The Recommendation tells States to preserve legal capacity, so that law should 'so far as possible' (no explanation as to why the qualification), 'recognise that different degrees of incapacity may exist and that incapacity may vary from time to time. Accordingly, a measure of protection should not result automatically in a complete removal of legal capacity. However, a restriction of legal capacity should be possible where it is shown to be necessary for the protection of the person concerned',[159] a statement which Article 12(2) of the CRPD would frown on. The Recommendation does not go on to define what protection means or who/what is to be protected from whom/what. It does, however, set out an important milestone in the development of legal capacity in international law by cutting the umbilical cord between legal capacity and subsequent losses of rights. No measure should 'automatically deprive the person concerned of the right to vote, or to make a will, or to consent or refuse

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[155] Ibid, Part 1(1).

[156] Ibid, Principle 3(1).

[157] Ibid, Principle 2(4).

[158] Ibid, Principle 2(5).

[159] Ibid, Principle 3(1).

consent to any intervention in the health field, or to make other decisions of a personal character at any time when his or her capacity permits him or her to do so'.[160]

Any measure should be necessary,[161] proportional to the person's functional capacity,[162] and time-limited[163] and should promote the adult's 'interests and welfare' (undefined),[164] all important principles for tailoring measures to the needs of the individual. The Recommendation embraces a model of substituted decision-making as necessary, and carried out as humanely as possible with an elaborate set of safeguards. The closest the Recommendation comes to endorsing supported decision-making (it does not use that term), is in describing a person representing or assisting an 'incapable adult,' who should

> *give [the adult] adequate information, whenever this is possible and appropriate, in particular concerning any major decision affecting him or her, so that he or she may express a view',[165] and that the adult's view on the choice of person to represent or assist him/her 'should be taken into account and, as far as possible, given due respect.*[166]

Deprivation or restriction of legal capacity can affect someone's health decisions. As the European Court of Human Rights noted in its *Stanev v Bulgaria* judgment,[167] guardians can impose treatment on people living in the community as well.[168] With this in mind, Recommendation R(99)4 contains a section on healthcare interventions, in which it states that when adults are capable of giving free and informed consent to a given intervention in the health field, the intervention may only be carried out with their consent. If an adult is not in fact capable of giving free and informed consent (all of which is

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[160] Ibid, Principle 3(2).
[161] Ibid, Principle 5.
[162] Ibid, Principle 6.
[163] Ibid, Principle 8.
[164] Ibid, Principle 8.
[165] Ibid, Principle 9(3).
[166] Ibid, Principle 9(2).
[167] See chapter 6 of this book.
[168] For an examination of disability, legal capacity and healthcare interventions, see chapter 7 of this book.

open to interpretation), 'the intervention may, nonetheless, be carried out provided that: it is for his or her direct benefit; and authorisation has been given by his or her representative or by an authority or a person or body provided for by law'.[169] Similarly, 'subject to protective conditions prescribed by law, including supervisory, control and appeal procedures, an adult who has a mental disorder of a serious nature may be subjected, without his or her consent, to an intervention aimed at treating his or her mental disorder only where, without such treatment, serious harm is likely to result to his or her health'.[170] R(99)4's footprint made it into later documents also.

The Council of Europe Disability Action Plan of 2006 is another Recommendation of the Committee of Ministers and urges Member States 'to implement the relevant provisions' of the 1999 Recommendation.[171] One of the 'fundamental principles' governing the Disability Action Plan is 'dignity and individual autonomy including the freedom to make one's own choices',[172] and 'Action line number 12' on 'legal protection' requires that '[p]eople with disabilities have the right to recognition everywhere as persons before the law. Assistance to exercise legal capacity should', the Disability Action Plan recommends, be 'appropriately safeguarded by law'.[173] It encourages States 'to provide appropriate assistance to those people who experience difficulty in exercising their legal capacity and ensure that it is commensurate with the required level of support'.[174]

Prevention of financial and other abuse against people with mental disabilities is one of the animating concerns underlying legal capacity laws. The Disability Action Plan points out that abuse 'can occur in institutions or other types of care and situations, including the family environment. It can be inflicted by strangers or persons known to the individual and can take many forms, for

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[169] Committee of Ministers of the Council of Europe (1999), Recommendation No. R(99)4E on principles concerning the legal protection of incapable adults, adopted on 23 February 1999, Principle 22 (consent). Principle 23 provides for alternative rules on consent for States unable to accept Principle 22, but on the point which has been mentioned, these alternative rules present no difference with the main rule.

[170] Ibid, Principle 25.

[171] Committee of Ministers of the Council of Europe (2006) *Disability Action Plan to promote the rights and participation of people with disabilities in society for 2006-2015,* Recommendation Rec(2006)5, para 3.12.3.x.

[172] Ibid, para. 2.87.

[173] Ibid, para. 3.12.1.

[174] Ibid, para. 3.12.3.vii.

instance verbal abuse, violent actions, or the refusal to meet basic needs'.[175] In 2005, a year before the CRPD was adopted, the Committee of Ministers took action in this regard by adopting a text specifically on protecting adults and children with disabilities from abuse.[176] The document contains useful guidance on establishing and maintaining adult protection systems.

In 2009 the Committee of Ministers produced another Recommendation setting out very brief guidance to States on how to legislate issues around planning for future incapability.[177] This document describes Recommendation No. R(99)4 as 'a valuable and up-to-date international instrument',[178] but does not give reasons why it endorses the 1999 document rather than the 2006 CRPD which purely in chronological terms is more 'up-to-date'. The 2009 document focuses only on planning documents which dictate what happens when someone lacks functional capacity in the future, and recommends that States adopt legislation to ensure that people can appoint a continuing power of attorney, defined as 'a mandate given by a capable adult with the purpose that it shall remain in force, or enter into force, in the event of the granter's incapacity'.[179] A continuing power of attorney should cover 'economic and financial matters, as well as health, welfare and other personal matters'.[180] The Recommendation also sets out the advantages of making available advance directives, which 'may apply to health, welfare and other personal matters, to economic and financial matters, and to the choice of a guardian, should one be appointed'.[181]

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[175] Ibid, para. 3.13.1.

[176] Committee of Ministers of the Council of Europe (2005) Resolution ResAP(2005)1 on safeguarding adults and children with disabilities against abuse.

[177] Committee of Ministers of the Council of Europe (2009) *Recommendation on monitoring the protection of human rights and dignity of persons with mental disorder*, CM/Rec(2009)3, adopted on 20 May 2009.

[178] Ibid, Preamble.

[179] Ibid, Principle 2.

[180] Ibid, Principle 3.

[181] Ibid, Principle 14. The CRPD Committee has said that 'the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others', CRPD GC1, para. 17.

B. Parliamentary Assembly

In January 2009 the Parliamentary Assembly of the Council of Europe (PACE) adopted a Resolution[182] and Recommendation, both entitled 'Access to rights for people with disabilities and their full and active participation in society.' Comprised of national level parliamentarians, one expects PACE to be more critical of governance than documents emanating from the Committee of Ministers, a body comprised of the governments of each Member States. Noting that 'in practice, the access of people with physical or mental disabilities to their rights on an equal basis with those of people without disabilities frequently remains wishful thinking and proves inadequate',[183] PACE chose legal capacity as the first substantive disability rights issue to be tackled.[184] It thus provides that States should 'guarantee that people with disabilities retain and exercise legal capacity on an equal basis with other members of society'.[185]

Echoing the spirit and wording of Article 12 of the CRPD, as well as the CRPD Committee's first concluding observations (on Tunisia – see section 3(A), above), the PACE promotes the move from substituted decision-making towards supported decision-making.[186] It recommends to governments to ensure that people's rights are 'not limited or substituted by others, [but] that measures concerning them are individually tailored to their needs and that they may be supported in their decision making by a support person'.[187] The Resolution appeals to governments to legislate so that any restrictions on legal capacity do not affect the right to vote, to draw up a will (these are also mentioned in Committee of Ministers' Recommendation No. 4 of 1999, as laid out in above) as well as the rights to own property, to work, to a family life, to

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[182] Parliamentary Assembly of the Council of Europe (2009) *Access to rights for people with disabilities and their full and active participation in society*, Resolution 1642 (2009), 26 January 2009.

[183] Ibid, para. 3.

[184] This was partly becuase of the outreach which the rapporteur conducted to non-governmental organisations, including the Mental Disability Advocacy Cenrer, where the author is employed as Executive Director.

[185] Parliamentary Assembly of the Council of Europe (2009) *Access to rights for people with disabilities and their full and active participation in society*, Resolution 1642 (2009), 26 January 2009, para. 7.

[186] Ibid, para. 7.2.

[187] Ibid, para. 7.1.

marry, to form and join associations, and to bring legal proceedings (these rights are not mentioned in Recommendation No. 4 of 1999). Adopting the language of Article 12(4) of the CRPD, the Resolution finally sets out a range of safeguards such as compulsory periodic reviews of any measures with full participation of the adult in question.[188]

C. Commissioner for Human Rights

The Committee of Ministers is the governmental body of the Council of Europe whereas the Parliamentary Assembly is comprised of national level members of parliament who also sit in Strasbourg four times a year. The Commissioner of Human Rights is an independent institution of the Council. The Committee of Ministers draws up a shortlist of candidates based on nominations by States, and from this shortlist the Parliamentary Assembly elects the winner.[189] Thomas Hammarberg was the second Commissioner and served a full term from 2006 to 2012. In October 2008 his office released an Issue Paper on 'Human Rights and Disability: Equal rights for all'.[190] The paper deals with 'the right to make decisions' and starts by setting out the problem as follows:

> *The right to decide where we want to reside, how to spend our money, whether and with whom to get married is something many of us take for granted. But for thousands of Europeans placed under guardianship the reality is very different.*[191]

The paper points out that some systems allow partial guardianship with safeguards and regulations. Citing Recommendation No. R(99)4, [192] (examined in section 4(A), above), Hammarberg highlights the principles of maximum preservation of capacity and respect for choice as far as possible. In

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[188] Ibid, para. 7.3.

[189] Council of Europe, Committee of Ministers Resolution (99) 50 on the Council of Europe Commissioner for Human Rights, 7 May 1999.

[190] Thomas Hammarberg (2008) *Human Rights and Disability: Human Rights for All*, CommDH / IssuePaper (2008), 20 October 2008.

[191] Ibid, para 5.

[192] Committee of Ministers of the Council of Europe (1999), Recommendation No. R(99)4E on principles concerning the legal protection of incapable adults, adopted on 23 February 1999.

a similar way to the PACE Resolution adopted a year later (examined in section 4(B), above), he develops no-go areas of rights, areas which should remain intact whatever the person's legal status:[193]

Relying on Article 12 of the CRPD, and supported by the principles in Article 3 of the CRPD, Hammarberg observes that '[t]he focus is on enabling people to make and communicate their decisions. This approach of 'supported decision-making' is strongly advocated by the disability movement globally and is founded on the notion that 'everyone can make choices and communicate them to others, while recognising that sometimes this requires support' he notes.[194] Hammarberg makes the important point 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'.[195] In other words, independence is more connected with notions of autonomy and supports than atomism and best interests.

In September 2009 Hammarberg issued a Viewpoint (a shorter document setting out the official view of the Commissioner) on the rights of people with intellectual disabilities.[196] This document stated:

> *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.*

Another Viewpoint published a week later addresses the removal of decision-making rights of people with disabilities, stating that people with disabilities

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[193] Thomas Hammarberg (2008) *Human Rights and Disability: Human Rights for All*, CommDH / IssuePaper (2008), 20 October 2008, para. 5.1.

[194] Ibid.

[195] Ibid.

[196] Thomas Hammarberg (2009) *A neglected human rights crisis: persons with intellectual disabilities are still stigmatised and excluded*, Viewpoint, 14 September 2009.

‘have been treated as non-persons whose decisions are meaningless’.[197] This Viewpoint was at that time the most developed articulation by a human rights official of the right to legal capacity. Hammarberg notes that the aim of the CRPD is to promote inclusion and full participation in society, and that the aim cannot be achieved ‘[w]hen we deprive some individuals of their right to represent themselves’. He goes on to say that ‘a range of alternatives to guardianship [need] to be provided for adults with disabilities’. The ‘starting point’ for law reform is ‘full legal capacity combined with the right of the individual to seek support.’ As to the availability of supports which States are obliged to ensure:

> *[s]upported decision-making is a developing field in some Council of Europe member States, and the practice has been embedded for several years in many Canadian provincial laws. What happens in those jurisdictions is that a network of supporters are recognised – but not imposed on the adult – and these supporters provide information and options for the adult to make a decision.*

Hammarberg addresses the need to ensure that safeguards are in place ‘in order to prevent abuse’, including ensuring that the ‘will and preferences of the concerned person should be respected and there should be no conflict of interest and undue influence between those supporting the adult, and the adult him- or herself.’ He explains the *Shtukaturov v. Russia* judgment of the ECtHR,[198] observing that the judgment must be interpreted to promote an approach in line with the CRPD, adding that there must be tailor-made responses to the individual’s needs, be ‘genuinely justified’ and flow from ‘rights-based procedures and combined with effective safeguards.’

In October 2010 Hammarberg issued another Viewpoint, explicitly linking legal capacity and ill-treatment, saying that, ‘[p]ersons with disabilities are placed under guardianship and have their legal capacity removed. In a number of cases they are detained, deprived of their liberty - sometimes

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[197] Thomas Hammarberg (2009b) *Society has an obligation to support abandoned children and offer them a positive home environment - also when budget resources are limited,* Viewpoint, 28 December 2009.

[198] Chapter 5 of this book elaborates this point.

without these decisions being subjected to judicial review. This is not acceptable'.[199] This statement illustrates how human rights are interrelated and indivisible and directly connect with the right to community living, rights in institutional settings and access to justice.[200]

In March 2012 Hammarberg published an extended 'issue paper' on legal capacity.[201] In the paper, Hammarberg endorses the CRPD very strongly, and echoes the calls from the CRPD Committee to 'abolish mechanisms providing for full incapacitation and plenary guardianship', and to review laws to remedy any deprivations of 'human rights in relation to legislation concerning, inter alia, guardianship, voting rights and compulsory psychiatric care and treatment.' Hammarberg calls for an end of 'voluntary' psychiatric placements in circumstances where the guardian 'volunteers' the placement and forced treatment of the person under guardianship. This was the situation dealt with by the European Court of Human Rights in the case of *Shtukaturov v. Russia*.[202] He also calls for States to '[d] evelop supported decision-making alternatives for those who want assistance in making decisions or communicating them to others.'[203]

5. European Union

The CRPD is the first UN human rights treaty that the European Union has ratified.[204] The mapping of issues of legal capacity onto spheres and levels of EU competence poses interesting and difficult questions which do not yet

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[199] Thomas Hammarberg (2010) *Country report on Bulgaria,* CommDH(2010)1, 9 February 2010.

[200] Chapters 6 and 8 of this book explore these points further.

[201] Thomas Hammarberg (2012) Issue Paper: 'Who Gets to Decide? Right to legal capacity for persons with psychosocial disabilities and intellectual disabilities'. Strasbourg.

[202] See chapter 5 of this book.

[203] All these quotations are from the 'Recommendations' section of the issue paper.

[204] Article 44 of the CRPD allows it to be 'regional integration organizations' to ratify. The same article defines the phrase means 'an organization constituted by sovereign States of a given region, to which its member States have transferred competence in respect of matters governed by this Convention. Such organizations shall declare, in their instruments of formal confirmation or accession, the extent of their competence with respect to matters governed by this Convention.' The EU constitutes such an entity with transferred legal competences with respect for example to employment issues which is a right under Article 27 of the Convention, whereas for example, States have not transferred any such competences to the Council of Europe.

appear to have been resolved. The Code of Conduct between EU institutions and Member States setting out internal arrangements for matters relating to the CRPD does not contain information about which CRPD Articles and provisions are matters of exclusive Member State competence; of exclusive EU competence; and of shared competence.[205]

The denial or restriction of legal capacity has powerful implications for the EU such as citizenship, non-discrimination, consumer protection and free movement. For instance, in many Member States, people whose legal capacity is restricted are prohibited from signing employment contracts and are therefore automatically excluded from the labour market.[206] 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 the participation in political life of people with disabilities.[207]

Legal capacity has been notably absent from European disability plans. No word about legal capacity or autonomy was contained in the European Commission's Disability Action Plan 2003-2010. The 2004-2005 action plan (focusing on employment),[208] the 2006-2007 action plan (focusing on active inclusion),[209] and the 2008-2009 action plan (focusing on accessibility),[210] were all silent on legal capacity. In none of these documents is the link

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[205] European Council, *Code of Conduct between the Council, the Member States and the Commission setting out internal arrangements for the implementation by and representation of the European Union relating to the United Nations Convention on the Rights of Persons with Disabilities*, 2010/C 340/08 , Official Journal C 340 , 15/12/2010 P. 0011 – 0015.

[206] See EU Agency for Fundamental Rights, 'Legal capacity of persons with intellectual disabilities and persons with mental health problems', Vienna, July 2013.

[207] EU Agency for Fundamental Rights (FRA) (2010a) *The right to political participation of persons with mental health problems and persons with intellectual disabilities*, October 2010.

[208] European Commission, *Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions, 'Equal Opportunities for people with disabilities: A European Action Plan'*, COM (2003) 650 final.

[209] European Commission, *Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions, 'Situation of disabled people in the enlarged European Union: The European Action Plan 2006-2007'* COM (2005) 604 final.

[210] European Commission, *Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions: 'Situation of disabled people in the European Union: the European Action Plan 2008-2009'*. Brussels, 26 November 2007 COM(2007) 738 final.

between access to the employment market and the right to legal capacity explicitly recognised, despite the CRPD being adopted in 2006.

Legal capacity was discussed at a ministerial level meeting on 22 May 2008, which was organised by the Slovenian Presidency. Based on the information provided by the Member States and the discussion held by the EU Disability High Level Group (DHLG), the ministers concluded that legal capacity was an issue of common interest on which added European value would be derived from exchange of good practice,[211] but beyond these vague statements no action was felt necessary to be taken.

In its first annual report in 2008 (two years after the CRPD was adopted and two years before the EU ratified it), the DHLG listed legal capacity as a key challenge of implementing the CRPD and attempted to share good practice in this regard. The DHLG reported that in some Member States legal capacity was restricted through guardianship, and that the CRPD required this approach to change to a support-based system, concluding that '[t]his is a complex area of law and requires consultation and reflection'.[212] An annex to the DHLG's report lists some of the complexities in more detail.[213]

The DHLG's second annual report, published in 2009, contained achievements and challenges in legal capacity in each of the Member States.[214] 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 per Member State, so some aspects of Article 12 are set out for one State but not others, making comparisons across Member States very challenging.

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[211] European Commission, *Second Disability High level Group Report On Implementation of the UN Convention on the Rights of Persons with Disabilities*, June 2009.

[212] European Commission, *First Disability High level Group Report On Implementation of the UN Convention on the Rights of Persons with Disabilities*, 2008, p. 35.

[213] European Commission, *Annex to the First Disability High level Group Report On Implementation of the UN Convention on the Rights of Persons with Disabilities (Note for the Ministerial Meeting of 22 May 2008).*

[214] European Commission, *Second Disability High level Group Report On Implementation of the UN Convention on the Rights of Persons with Disabilities*, June 2009.

Third, there is no synthesis or analysis, making it difficult to compare progress or identify emerging good practice.

Legal capacity did not feature at all in the 2010 or 2011 DHLG annual reports,[215] rendering it impossible to compare progress over time and raising into question the credibility of the European Commission's 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'.[216]

Then in 2010 the EU published the 'European Disability Strategy 2010-2020'.[217] It briefly notes in the section on 'Equality' 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'.[218] The accompanying action plan document contains a specific equality objective of promoting 'exchange of good practices on legal capacity', an objective which was planned to be carried out between 2010 and 2013. No reports exist about whether this actually happened.

The EU's approach to legal capacity is rather minimal.[219] Many EU treaties contain provisions relevant to the right to legal capacity, and may provide the EU with competency to act.[220] The EU Disability Strategy 2010-2020 lists eight priority areas where the EU plans to take action. As noted, legal capacity is listed only in the section about 'Equality', despite legal capacity having the potential to play an important role in many of the eight priority areas.

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[215] European Commission, *Third Disability High level Group Report On Implementation of the UN Convention on the Rights of Persons with Disabilities*, March 2010.

[216] European Commission, *First Disability High level Group Report On Implementation of the UN Convention on the Rights of Persons with Disabilities*, 2008, p. 35.

[217] European Commission, *European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*, COM(2010)0636 final, para 3.

[218] Ibid, para 3.

[219] This section analyzing the responsibility which the European Union has with regards to legal capacity draws heavily on Mental Disability Advocacy Center's 2013 report 'Legal Capacity in Europe: A Call to Action to Governments and to the European Union', of which I was one of the primary authors.

[220] 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).

Three examples suffice. The first is 'participation'. Under this heading, the Commission promises to, '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'.[221] The reality is that a person deprived of legal capacity in an EU Member State is legally prohibited from participating in the life of the community as he/she is denied the right to vote in local, national and European parliamentary elections.[222] The EU Agency for Fundamental Rights (FRA) drilled down into this topic in a 2010 report,[223] drawing attention to the way in which restrictions on legal capacity imposed in many Member States undermine political rights set out in the EU Charter of Fundamental Rights and the TFEU.

Further, EU citizens deprived of their legal capacity are denied freedom of association that prevents them from taking advocacy action to demand their rights.[224] In many countries a person under guardianship is prohibited from joining foundations or political parties. The EU's goal is to 'ensure that people with disabilities enjoy all benefits of EU citizenship', yet there is no evidence yet that it has taken actions to ensure that the goal becomes real for the hundreds of thousands of EU citizens whose legal capacity has been denied or restricted. As the MDAC report points out,[225] participation includes consumer protection: an EU legal competency.[226] The EU institutions have established rules that contribute to the proper functioning of the internal market.[227] EU

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[221] *Ibid.*

[222] Article 29 of the CRPD sets out the right to vote and stand for election for all people with disabilities. See EU Fundamental Rights Agency (FRA), *The right to political participation of persons with mental health problems and persons with intellectual disabilities*. October 2010.

[223] EU Agency for Fundamental Rights (FRA) (2010) *The right to political participation of persons with mental health problems and persons with intellectual disabilities*, October 2010. Political rights was also covered in FRA's 2013 report 'Legal capacity of persons with intellectual disabilities and persons with mental health problems'.

[224] Article 29 of the CRPD places a positive obligation on States to facilitate access by people with disabilities into civil society organisations.

[225] I was one of the co-authors of this report.

[226] *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.

[227] See Article 1 of the Directive 2011/83/EU of the European Parliament and of the Council of 25 October 2011 on consumer rights.

directives govern contracts 'for supply of water, gas, electricity or district heating',[228] promote consumer protection and promote people's right to information and education.[229] Yet, across the Union, a person restricted of legal capacity is not allowed to enter into contracts, so it is impossible for them to be considered as consumers on an equal basis with others.

The second example is employment, another EU competence and listed as a priority in the EU Disability Strategy. Given the disproportionately high unemployment rates of people with disabilities within EU Member States,[230] the EU Disability Strategy states that the Commission will 'raise significantly the share of persons with disabilities working in the open labour market'.[231] People with disabilities who have their legal capacity denied in EU Member States are prohibited from signing contracts, including employment contracts, as their signatures are invalid under domestic law. In this way, legal capacity laws exacerbate poverty when the policy goal points in the opposite direction.

The European Commission has options open to it in the Treaty of the Functioning of the EU to take measures to 'encourage cooperation between Member States',[232] in order to ensure the integration of people excluded from the labour market.[233] The Employment Framework Directive, which seeks to eliminate discrimination on many grounds including disability in the field of employment and occupation provides another legal basis on which the Commission may take action.[234] Given that it is only people with disability who are deprived of legal capacity, the Commission could arguably view the link between legal capacity and employment as a matter of disability-based discrimination. The European Commission could also support and

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[228] *Ibid,* Article 3.

[229] Article 169(1) TFEU.

[230] See the EU's statistics on unemployment across the Union: http://epp.eurostat.ec.europa.eu/statistics_explained/index.php/Unemployment_statistics.

[231] Stefanos Grammenos, *IDEE Indicators of Disability Equality in Europe, ANED 2011 Task 4*, op cit.

[232] Article 153(2)(b) TFEU. Also the European Commission has the basis of the Employment Framework Directive - Directive 2000/78/EC – which seeks to eliminate discrimination on many bases including disability, in the field of employment and occupation. Given that it is only people with disability who are deprived of legal capacity, this can properly be dealt with as a matter of disability-based discrimination.

[233] Article 153(1)(h) TFEU.

[234] Directive 2000/78/EC.

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.[235]

The third example is health. The EU Disability Strategy obliges the Commission to 'promote equal access to health services and related facilities'.[236] A person deprived of legal capacity is as a direct consequence denied their right to consent to or refuse medical interventions. This results in unequal access to health services, because at once there is over-treatment (especially in mental health facilities where the guardian consents on the person's behalf) and under-treatment (where the person's healthcare for whatever reason is overlooked, or communications are misunderstood).[237]

In 2010, as a result of research funded by the European Commission, a consortium managed by the European Foundation Centre published a report on challenges to CRPD implementation. Among other issues, the report listed as a challenge the interpretative declarations or explanatory memorandums that some States have submitted, or may consider submitting, in relation to Article 12 of the CRPD. In separate reports, the consortium provided an overview of Article 12 obligations and practices,[238] and a checklist on how to assess implementation.[239]

2010 was a busy year for EU-level pronouncements on disability. A document produced by the Belgian Presidency of the EU in that year stated that as substituted decision-making is not explicitly mentioned in the CRPD and there is no wording which calls on States to abolish it (because, the document speculates, such wording 'would probably have had a chilling effect on the

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[235] Article 153(1)(h) and (j) of the TFEU.

[236] Stefanos Grammenos, *IDEE Indicators of Disability Equality in Europe,* op cit.

[237] For more on the connections between health and disability, see chapter 7 of this book. Much research has been done on this phenomena, particularly in the UK. See for example, Pauline Heslop et al, 'Confidential Inquiry into premature deaths of people with learning disabilities', University of Bristol, UK.

[238] UN Office of the High Commissioner for Human Rights (OHCHR) (2008), *Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities*, VC/2008/1214, Final Report', p. 90.

[239] European Foundation Centre (2010) *Study on Challenges and Good Practices in the Implementation of the UN Convention on the Rights of Persons with Disabilities*, (VC/2008/1214): Final Report for the DG Employment, Social Affairs and Equal Opportunities of the European Commission, Brussels.

ratification of the CRPD by a large number of States').[240] As much as any government or the EU may wish that they did not have to abolish substituted decision-making, the CRPD Committee's view is clear on the action they should take, as section 3(A) above sets out.

6. Conclusions

Already in 2009 the OHCHR highlighted the 'centrality of [Article 12] in the structure of the Convention and its instrumental value in the achievement of numerous other rights'.[241] Legal capacity should be a 'priority area for legislative review and reform' for all countries.[242] Since then, many bodies at the UN and European levels have issued authoritative statements. The CRPD Committee decided to hold its first day of general discussion on the conundrums of Article 12, and issued its first general comment on the topic. As this chapter has set out, the Committee has been steadfast in its recommendations to States that they must abolish regimes where decisions are made on behalf of people with mental disabilities to systems wherein laws enable people to access the supports which they may need to exercise their legal capacity which respect their will and preferences.

There is universal agreement at the inter-governmental level both about how legal capacity sits at the core of the paradigm shift which the CRPD seeks to usher in, and also about the need for action at legislative, policy and service delivery levels. The content of the action is, however, a matter of significant contention. At the conceptual level not one 'model' is generally agreed on, although Michael Bach's approach is perhaps the most appealing to policy-makers in that it recognises that there are some people whose will and preferences are impossible to interpret, and for those people decisions (about

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[240] European Council (2010) Belgian Presidency of the Council of the European Union (2010) *The UN Convention on the Rights of Persons with Disabilities: an Integral and Integrated Approach to the Implementation of Disability Rights', Background document prepared for the international conference 'Work Forum for the Implementation of the UN Convention on the Rights of People with Disabilities*, p. 15.

[241] United Nations Office of the High Commissioner for Human Rights (OHCHR) (2009), *Thematic study of the Office of the United Nations High Commissioner for Human Rights on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities*, A/HRC/10/48 (2009), para. 43.

[242] Ibid, para. 45.

healthcare, daily care and finances at least) do need to be made lawfully by someone else.

The silence on how States are to handle these difficult issues speaks to the nub of what is most striking in the normative statements. There are two main sources of discontent. One is the plethora of reservations and reservations-in-disguise which fourteen States have entered, and which arse discussed in section 3(d), above. Another are the submissions from States, national human rights institutions and non-governmental organisations before the deadline at the end of February 2014 in response to the CRPD Committee's draft general comment. The draft is by and large the same as the final general comment adopted in April 2014, raising serious doubts about how many submissions were actually read and translated, let alone whether the questions they raise were discussed.

What is the precise nature of the obligation under Article 12? The most pubic critic of the CRPD Committee's approach is not an academic commentator or a non-governmental organisation, but the Federal Republic of Germany, whose two-page pithy submission to the CRPD Committee in response to the draft general comment expels all extraneous issues and zeroes in on the key problematic. General comments must not extend the scope of a treaty obligation, so why is it, the German goverment asks, that 'the Committee itself concedes that its understanding of Article 12 diverges from the understanding common to the Contracting States, as evidenced by all the initial reports of State Parties so far'?[243] Germany observes that the many reservations indicate countries' 'firm intent to retain the necessary options of substitute decision-making'. Given that, 'the Committee's interpretation is not shared by the State Parties in general; not even by a substantial minority, Germany doubts that it is appropriate to call an understanding of Article 12 common to the States Parties a "misunderstanding".' The authors of the German submission outline how the German government is 'convinced that there are situations in which persons with disabilities simply are not able to make decisions even with the best support available' and that 'the Convention could not and in Germany's

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[243] Federal Republic of Germany, 'German Statement on the Draft General Comment on Article 12 CRPD', 20 February 2014.

view does not rule out the possibility of substitute decision-making in some cases.'

Not only States have tried to nudge the Committee to more provide feasible guidance. 'The abuse of systems of substitute decision-making in practice in most of the world does not [...] remove the real difficulties for a small but significant number of people, where meaningful instructions cannot be obtained,' said the non-governmental organisation which I direct in its submission.[244] These must not have been easy submissions to read for the Committee, but the Committee ignored these warnings about remaining at the high-level of principles and these requests for clarity about the operationalization of Article 12.

Some academic commentators have noted delicately that 'the distinction between supported and substituted decision-making is not always entirely clear'.[245] If the support person takes over the decision of a person whose will and preferences are unknown, the risk is that the person with disabilities gets a substituted decision made for them, a system which the Committee has told States to 'abolish'. These are normative problems but they raise profound challenges for policy-makers, service providers and families of people with mental disabilities throughout the world on an everyday basis.

This book analyses the potential horrors of substituted decision-making that have become real for many people. The Committee has done these victims of human rights violations a disservice by ignoring the fact that some people require more intense supports. The Committee has ignored the concerns of States and civil society organisations alike and has begun to thrash out a path which States are not willing to follow. It is naïve to think of human rights as solely a normative project where the UN authorities speak and the subservient States act. The architecture of contemporary human rights sets out a framework within which diplomacy is carried out. That means listening to

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[244] Mental Disability Advocacy Center, 'Written Comments on draft General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities, submitted to the UN Committee on the Rights of Persons with Disabilities', 27 February 2014, p. 10.

[245] Piers Gooding (2013) 'Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law', *Psychiatry, Psychology and Law*, 20:3, 431-451at 434.

concerns, facilitating differing opinions, interrogating systems which work and those that do not (and investigating why they do not), and on the basis of norms and empirical evidence, persuading people to do things differently.[246]

The accepted way of thinking and doing in relation to how people with mental disabilities author their own lives, and how others around them interact with their authorship, ought now to change. That the CRPD heralds a 'paradigm shift' is a hackneyed phrase whose promise now hangs in the balance, thanks in no small part to the Committee established by the Convention. It is clear that the Committee's interpretation is gaining little traction with States. It refuses to listen to States' requests to provide guidance about the difficult cases. It has created a significant risk that States turn their back on the Committee and therefore the Convention itself, that they enter more reservations and reject the human rights-based approach to disability altogether. After flirting with whole-scale reforms, countries may choose to retain laws constructed on the discriminatory scaffold of Roman law.

The CRPD recognises the importance of legal capacity as a human right. However, as demonstrated in this chapter, conceptual and practical hurdles stand in the way from a utopic implementation set out by CRPD Committee. It is therefore important for States to carry out legal changes, to learn from laws and services in other countries, and to bring round the policy table those with most expertise, namely people with mental disabilities themselves.

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[246] This approach is analysed in chapter 4 of this book.

Chapter 3: Legal Capacity Guardianship and Supported Decision-Making

This chapter originally appeared as Chapter 6 of the book “Mental Disability and the European Convention on Human Rights”, by Peter Bartlett, Oliver Lewis and Oliver Thorold, published by Brill (Martinus Nijhoff) in 2007. Oliver Lewis was the primary author of this chapter. In this chapter, references to other chapters refer to the chapters of the above-mentioned book for which the paper was originally written, not the chapters of the PhD book.

1. Introduction

Most countries have legal mechanisms to respond to situations where an individual needs assistance with making particular decisions. Such assistance may be required when a person has a difficulty with cognitive functioning caused, for example, by intellectual disabilities, some forms of "mental illness", brain damage or degenerative diseases such as Alzheimer's disease. This chapter deals mainly with safeguards required during the process of depriving someone of legal capacity, appointing a guardian, contesting decisions made by a guardian, displacing a guardian and reviewing the need for being deprived of decision-making powers. People who have been deprived of their legal capacity are, by definition, deprived of the ability to decide upon certain aspects of their life. These other aspects are considered in different chapters of the book: consenting to or refusing treatment (chapter 4), deciding where to live (chapter 2), having the right to participate in various aspects of community living (chapter 7).

Five examples illustrate different scenarios:

1. Andras, aged 40, has Down's syndrome and lives with his family. His relatives are get- ting old and are worried about where Andras will live when they cannot care for him, and concerned about how he will manage the money which one day he will inherit.

2. Beata, a woman in her 20s, has been diagnosed with 'bi-polar affective disorder'. Every few months for the past two years her behaviour becomes manic or 'high', during which time she goes out to shops and spends all her money on things which, later, she realises she does not need at all.

3. Charles had a motorcycle accident and sustained a head injury. He is currently in a coma but doctors say he may well regain consciousness in a few weeks.

4. Dora is in her 70s and lives alone without any social support. She has been diagnosed with Alzheimer's disease, and is starting to forget things and is finding it difficult to cook.

5. Edgar has mild learning difficulties. He has a part time job, but cannot do arithmetic, so finds it difficult to manage his personal finances, such as monthly budgeting and arranging bank transactions.

Different legal responses would be appropriate for each of these people. Edgar's difficulties could be solved if someone provided him with occasional assistance in his mathematics. There may be no need to recognise this relationship in law, because Edgar is able to make choices about every aspect of his life – he just needs assistance with sums. Andras is capable of taking many decisions, but does need someone to live with him to look after him. He requires plans to be put into place in the event that his parents can no longer look after him. For Andras perhaps a person could be assigned to have the legal responsibility and authority to make decisions in conjunction with Andras in the event of him being left without carers.

Beata, Charles and Dora had or have the capacity to make all decisions. Beata has a fluctuating mental illness which means that for those periods she may well feel that she needs someone to temporarily have the authority to make financial decisions for her (pay the bills, limit her credit card, allow her some spending money). She could assign these rights to someone by signing a legal document which is sometimes called an enduring power of attorney or lasting power of attorney. Beata could also consider making a decision about treatment which may detail for example the sorts of treatment options which she likes and does not like when she is in a manic state. Such advance planning of medical treatment in some countries is valid even if the person – at the time of the manic behaviour – refuses treatment.

Dora has a degenerative disease which, unfortunately, will probably get worse with time. She may well want to plan ahead, so she could also appoint a trusted person to make legal decisions for her in the event that she cannot make them herself. She could also think about making a 'living will'; that is an advance decision about treatment, meaning that a person can make a decision now, about treatment which he or she would not want in future when that person has lost capacity.

Lastly, Charles does not currently have capacity to make any decisions as he is in a coma. For him a different legal mechanism would be appropriate, perhaps one in which a trusted family member or friend who can be appointed to take decisions on his behalf. However Charles may at some point recover, so the legal arrangement would need to be regularly reviewed to ensure that his autonomy is respected when he regains the capacity to express his wishes.

The issue of capacity then, is a complex one. One-size-fits-all legal frameworks are inappropriate, for two main reasons: (1) capacity often fluctuates throughout a person's life, sometimes in a remarkably short space of time such as days or, sometimes, hours, and (2) capacity is specific to a particular decision. Andras, for example, probably has the capacity to decide on personal welfare issues such as clothes and food, but may not have capacity to understand complex medical procedures or financial transactions.

Capacity issues are dealt with differently by different countries. Some legal systems are designed to ensure that alternative decision-making processes are available for only those decisions an individual is actually incapable of making.[247] Others are less subtle, and some do not allow for partial capacity at all: if the individual is given a guardian, the guardian acquires authority over all the decisions relating to that person. This latter approach is often based on Roman law,[248] which deprives such persons of 'legal personhood'. In law, the person effectively loses all rights: in the eyes of the law, the person becomes a non-person. As the above examples show, such persons may in fact have capacity to make many decisions that affect them, but these legal systems preclude them from doing so. Of particular relevance, these legal systems do not allow people under guardianship to instruct their own lawyer, and commence proceedings (even if they are in fact capable of doing so). In some countries, people under guardianship are not even legally entitled to lodge a case at a domestic court to challenge their guardianship.[249] As discussed elsewhere in this volume,[250] that restriction does not apply for applications to the European Court of Human Rights: the ECHR provides rights to all people within countries which have ratified the Convention, whether or not they have capacity, and anyone in fact (even if not in law) capable of doing so can apply for the enforcement of those rights.

2. Definitions, and the Meaning of Functional Incapacity

The terms most often used in the context of legal incapacity and guardianship issues are 'capacity;' and 'competence'. The World Health Organization's definition is that capacity refers specifically to the presence of mental abilities to make decisions or to engage in a course of action, while competence refers to the legal consequences of not having the mental capacity.[251] In the view of the WHO, the former is determined by (health) professionals, the latter by judges (albeit on the basis of the expert opinions of health and other

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[247] See, for example, the English and Welsh Mental Capacity Act 2005.

[248] See in particular the cura furiosi in the Twelve Tables of Justinian, especially I.1.23.3.4.

[249] For example, Russia.

[250] See below in this chapter, but also chapters 2 (detention) and 9 (representation).

[251] World Health Organization (2005), Resource Book on Mental Health, Human Rights and Legislation, page 39, section 7.1.

professionals). That said, it must be admitted that the terms are sometimes used inter-changeably.

As noted above, individuals may be able to make some decisions and not others. The question of the individual's actual ability actually to make a given decision refers to 'functional' capacity, as distinct from whether he or she is precluded by law from making a decision, which may be termed 'legal' capacity.

Functional incapacity is not the same thing as having a mental disability. Some mental disabilities, be they mental illnesses or intellectual disabilities, will cause such incapacity; others will not. Indeed, empirical studies show that a significant majority of people, even with serious mental illnesses such as schizophrenia and clinical depression, are nonetheless no less competent than the general public to make decisions regarding medical treatment [252] Functional capacity instead is about the individual being able to understand the information relevant to the decision, possessing the reasoning ability to reach a decision, and to appreciating both the relevance of the information at issue and the likely results of the various choices that may be made.[253] How these criteria are to be applied will of course depend on the decision in question. Nonetheless, a few comments are appropriate.

As noted, the fact that an individual has a serious mental disability does not necessarily mean that he or she lacks functional capacity to make a decision. The question is how that disability affects their view of the information. If an individual is experiencing an episode of psychosis, for example, he or she may still have functional capacity, as long as the psychosis does not affect the decision in question. The fact that an individual has psychotic beliefs about one medication, for example, does not mean he or she lacks capacity to make treatment decisions regarding medications not affected by the psychosis.

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[252] T. Grisso and P. Appelbaum, 'The MacArthur Treatment Competence Study III: Abilities of Patients to Consent to Psychiatric and Medical Treatments' (1995), 19:2 Law and Human Behavior 149.

[253] The classic paper on standards of capacity is L. Roth, A. Meisel and C. Lidz, 'Tests of Competency to Consent to Treatment' (1977) 134:3 American Journal of Psychiatry 279.

Reaching a decision that professional people or family members believe is not in the individual's best interests is not in itself evidence of incapacity. The fact that an individual may spend a lot of money may have serious impact on the family budget, but it does not of itself make the person functionally incapacitous of handling money. Beata's case, above, provides a helpful guide. The fact that she buys things she later decides she did not need does not mean that she lacks functional capacity to make those purchases. The fact that the purchases occur at specific times in her experience of her disability makes it much more likely that she lacks such capacity, however. The question is, at the time she is making the purchases, whether she appreciates what she is doing, or whether the mania she is experiencing has the effect of removing her appreciation of the decisions she is making at the time she is making them.

The need to separate best interests from capacity flows throughout the determination of functional capacity. People with mental disabilities frequently complain that they are found to lack capacity for treatment only when they disagree with the doctor's assessment of their best interests. Disagreeing with a doctor does not in itself imply incapacity, so long as it does not flow directly as a symptom of the disorder or disability with which the individual is affected. Similarly, in decisions regarding institutionalisation, individuals do not lack capacity merely because they are unduly optimistic about whether they can survive outside the institution.

Functional capacity refers to the ability of the individual to understand the information relevant to a decision. This is not the same as requiring the individual to believe the information without question. If an individual does not believe the information the professional or family member believes to be relevant to a decision, the reasons for the non-belief should be examined. In some cases, it may be the direct result of psychosis: an individual may believe, for example, that medication has been poisoned by nurses who have been brainwashed by foreign spies. Such a delusion would obviously be relevant to the individual's functional capacity to consent to the treatment. An individual does not necessarily lack functional capacity just because he or she refuses medication because he or she thinks it does not help, or because he or she has (sometimes for understandable reasons) lost trust in the doctor prescribing it.

3. Positive duty to protect

It could be argued that Article 8 of the ECHR establishes a positive obligation on the State to ensure that the law adequately protects the rights of people who lack the capacity to make decisions. If a person with intellectual disabilities, for example, inherits a large sum of money, she may require assistance to manage that money. If the law does not provide for the person to be assisted in such decision making she may not be able to take advantage of what is rightfully hers. The person may have a claim under the Convention that her Article 8 right to a private life (to manage her own affairs) remains merely 'theoretical and illusory'[254] without such assistance. The argument is particularly strong when one considers the overarching duty under Article 1 of the Convention to secure to everyone the rights and freedoms set out in the Convention. If the ECtHR finds that such a positive obligation exists, the sorts of mechanisms which a State would have to ensure are in place would include a mechanism so that people who are thought to lack capacity can have access to speedy, accurate and independent incapacity evaluations. It would also include provisions that a person judged to lack capacity is able to enjoy the maximum possible respect for private and family life, which may necessitate appointing someone to act on that person's behalf. To date, there has been no such case on such positive obligations relating to incapacity at the European Court of Human Rights. Indeed there is little case law brought by adults who lack capacity in an area of their life. Similarly there have been few cases brought by children, especially children with disabilities who face dual discrimination of being both a child and a disabled person. The lack of cases may have more to do with access to justice (see conclusion, chapter 10) than providing us with an indication of numbers of people affected.

4. Guardianship as a human rights issue

As noted above, some legal systems are organised to ensure that the person with mental disabilities can continue to make those decisions for which he or

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[254] *Airey v. Ireland*, Application No. 6289/73, judgment 9 October 1979, (A/32) (1979–80) 2 EHRR 305, para. 24.

she has functional capacity. In other countries, instead of the law providing tailor-made options to fit an individual's needs, people are subject to a one-size-fits-all legal approach, in which they are subjected to restrictions (or complete deprivation) of their legal authority to make decisions. Such an approach is disproportionate to functional incapacity. There is growing evidence that in some countries judges routinely deprive people with mental disabilities of their legal capacity in procedures which do not meet fair trial guarantees.[255] Once the person is legally incapacitated, their right to decide on many important issues is taken away and handed over to another person, sometimes called a 'guardian'. The adult who has been legally incapacitated (hereinafter 'the adult')[256] may be subject to total guardianship[257] in which the individual retains almost none of the areas of decision making capacity. Or, the adult may be placed under 'partial guardianship' where the individual retains the legal ability to make some decisions (e.g. small financial transactions) but not others. Guardianship issues are therefore human rights issues.

The Secretary General of the United Nations has observed:

> *The function of guardianship is to protect the individual from any danger which his or her mental conditions may cause. International human rights law requires the adoption of substantial and procedural guarantees to prevent improper recourse to, and use of, guardianship arrangements.*[258]

Much of this chapter necessarily focuses on problematic aspects of guardianship systems and offers some insights through the lens of the ECHR. There are of course legitimate reasons for establishing systems in which the

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[255] See Mental Disability Advocacy Center (2006) Human Rights and Guardianship in Bulgaria. See similar reports on Hungary, Russia and Serbia. Available from www.mdac.info.

[256] The adult to whom guardianship applies is sometimes referred to as a 'ward', but this term is avoided in this book as unduly condescending. The simple word 'adult' is used to denote the 'person under guardianship'.

[257] Sometimes referred to as 'plenary guardianship'

[258] Report of the United Nations Secretary-General presented to the Fifty-eighth session of the General Assembly, 24 July 2003, Ref: A/58/181, 'Progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities'. Report of the United Nations Secretary-General presented to the Fifty-eighth session of the General Assembly, 24 July 2003, Ref: A/58/181.

decision-making powers of a person who lacks capacity to make such decisions is given to someone else. Indeed if there were no systems established to protect the well-being and support decision-making of people who, temporarily or otherwise, lack functional capacity, the State may violate people's right to a private life under Article 8 of the ECHR. This view is supported by a United Nations instrument, the 'Declaration on the Rights of Mentally Retarded Persons', which points out that a person with intellectual disabilities 'has a right to a qualified guardian when this is required to protect his personal well-being and interests'.[259]

The issue, which we estimate to affect several hundreds of thousands of people within the Council of Europe region[260] is the opposite hypothesis, that 'human rights abuses pervade guardianship: from judicial enquiry into incapacity, appointment of the guardian, the guardian's powers, oversight of the guardian and review of necessity of guardianship'.[261]

There is growing concern that guardianship systems which are established with benevolent intentions, are now used intentionally to deprive people of their civil and political as well as economic, social and cultural rights. Guardianship has only recently been considered at the highest political levels. In the report already cited, the UN Secretary General explains:

> *The right to recognition as a person before the law is often neglected in the context of mental health. The concept of guardianship is frequently used improperly to deprive individuals with an intellectual or psychiatric disability of their legal capacity without any form of procedural safeguards. Thus, persons are deprived of their right to make some of the most important and basic decisions about their life on account of an actual or perceived disability without a fair hearing and/or periodical review by competent judicial authorities. The lack*

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[259] 'Declaration on the Rights of Mentally Retarded Persons', Proclaimed by General Assembly resolution 2856 (XXVI) of 20 December 1971.

[260] Figures based on Mental Disability Advocacy Center research on legal incapacity in seven Council of Europe Member States: Bulgaria, Croatia, Czech Republic, Georgia, Hungary, Russia and Serbia and Montenegro. Reports on legislation and practice are forthcoming.

[261] O. Lewis, 'Mental Disability Law in Central and Eastern Europe: Paper, Practice, Promise', 8 *Journal of Mental Health Law* (2002) 293.

> *of due process guarantees may expose the individual whose capacity is at stake to several possible forms of abuse. An individual with a limited disability may be considered completely unable to make life choices independently and placed under "plenary guardianship". Furthermore, guardianship may be improperly used to circumvent laws governing admission in mental health institutions, and the lack of a procedure for appealing or automatically reviewing decisions concerning legal incapacity could then determine the commitment of a person to an institution for life on the basis of an actual or perceived disability.*[262]

Professor Paul Hunt, the UN Special Rapporteur on the Right to the Highest Attainable Standard of Physical and Mental Health highlighted this concern in his thematic report on the interface between mental disabilities and the right to health. Commenting in a section discussing the concerns of people with intellectual disabilities, Professor Hunt states:

> *Guardianship has been overused and abused in the medical, as well as other, contexts, including at the most extreme level to place persons with intellectual disabilities in psychiatric institutions. This is inappropriate medically and socially, and is inconsistent with the rights of persons with intellectual disabilities to health, autonomy, participation, non-discrimination and social inclusion.*[263]

The same words could equally be used in relation to people with mental illness. The stigma and discrimination experienced by people with such disabilities can only be perpetuated by guardianship systems which do not comply with international law and standards.

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[262] See para. 15 of the UN Secretary-General's report, cited above.

[263] Report of the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt, Report to the Sixty-first session of the Commission on Human Rights, 11 February 2005, Ref: E/CN.4/2005/51. Para. 79.

5. Recommendation R(99)4: Principles Concerning the Legal Protection of Incapable Adults

In 1999 the Council of Europe focused its attention on decision making of people who lack capacity by issuing 'Recommendation No. R(99)4 of the Committee of Ministers to Member States on Principles Concerning the Legal Protection of Incapable Adults'.[264]

Recommendation No. R(99)4 is the only Council of Europe instrument which sets detailed standards in this area. The Commissioner of Human Rights of the Council of Europe has urged States to implement Recommendation No. R(99)4:

> *Legislation and practises in several countries relating to the judicial finding of incapacity and the placement under guardianship give rise to concern. The transfer of civil, political and welfare rights with inadequate or only formal judicial control obviously opens up the possibility of abuse by unscrupulous family members, "professional guardians" and directors of institutions. The implementation of Recommendation No. R(99)4 of the Committee of Ministers of the Council of Europe on Principles concerning the legal protection of incapable adults would greatly reduce such abuses, whilst enabling people to act appropriately on behalf of others in need of assistance.*[265]

As a human rights document, Recommendation No. R(99)4 is authoritative and useful because it helps to put flesh on the bones of the ECHR in relation to legal incapacity and guardianship law. The ECtHR has already cited Recommendation No. R(99)4 with authority in one guardianship case.[266] This section of the chapter will offer guidance on how the Recommendation can be used by litigants, lawyers and judges to support Convention arguments in future cases in domestic courts and at the Strasbourg Court.

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[264] Adopted by the Committee of Ministers on 23 February 1999 at the 660th meeting of the Ministers' Deputies.

[265] Conclusions of the Commissioner, Seminar organized by the Council of Europe Commissioner for Human Rights and hosted by the World Health Organization Regional Office for Europe, Copenhagen, Denmark 5–7 February 2003, paragraph 11.

[266] *H.F. v. Slovakia*, Application No. 54797/00, judgment 8 November 2005.

Recommendation No. R(99)4 concerns 'the protection of adults who, by reason of an impairment or insufficiency of their personal faculties, are incapable of making, in an autonomous way, decisions concerning any or all of their personal or economic affairs, or understanding, expressing or acting upon such decisions, and who consequently cannot protect their interests'.[267] The Explanatory Memorandum to Recommendation No. R(99)4 explains that the concept of autonomy 'is used in a wide sense – based on the idea of the authenticity of decisions in the light of a person's character, values and life history. An autonomous decision must be free from external coercion and internal compulsion due, for example to such factors as schizophrenic delusions or severe depressive episodes. It should also be based on a sufficient understanding of the importance and consequences of the decision'. The Explanatory Memorandum makes it clear that the concept of rationality has no part in Recommendation No. R(99)4, as it could be easily misinterpreted. As discussed above in this chapter and in chapter 4, capacity must not be allowed to boil down to whether the patient agrees with the doctor. A similar argument can be made in relation to other areas where there is a substitute decision maker. The Explanatory Memorandum goes on to explain that '[t]he incapacity may be due to a mental disability, a disease or a similar reason,' the latter category of which may include accidents or states of coma in which the person is unable to formulate his or her wishes or to communicate them.[268]

6. The Need for a Flexible Approach

One of the main criticisms of guardianship systems is that they allow for solutions which are not tailor-made to the individual's needs. In many countries only total (or 'plenary') guardianship is available. That is to say, in law the person retains either all or no rights. This makes no logical or legal sense considering that many people can make some but not all decisions on their own or with appropriate support, and given the general principles underlying the Recommendation of maximising autonomy, self-determination

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[267] Part 1, para. 1.

[268] Explanatory Memorandum to Recommendation No. R(99)4, para. 20.

and social inclusion, and the fundamental principle running through the Convention of proportionality.

People with mental health problems raise different sorts of practical problems for systems of guardianship, because their capacity can vary over time. Sometimes such variation will be unpredictable; in other circumstances there may be some warning that changes are occurring. Sometimes the incapacity will be a single occurrence, if caused for example by some forms of psychosis; sometimes it may be recurrent, if caused by bipolar disorder ('manic depression'), for example. In many cases, recurrence may depend on the medical régime prescribed, and whether the individual chooses to continue on the medication. The difficulty from a guardianship perspective is how to create a system that will have sufficient human rights protections, but at the same time will be flexible and sensitive enough that the individual has control over decisions at the time when they have capacity, and have appropriate protection in the form of a guardian when they lose that capacity. The processes taken as standard in determination of a person's rights can be too cumbersome to react swiftly to these situations, and, if repeated for periodic incapacity, can prove expensive.

Recognising the need for a flexible legal approach, Recommendation R(99)4 advises that measures to protect the personal and economic interests of the person in question 'should be sufficient, in scope or flexibility, to enable a suitable legal response to be made to different degrees of incapacity and various situations'.[269] Further, the Recommendation goes on to say that laws should preserve legal capacity as far as possible:

> *The legislative framework should, so far as possible, recognise that different degrees of incapacity may exist and that incapacity may vary from time to time. Accordingly, a measure of protection should not result automatically in a complete removal of legal capacity. However, a restriction of legal capacity should be possible where it is shown to be necessary for the protection of the person concerned.*[270]

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[269] Recommendation No. R(99)4, Principle 2(1).

[270] Recommendation No. R(99)4, Principle 3(1).

The legal measure should be 'proportional to the degree of capacity of the person concerned and tailored to the individual circumstances and needs of the person concerned',[271] and the 'measure of protection should interfere with the legal capacity, rights and freedoms of the person concerned to the minimum extent which is consistent with achieving the purpose of the intervention'.[272]

The Recommendation uses ECHR language of 'necessity', warning that a measure of protection should not be pursued 'unless the measure is necessary, taking into account the individual circumstances and the needs of the person concerned'.[273] Anticipating that the national legislation allows for alternatives to guardianship (which in many countries it does not) the Recommendation suggests that, 'account should be taken of any less formal arrangements which might be made, and of any assistance which might be provided by family members or by others.'[274] Later, it emphasises this point by elaborating that it is for 'national law to determine which juridical acts are of such a highly personal nature that they can not be done by a representative.[275]

The Explanatory Memorandum to the Recommendation makes clear that there are some matters which almost everyone would agree are so personal that a guardian should never undertake on behalf of the person under guardianship – these include voting, marrying, and recognising and adopting a child.[276]

Conversely, national law must 'determine whether decisions by a representative on certain serious matters should require the specific approval of a court or other body'.[277] The Explanatory Memorandum explains that such a technique can be used to require a court to give specific approval before

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[271] Recommendation No. R(99)4, Principle 6(1).

[272] Recommendation No. R(99)4, Principle 6(2). The World Health Organization emphasises that 'legislation should contain provisions and procedures for discharge from guardianship when the affected person regains competence in the future'. World Health Organization, Resource Book on Mental Health, Human Rights and Legislation, (Geneva: WHO, 2005), p. 42.

[273] Recommendation No. R(99)4, Principle 5(1). See also ECHR 'necessity' language in Article 8 of the Convention and related case law.

[274] Recommendation No. R(99)4, Principle 5(2).

[275] Recommendation No. R(99)4, Principle 19(1).

[276] Explanatory Memorandum to Recommendation No. R(99)4, para. 67.

[277] Recommendation No. R(99)4, Principle 19(2).

decisions of a certain nature are made, such as consent to a certain serious or controversial health decision, disposal of certain capital, or incurring a certain type of obligation.[278]

Recommendation No. R(99)4 makes a series of points urging States to consider reforming their laws so as to reflect the following legal arrangements. Laws could include the legal recognition of advance directives, which are decisions made by a person who has capacity to provide for any subsequent incapacity.[279] Laws could regulate measures under which the appointed person acts jointly with the adult concerned, and of measures involving the appointment of more than one representative.[280] Finally, laws need 'to provide expressly that certain decisions, particularly those of a minor or routine nature relating to health or personal welfare, may be taken for an incapable adult by those deriving their powers from the law rather than from a judicial or administrative measure'.[281]

7. Procedural Aspects of Legal Incapacity and Guardianship

It has been emphasised in chapter 2 on detentions for reason of mental disability that the vast majority of mental disability cases brought to the European Court on Human Rights have been about process rather than substance. A similar observation may be made regarding capacity, where the Court has been more forthcoming on matters of process than substance, even in interpreting Articles that on their face appear to be primarily about substance. Thus in a case brought by people with mild intellectual disabilities, the Court held that, 'whilst Article 8 contains no explicit procedural requirements, the decision-making process leading to measures of

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[278] Explanatory Memorandum to Recommendation No. R(99)4, para. 67. For a further discussion of right to property in chapter 7 on "participation in society".

[279] Recommendation No. R(99)4, Principle 2(7).

[280] Recommendation No. R(99)4, Principle 2(6).

[281] Recommendation No. R(99)4, Principle 2(8).

interference must be fair and such as to afford due respect to the interests safeguarded by Article 8'.[282]

The ECHR Article most relevant in procedural matters is Article 6, the right to a fair trial. Article 6(1) states:

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

Guardianship that affects someone's property rights falls within 'civil rights' and is thus afforded the protection of Article 6. In the earliest mental health case, *Winterwerp v. the Netherlands*,[283] Mr Winterwerp was detained in a psychiatric hospital. As a result of the detention, he was automatically deprived of his legal capacity to administer property. The European Court of Human Rights examined this aspect of the case under Article 6, stating:

> *The capacity to deal personally with one's property involves the exercise of private rights and hence affects "civil rights and obligations" within the meaning of Article 6 para. 1 [. . .]. Divesting Mr. Winterwerp of that capacity amounted to a "determination" of such rights and obligations.*[284]

The Court went on to point out that '[w]hatever the justification for depriving a person of unsound mind of the capacity to administer his property, the guarantees laid down in Article 6 para. 1 (art. 6–1) must nevertheless be

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[282] *Kutzner v. Germany*, Application No. 46544/99, judgment 26 February 2002, (2002) 35 EHRR 25, para. 56.

[283] *Winterwerp v. the Netherlands*, Application No. 6301/73, judgment 24 October 1979, (A/33) (1979).

[284] *Winterwerp v. the Netherlands*, op. cit., para. 73.

respected'.[285] In the case of *Matter v. Slovakia*, decided twenty years after *Winterwerp*, the Court re-stated its position:

> *The purpose of the proceedings is to determine whether or not legal capacity can be restored to the applicant, i.e. whether or not he is entitled, through his own acts, to acquire rights and undertake obligations set out, inter alia, in the Civil Code. Their outcome is therefore directly decisive for the determination of the applicant's "civil rights and obligations". Accordingly, Article 6 § 1 is applicable.*[286]

The scope of Article 6 is not restricted to decisions regarding property, however, but applies to the determination of civil rights generally. The right to sick pay at work,[287] the right to receive disability living allowance,[288] and the right to register an association,[289] for example, have been found by the Court to be 'civil rights' and therefore to engage Article 6. The right to liberty has also been held by the ECtHR to be a 'civil right' under Article 6,[290] suggesting that the Court may be prepared to ensure a wide reading of the term. In that event, it is likely that the right to consent to treatment and the right to make other personal decisions may well be within the scope of Article 6, and a court hearing would be available to challenge the restriction of any restriction on those rights.

Recommendation No. R(99)4 states that there should be 'fair and efficient procedures for the taking of measures for the protection of incapable adults'.[291] The Recommendation continues that there 'should be adequate procedural safeguards to protect the human rights of the persons concerned

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[285] *Winterwerp v. the Netherlands*, op. cit., para. 75.

[286] *Matter v. Slovakia*, Application No. 31534/96, judgment 5 July 1999, (2001) 31 EHRR 32, para. 51.

[287] *Feldbrugge v. the Netherlands*, Application No. 8562/79, judgment 29 May 1986, (A/99) (1986) 8 EHRR 425.

[288] *Salesi v. Italy*, Application No. 13023/87, judgment 26 February 1993, (A/257–E) (1998) 26 EHRR 187.

[289] APEH Üldözötteinek Szövetsége and others v. Hungary, Application No. 32367/96, judgment 5 October 2000, (2002) 34 EHRR 34.

[290] *Aerts v. Belgium*, Application No. 25357/94, judgment 29 June 1998, (1998) 29 EHRR 50, para. 59.

[291] Recommendation No. R(99)4, Principle 5(1).

and to prevent possible abuses,'[292] with the Explanatory Memorandum warning that:

> *It is necessary to be on guard against the danger that a change to welfare terminology will conceal the essential nature of what is being done. A measure which is called a measure of protection or assistance may in reality be an infringement of rights and freedoms from the point of view of the adult concerned.*[293]

The Court has echoed this approach, although not yet in a guardianship context. In cases concerning paternity, for example, the Court has been careful to articulate that 'particular diligence is required in cases concerning civil status and capacity'.[294]

In this chapter typical guardianship proceedings will be examined in as near chronological order as is possible, and some suggestions will be made as to how the Court may deal with these issues in future cases. During domestic court proceedings at which a person's legal capacity is in question, a number of issues may arise, namely: notification about the hearing, expert evidence, right to be heard in person, entitlement to test the evidence, legal representation and its quality, access to court and medical file, and appeal rights. These issues will be taken in turn.

Sufficient notice

The person whose capacity is in question must obviously be informed of the proceedings, and be given a reasonable time to prepare a case. Recommendation No. R(99)4 specifies:

> *The person concerned should be informed promptly in a language, or by other means, which he or she understands of the institution of proceedings which could affect his or her legal capacity, the exercise of his or her rights or his or her interests unless such information*

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[292] Recommendation No. R(99)4, Principle 7(2).

[293] Explanatory Memorandum to Recommendation No. R(99)4, para. 48.

[294] *Szarapo v. Poland*, Application No. 40835/98, judgment 23 May 2002, para. 40.

> *would be manifestly without meaning to the person concerned or would present a severe danger to the health of the person concerned.*[295]

It is not clear why the ‘manifestly without meaning’ provision was included, as there appears to be no disadvantage to anyone to provide information in all situations. It is difficult to imagine a situation where someone’s health would be put in ‘severe danger’ on being told about an incapacity procedure.

Any procedure in which civil rights are determined without hearing the parties is plainly in violation of Article 6(1). In the criminal law context, the Court has held that a person can waive his or her rights to be present at the court hearing only if sufficient notice has been served, and such a desire not to be present has unequivocally been made.[296] Such safeguards are not always provided in guardianship proceedings. In some countries it sometimes happens that the entire proceedings in which a person is deprived of their legal capacity without notifying or involving the person in question.[297]

Incapacity assessment

If the State is under a positive obligation to provide assistance in decision making where a person lacks capacity to make that particular decision, then it would seem logical that the package of positive obligations should contain a right to have one’s capacity assessed. There has been no case law on this point. Recommendation No. R(99)4 advises that the list of those entitled to institute guardianship proceedings (or other measures) should be sufficiently wide to ensure that measures of protection can be considered in all cases where they are necessary.[298] Carers (such as family members) may be in good position to apply for an incapacity assessment in order to instigate legal protection. However, as ECHR cases have illustrated, family members may sometimes

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[295] Recommendation No. R(99)4, Principle 11(2).

[296] See *Poitrimol v. France*, Application No. 14032/88, judgment 26 October 1993, (1993) 6 EHRR 516, (para. 31).

[297] The Mental Disability Advocacy Center, to which the authors are connected, is currently litigating cases from Bulgaria, Czech Republic, Estonia and Russia at the European Court of Human Rights where the applicant has been placed under guardianship without having been notified of the proceedings.

[298] Recommendation No. R(99)4, Principle 11(1).

have ulterior motives for instigating guardianship proceedings.[299] A court therefore needs to carry out a rigorous assessment as to the need for an adult's decision-making rights to be limited or removed altogether, and not make assumptions based on diagnoses. There is an argument that the adult's lawyer or at least an independent person, should be present during the incapacity assessment itself, as an extra safeguard against abuse.

The more common issue is that during the course of incapacity / guardianship the adult's capacity is assessed without that person's consent. In such circumstances there is a tension between respecting the person's right to privacy (and therefore right to assistance if the person lacks capacity), and another aspect of the person's right to privacy (in terms of unnecessary psychiatric and other examinations).

Various aspects of the incapacity assessment may engage the Convention. For example, the expert's independence from the parties could be brought into question if there is any collusion, or if the family member pays for the assessment. The expert must be, in the words of Recommendation No. R(99)4, 'suitably qualified',[300] which probably means a psychiatrist or psychologist.[301] Interestingly, a UN document from 1971 specifies that the incapacity assessment should include an evaluation of the 'social capability' of the person in question.[302] The expert must provide a report within a reasonable period of time.[303]

In the case of *Bock v. Germany*,[304] on the face of it a length of time case, the applicant's wife insisted during protracted divorce proceedings, that he lacked the capacity to conduct legal proceedings. Over a period of six years the applicant underwent a total of five psychiatric examinations resulting in two

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[299] See, for example, *Bock v. Germany*, Application No. 11118/84, judgment 21 February 1989, (1987) 9 EHRR CD562 [sub nom A. v. Germany].

[300] Recommendation No. R(99)4, Principle 12(2).

[301] This could itself be an area of challenge by a lawyer or the adult him/herself. In some countries there are questions to be asked as to the training which psychiatrists receive in assessing incapacity.

[302] 'Declaration on the Rights of Mentally Retarded Persons', Proclaimed by General Assembly resolution 2856 (XXVI) of 20 December 1971, para. 7.

[303] *Martins Moreira v. Portugal*, Application No. 11371/85, judgment 7 October 1988, (1991) EHRR 517.

[304] Application No. 11118/84, judgment 21 February 1989. See also the Commission Report, 13 November 1987.

failed attempts by the wife to have the husband placed under guardianship. In examining length of time issues under Article 6 of the Convention, the Court said that, 'there was not so much a lack of judicial activity as an excessive amount of activity which focused on the petitioner's mental state.' The Court went on to say that despite the protracted legal proceedings, 'doubts still persisted in the national courts as to his soundness of mind, although, by the time of the final divorce judgment, there was a total of five reports attesting Mr Bock's soundness of mind [. . .] Finally, the Court cannot disregard the personal situation of the applicant who, for some nine years, suffered by reason of the doubts cast on the state of his mental health which subsequently proved unfounded. This represented a serious encroachment on human dignity'.[305] The Court (perhaps because it was not raised by the parties) did not consider whether this encroachment constituted a violation of Article 8.

Two Polish cases illustrate the Court's approach to forced psychiatric evaluations. In the first case, decided in 2002, *Nowicka v. Poland*,[306] the applicant had been detained on several occasions for a total period of eighty-three days and was imposed in the context of a private prosecution arising out of a neighbours' dispute. The Court found that even though the detention was 'lawful' under Article 5(1)(b) following a court order, any deprivation of liberty should be consistent with the purpose of Article 5, namely to protect individuals from arbitrariness. It went on to hold that a balance must be struck between the fulfilment of a court order and a person's right to liberty. The Court found that the balance had not been struck and found a violation of Article 5.

The case of *Worwa v. Poland*, decided in 2003, was again not a guardianship case, but one in which the district court had, at very short intervals, ordered medical reports on the applicant's mental state in connection with a number of similar criminal cases pending before it. The ECtHR found that these constituted interference by a public authority in her private life, within the meaning of Article 8(1) of the Convention, and that that interference was in accordance with the law. The Court went on to find a violation of Article 8,

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[305] *Bock v. Germany*, op. cit., para. 48.

[306] Application No. 30218/96, judgment 3 December 2002, [2003] 1 FLR 417.

because the domestic court did not strike a fair balance between the rights of the individual's right to respect for private life, and the concern to ensure the proper administration of justice, and therefore that interference with the applicant's private life was unjustified.[307]

The Court has recently for the first time referred authoritatively to Recommendation R(99)4 in the case of *H.F. v. Slovakia*.[308] In this case the applicant had been deprived of her legal capacity in November 1997 by the Bratislava District Court based on a psychiatric report of July 1996 and statements from the applicant's former husband and witnesses he had called. The applicant was given no opportunity to give evidence to the district court. The European Court of Human Rights considered that the psychiatric report could not be regarded as 'up-to-date' as per Recommendation No. R(99)4, which speaks of 'at least' one qualified expert.[309] The Court noted that a second psychiatric expert should have been instructed to report. This was not only in the interests of the applicant, whose mental condition was liable to evolve with treatment, but also in the interests of the truth, which the district court had an obligation to establish. In finding a violation of Article 6 of the Convention, the Court stated that a further report would have enabled the district court to establish more effectively whether the psychiatrist's recommendation in 1996 that it should not hear evidence from the applicant remained valid at the date of its decision.

In summary, forced psychiatric examinations have been found by the Court in different cases to violate Articles 5, 6 and 8 of the Convention. State authorities must carefully balance external interests with the fundamental rights guaranteed in the Convention.

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[307] Application No. 26624/95, judgment 23 November 2003.

[308] Application No. 54797/00, judgment 8 November 2005.

[309] Recommendation No. R(99)4, Principle 12(2).

Right to be heard in person

Recommendation No. R(99)4 states that '[t]he person concerned should have the right to be heard in person in any proceedings which could affect his or her legal capacity'.[310]

Phrased in this way, the person is entitled to be heard not just in the trial itself, but in administrative proceedings leading up to the trial, as well as case management hearings. The Recommendation also advises that the judge should personally see the adult or be satisfied as to the adult's condition.[311] It sometimes happens that that the person whose capacity is in question does not attend court because the psychiatrist author of the report on capacity has additionally recommended that the person is 'too mentally ill' to attend court. This situation creates a conflict of interests because the person supporting the application for deprivation of legal capacity is also asking the court not to see the person in question. It is a Convention right under Article 6 to attend proceedings concerning one's civil rights, and the judge is put in the impossible position of relying only on one side of the story, without hearing from the very person whose rights are in question. In these circumstances, it is our view that the judge should hold the court procedure at the hospital or institution in which the person whose capacity in question is being cared for. The judge should insist on seeing and speaking with the person, however 'mentally ill' the person is reported to be.

Adequacy of evidence

Related to the question about the adult attending the court hearing is the quality of evidence of the application. In the *H.F. v. Slovakia* case referred to above,[312] the district court deprived Mrs H.F. from her legal capacity in a court hearing at which she did not give evidence. Instead, the district court relied on a psychiatric report written one and a half years previous, and on statements by the applicant's former husband and witnesses he had called. These and

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[310] Recommendation No. R(99)4, Principle 13.

[311] Recommendation No. R(99)4, Principle 12(2).

[312] *H.F. v. Slovakia*, Application No. 54797/00, judgment 8 November 2005.

other procedural defects led the European Court of Human Rights to find a violation of Article 6(1) of the Convention. It is to be expected that future cases will challenge flimsy evidence supporting incapacity applications. In such cases the Court may import guarantees now well established under Article 5 into the Article 6 guardianship arena. Such basic safeguards may include fresh medical evidence,[313] written by a qualified person,[314] and the basic fair trial guarantee that evidence should be served on the person enough in advance of the court hearing for that person to instruct alternative experts, if required. It bears repeating that these guarantees are so low to make the 'rights' almost meaningless: as was discussed in chapter 2 on detention, the Court must be prepared to set some standards in substantive issues.[315]

Experts' reports should be in written form,[316] and the expert should give oral evidence at the incapacity hearing so that the adult in question and his/her lawyer as well as the judge can cross-examine the expert and challenge the opinions put forward. Any reports from experts instructed by or on behalf of the person whose capacity is in question should be considered by the court in the same way as other expert reports.[317]

Disclosure of documents

The person whose capacity is in question and that person's lawyer must have access to documents held by the other party and by the court, such as the application by the family member or local government, expert psychiatric or psychological opinions and medical records. In civil proceedings a party is entitled to documentation in the possession of the State if this is relevant to the civil claim. This requirement is consistent with the Article 6(1) case-law in which the Court has stated:

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[313] See *Varbanov v. Bulgaria*, Application No. 31365/96, judgment 5 October 2000, (1998) 25 EHRR CD154.

[314] *Winterwerp .v the Netherlands*, op. cit.

[315] The World Health Organization's International Classification of Functioning, Disability and Health moves away from a reliance on diagnosis and provides a helpful guide to psychologists, psychiatrists, lawyers and judges involved in guardianship proceedings.

[316] Explanatory Memorandum to Recommendation No. R(99)4, para. 54.

[317] In an analogous case of *Kutzner v. Germany* (see right to family life section in chapter 7 on participation in society), the Court said that reports could not be disregarded simply because the experts were acting privately.

> *[T]he principle of equality of arms is only one feature of the wider concept of a fair trial, which also includes the fundamental right that proceedings should be adversarial. [. . .] The right to an adversarial trial means the opportunity for the parties to have knowledge of and comment on the observations led or evidence adduced by the other party.*[318]

Courts which hear incapacity and guardianship cases must therefore ensure that the adults in question and their lawyers are given full disclosure of all documentation upon which the application is based.

Legal representation

There have been no cases directly concerning legal representation during incapacity procedures, but as was discussed in chapter 2 above, in the context of detention hearings the Court has stated that '[s]pecial procedural safeguards may prove called for in order to protect the interests of persons who, on account of their mental disabilities, are not fully capable of acting for themselves'.[319] The same must be true of incapacity and guardianship procedures.

During incapacity court hearings, if the very allegation made by the opposing party is that the adult in question cannot manage his or her affairs to the extent that the adult's very legal capacity is in doubt, then it follows, given the gravity of issues to be decided, that such a person be represented by a qualified lawyer. The necessity of good quality legal representation is even more strong when one considers (a) that in every such case there are expert witnesses, (b) that such a case will often have serious consequences for the per- son affecting many aspects of the person's civil, political, economic, social and cultural rights, and (c) that the person's mental health will undoubtedly be centre stage. It would be difficult for a government to muster arguments to suggest that Article 6 does not mandate legal representation in court

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[318] *Ruiz-Mateos v. Spain*, Application No. 12952/87, judgment 23 June 1993, (A/262) (1993) 16 EHRR 505, para. 63.

[319] *Megyeri v. Germany*, Application No. 13770/88, judgment 10 November 1992, (1992) 15 EHRR 584, para. 22.

proceedings concerning legal capacity. The arguments discussed regarding representation in challenges to deprivation of liberty under Article 5(4) apply mutatis mutandis.[320]

This position is enshrined in international law via Principle 6 of the UN Resolution 46/119 on the Protection of Persons with Mental Illness and the Improvement of Mental Health Care:

> *The person whose capacity is at issue shall be entitled to be represented by a counsel. If the person whose capacity is at issue does not himself or herself secure such representation, it shall be made available without payment by that person to the extent that he or she does not have sufficient means to pay for it. The counsel shall not in the same proceedings represent a mental health facility or its personnel and shall not also represent a member of the family of the person whose capacity is at issue unless the tribunal is satisfied that there is no conflict of interest.*[321]

The one ECHR case which touches on legal representation is again *H.F. v. Slovakia*, in which the European Court of Human Rights noted that the Slovak Code of Civil Procedure required the courts to appoint a guardian to act on behalf of those whose legal capacity was at issue, even if the person was assisted by a lawyer. In this case it appeared that the applicant had not been represented by a guardian in the district court and had only been represented in a formal way on appeal. Referring to Recommendation R(99)4, the ECtHR accepted the applicant's submission that the purpose of the appointment of a guardian had not been fulfilled in her case.[322]

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[320] See further chapters 2 and 9.

[321] See Principle 6 of the MI Principles, adopted by the General Assembly on 17 December 1991. Similarly, the World Health Organization adopts this position: '[i]deally, a legal counsel should routinely be made available to a person whose competence is in question. Where a person is unable to afford a counsel, legislation may require that counsel be provided to the beneficiary free of charge'. The WHO adds that '[l]egislation should ensure there is no conflict of interest for the counsel. That is, the counsel representing the concerned person should not also be representing other interested parties, such as the clinical services involved in the care of the concerned person and/or the family members of the concerned person.'

[322] See also a curious admissibility decision by the (now defunct) European Commission of Human Rights in the case of *Bocsi v. Hungary*, Application No. 24240/94,

Where legal representation is provided, where does the State's responsibility end? In general, where the State provides for legal representation, it must of course be adequate because the Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective.[323] In the chapter on detention (chapter 2 above), we discussed adequacy of counsel issues and made the point that Article 6 guarantees have been drawn by the Court into Article 5(4) jurisprudence. In the context of incapacity hearings of course, Article 6 is directly applicable.

In criminal cases, the Court has said in the context of Article 6 that the State has an ongoing duty to ensure adequate representation:

> *Mere nomination does not ensure effective assistance since the lawyer appointed for legal aid purposes may die, fall seriously ill, be prevented for a protracted period from acting or shirk his duties. If they are notified of the situation, the authorities must either replace him or cause him to fulfil his obligations.*[324]

As a matter of logic, if the State could meet Article 6 guarantees merely by nominating or appointing a lawyer, in many instances free legal assistance would prove to be worthless.[325] For a practical guide to representing people with mental disabilities, including in guardianship proceedings, see appendix 7 of this volume.

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admissibility decision 21 May 1998. In this case the Commission considered an application by a woman who was deprived of her legal capacity and who complained about the lack of legal representation at the Supreme Court relating to her incapacity case. Recalling the general right to legal representation for people who do not have the capacity to conduct litigation themselves, the Commission stated that 'a refusal to appoint a guardian to a person not able to litigate in connection with a case which has no prospect of success does not interfere with the right, in civil cases, of access to court'. In its decision the Commission went on to explain that the applicant, 'whose action had been based on the very claim that her mental state no longer required her to be placed under guardianship, could reasonably be expected to arrange for her representation before the Supreme Court. Her submissions do not, therefore, disclose any appearance of a breach of her right of access to court, as enshrined in Article 6 para. 1 [. . .] of the Convention'.

[323] Belgian Linguistic case, Application Nos. 1474/62, 1677/62, 1691/62, 1769/63, 1994/63 and 2126/64, judgment 23 July 1968, para. 31.

[324] *Artico v. Italy*, Application No. 6694/74, judgment 13 May 1980, (A/37) (1981) 3 EHRR 1, para. 33.

[325] See chapter 2 above on detention, and chapter 9 on legal representation, as well as appendix 7 of this volume. See also Mental Disability Advocacy Centre, Liberty Denied: Human Rights Violations in Criminal Psychiatric Detention Reviews in Hungary, (Budapest: MDAC, 2004).

Appeal rights

Article 6(1) does not guarantee appeals from a court of first instance. However, where domestic law allows for an appeal, the appeal process is subject to the guarantees of Article 6. Recommendation No. R(99)4 states that there should be a right to an adequate appeal.[326] The UN Resolution on the Protection of Persons with Mental Illness and the Improvement of Mental Health Care goes further by specifying who should have the standing to appeal: 'The person whose capacity is at issue, his or her personal representative, if any, and any other interested person shall have the right to appeal to a higher court against any such decision'.[327]

The fact that there may be no appeals available in domestic law should not prevent a thorough examination of the proceedings for any aspects that may not comply with the Convention. In these circumstances of course, the person affected has a right to remedies under Article 13 of the European Convention on Human Rights, and such complaints should be lodged with the relevant domestic authorities and courts and a case lodged at the European Court of Human Rights (see chapter 8 below on applying to the ECtHR). In the case of *Delcourt v. Belgium* the Court re-stated that Article 6(1) of the Convention does not compel countries to set up courts of appeal, but went on to say that '[n]evertheless, a State which does institute such courts is required to ensure that persons amenable to the law shall enjoy before these courts the fundamental guarantees contained in Article 6 '.[328]

Such guarantees are important because in some countries the person under guardianship lacks legal standing (legal ability) to appeal the court decision depriving him or her of legal capacity. It would not meet the spirit of *Delcourt v. Belgium* if an individual was denied access to legal remedies, precisely

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[326] Recommendation No. R(99)4, Principle 14(3). See also 'Declaration on the Rights of Mentally Retarded Persons, Proclaimed by the UN General Assembly resolution 2856 (XXVI) of 20 December 1971, para. 7.

[327] Principle 1(6) UN Resolution 46/119 on the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, adopted by the General Assembly on 17 December 1991.

[328] *Delcourt v. Belgium*, Application No. 2689/65, judgment 17 January 1970, (1979–80) 1 EHRR 355 para. 25.

because they had been deprived of their rights by the judgment he or she wished to appeal.

It is similarly important that other people are entitled under domestic legislation to challenge a decision to deprive a person of legal capacity, because the adult may not have the capacity to know that there have been procedural or other violations or how to go about challenging the decision.

Length of proceedings

The Court examined length of guardianship proceedings in *Matter v. Slovakia*. The proceedings relating to the decision to deprive the applicant of his legal capacity began in 1987 and were still pending at the time of the Court's judgment, over seven years since the former Czech and Slovak Federal Republic ratified the Convention and recognised the right of individual petition in March 1992. The Court noted that the case's complexity did not justify its length, and went on to identify periods of inactivity for which no satisfactory explanation had been provided by the Government. The Court found that the domestic courts had failed to act with the special diligence required by Article 6(1) in cases of this nature. This, 'and having regard to what was at stake for the applicant',[329] the Court found a violation of Article 6 of the Convention.

Choosing a guardian

Recommendation No. R(99)4 suggests that the paramount consideration when choosing a guardian should be the suitability of that person to safeguard and promote the 'interests and welfare' of the adult lacking capacity.[330] The Recommendation says that 'the wishes of the adult as to the choice of any person to represent or assist him or her should be taken into account and, as

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[329] *Matter v. Slovakia*, Application No. 31534/96, judgment 5 July 1999, (2001) 31 EHRR 32, para. 61.

[330] Recommendation No. R(99)4, Principle 8(2).

far as possible, given due respect'.[331] The Explanatory Memorandum to the Recommendation warns wisely, that whilst the invaluable and irreplaceable role of relatives must be recognised and valued, the law must watch out for unscrupulous family members.[332]

It follows that the law needs to have mechanisms for such issues to be dealt with in a manner compliant with the ECHR. It could be argued that there is a right under Article 8 of the Convention that the person whose personal decisions are being made by someone else should have an opportunity in deciding who that person should be.

The case of *J.T. v. the United Kingdom*,[333] illustrates a similar point. In the case, the applicant had a history of mental disability and had a difficult relationship with her mother, her closest relative. The difficult relationship arose in part to alleged sexual abuse by the applicant's stepfather. Under English law, the mother as the nearest relative had a variety of rights related to her detention in a psychiatric hospital, and the applicant did not want her mother to be given any information about her whereabouts, nor did she want her mother to be involved in any subsequent decisions relating to her care and treatment in hospital. At the level of the European Court of Human Rights the case reached a friendly settlement under Articles 37–39 of the Convention on an undertaking by the British government that the relevant law would be amended to allow a more flexible approach to appointing the nearest relative.[334]

Alternatively, a family member may have an argument that they should be the guardian, because of their rights under Article 8 of the Convention (right to private and family life). This remains untested at the European Court of Human Rights, but a coherent argument could be made that family members should be allowed to care for each other, unless there is a strong reason to the

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[331] Recommendation No. R(99)4, Principle 9(2).

[332] Explanatory Memorandum to Recommendation No. R(99)4, para. 44.

[333] 26494/95, judgment 30 March 2000, (2000) 30 EHRR CD77, [2000] 1 FLR 909. See also the more detailed decision of the European Commission on Human Rights, (1997) 23 EHRR CD81.

[334] In fact, the English law was not amended with reasonable dispatch, and the English courts ruled the relevant provision in violation of Article 8: R (M) v. Secretary of State for Health [2003] E.W.H.C. 1094.

contrary. However, rights under Article 8 are not absolute and evidence that guardianship by a specific family member would put the health or rights of the person with mental disability at risk, for example, would justify the refusal to appoint that person as guardian.

Contesting decisions made by a guardian

Recommendation No. R(99)4 advises that 'in implementing a measure of protection for an incapable adult the interests and welfare of that person should be the paramount consideration'.[335] The Recommendation goes on to say that '[i]n establishing or implementing a measure of protection for an incapable adult the past and present wishes and feelings of the adult should be ascertained so far as possible, and should be taken into account and given due respect'.[336] Similar to standards of proxy or supported decision making in the treatment context (see chapter 4), the person representing or assisting an adult should give that person adequate information, whenever this is possible and appropriate so that he or she may express a view.[337] If the adult is unable to give his or her views about the proposed decision,[338] the guardian is obliged 'so far as reasonable and practicable' to consult with people who have a close interest in the welfare of the adult concerned.[339]

The Explanatory Memorandum to Recommendation No. R(99)4 explains the background debate around these issues. When a person makes a decision on behalf of someone who does not have capacity to make that decision, the decision-maker can either act on the basis of the person's pre-expressed withes (if the person had them and they are known) or make a substituted judgment based on knowledge of the person's wishes, values and beliefs, or as a last resort, make a decision based on the person's 'best interests'.

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[335] Recommendation No. R(99)4, Principle 8(1).

[336] Recommendation No. R(99)4, Principle 9(1).

[337] Recommendation No. R(99)4, Principle 9(3).

[338] Naturally, whether someone is or is not able to give views about a particular situation may in many cases depend on the skill of the person explaining the different options.

[339] Recommendation No. R(99)4, Principle 10.

When the decision-maker wants to make a decision which runs contrary to the adult's known prior wishes, the question arises as to whose opinion should be respected: the person lacking legal capacity or the person with the legal authority to decide. The Explanatory Memorandum advises that when the choice is between the interests of the adult and the interests of other people and when the adult has no known wishes on the matter, it is reasonable to regard the interests of the adult as the paramount consideration. However, when the choice is between the current interests of the adult and the prior wishes of the adult, the Explanatory Memorandum suggests that it would be acceptable not necessarily to respect the prior wishes of the adult, but rather for the decision-maker to pay 'due respect' to the past and present wishes and feelings of the adult, insofar as they can be ascertained. In human rights terms, this probably means that the decision-maker (guardian) when making these difficult decisions should document the method of how a decision was made, with reasons why a particular option has been preferred.

If any of these recommended procedures have not been followed, the adult may have reason to complain using European Convention on Human Rights arguments. Each case will turn on its own facts, and issues such as the seriousness of the decision in question, or the length of time a person has been legally incapacitated, will have a bearing on the case. In some countries, the greatest hurdle for a person who would like to challenge bad performance by a guardian may be how to get the case to court in the first place – again access to justice issues to which we return in the Conclusion chapter. The situation is complicated even more where clear conflict of interest issues arise from the fact that the guardian is also the director of the residential institution where the person is living. The lack of standing is an issue to which we will return in appendix 7 on representing people with mental disabilities.

A crucial issue relevant in litigating against a guardian's poor performance is whether there are adequate control mechanisms monitoring the acts and omissions of guardians.[340] An active guardianship office at the local government may have such a responsibility of supervising and controlling guardians, and will be responsive to letters by (or on behalf of) the person

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[340] Recommendation No. R(99)4, Principle 16.

under guardianship. Such a body may well displace (remove) the guardian and appoint a more suitable person. However, experience in many countries is that such guardianship offices are in some cases unwilling to intervene, and remain content with a guardian neglecting and abusing the adult in question. Alternatively the guardianship office may have no adequate procedures in place to ensure that a person under guardianship has the means to lodge a complaint. Further, the guardianship office may have established no effective procedure for regular oversight of a guardian's performance.

If the guardianship office becomes aware that the guardian is not doing the job adequately, a new guardian must be appointed. Recommendation No. R(99)4 specifies that there should be a pool of 'suitably qualified persons for the representation and assistance of incapable adults'[341] who should be adequately trained.[342] The guardianship office should also have powers to challenge guardians in court where there are serious allegations of abuse or malpractice. Recommendation No. R(99)4 states that guardians 'should be liable, in accordance with national law, for any loss or damage caused by them to incapable adults while exercising their functions. [. . .] In particular, the laws on liability for wrongful acts, negligence or maltreatment should apply to representatives and others involved in the affairs of incapable adults'.[343] Under the Convention it is still questionable whether such abuse by private guardians can be litigated at the ECtHR because the Convention protects against abuses by State agents. However, the wording of the Recommendation supports an argument that there is a positive duty on the State under Articles 1 and 13 of the Convention to create accessible mechanisms for people to seek remedies for loss or damage caused by guardians.

Delay in appointing guardian

In some countries a person is deprived by a court of his or her legal capacity but there is a delay of several months before a guardian is appointed.[344] This

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[341] Recommendation No. R(99)4, Principle 17(1).
[342] Recommendation No. R(99)4, Principle 17(2).
[343] Recommendation No. R(99)4, Principle 20.
[344] Mental Disability Advocacy Centre, report on Bulgaria, (Budapest: MDAC, forthcoming, 2006).

situation could be challenged under Article 8 of the ECHR, because a court has found that a person needs to be assisted in order to protect the person's rights, but the State (normally a local authority) has not fulfilled its obligations to secure that person such assistance. It could be argued that this constitutes an interference with the person's private life.

Periodic Review of Guardianship

A problematic feature of many guardianship systems in Member States of the Council of Europe is that determinations of legal incapacity are not subject to periodic review. Recommendation No. R(99)4 states in Principle 14:

> *Measures of protection should, whenever possible and appropriate, be of limited duration. Consideration should be given to the institution of periodical reviews.*
>
> *Measures of protection should be reviewed on a change of circumstances and, in particular, on a change in the adult's condition. They should be terminated if the conditions for them are no longer fulfilled.*[345]

The Explanatory Memorandum to Recommendation No. R(99)4 emphasises that an indefinite incapacity order should be the exception, and this should happen only in cases where the individual has a condition, such as senile dementia or Alzheimer's disease, for which currently there is no cure and, save small periods of lucidity, the person's condition will unfortunately worsen. The wording of Recommendation No. R(99)4 on periodic review is surprisingly weak given other parts of the Recommendation such as Principle 6(2) which speaks of minimal measures of protection consistent with

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[345] Recommendation No. R(99)4, Principle 14. See also Principle 1(6) of the UN Resolution 46/119 on the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, adopted by the General Assembly on 17 December 1991: 'Decisions regarding capacity and the need for a personal representative shall be reviewed at reasonable intervals prescribed by domestic law.' See also the World Health Organization (2005), Resource Book on Mental Health, Human Rights and Legislation which states at page 41, section 7.3 that '[l]egislation should contain a provision for automatic review, at specified periodic intervals, of the ending of lack of competence'.

achieving the purpose of the intervention. Given that many people's capacity fluctuates throughout the person's lifetime, the logical legal response is one which is proportionate, and therefore the necessity of the legal measure must be regularly reviewed. The Explanatory Memorandum states that the person whose legal capacity has been deprived 'should be entitled to demand a review'.[346]

The Court agreed with this approach in the case of *Matter v. Slovakia*,[347] discussed above, in which the applicant had been deprived of his legal capacity for over seven years, notably described by the Court as 'a serious interference with his rights under Article 8 § 1'.[348] In the Court's view, 'it may be appropriate in cases of this kind that the domestic authorities establish after a certain lapse of time whether such a measure continues to be justified. Such a re-examination is particularly justified if the person concerned so requests'.[349]

Having found that forced examination in a psychiatric hospital engaged Article 8(1) of the Convention in the *Matter* case, the Court examined whether this interference with private life was justified under Article 8(2). In the domestic proceedings the district court – as it had been instructed by the Supreme Court – had sought to obtain an expert opinion on the applicant's mental health. The medical expert tried to examine the applicant on a voluntary basis which the applicant refused. The district court invited the applicant twice to submit to the examination in the psychiatric hospital and warned him that if he did not comply he could be forcibly brought there. The applicant failed to comply again and the district court ordered that the applicant be brought to the hospital. The applicant was indeed brought to the hospital on 19 August 1993 and he was discharged on 2 September 1993, when the examination was concluded. The European Court of Human Rights decided that the interference in question was not disproportionate to the legitimate aims pursued. It was therefore 'necessary in a democratic society'

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[346] Explanatory Memorandum to Recommendation No. R(99)4, para. 56.

[347] *Matter v. Slovakia*, Application No. 31534/96, judgment 5 July 1999, (2001) 31 EHRR 32.

[348] *Matter v. Slovakia*, op. cit., para. 68.

[349] *Matter v. Slovakia*, op. cit., para. 68.

within the meaning of Article 8(2) of the Convention and therefore found no violation of Article 8.[350]

This is a strange reasoning. Although the applicant himself had instigated a review of guardianship which probably requires some sort of expert evaluation, the Court could have found an Article 8 violation for at least two reasons. First, the ECtHR could have noted that the domestic court could have better balanced competing rights. The Court could have decided that protecting the applicant's right to liberty (he did not want to be detained in a psychiatric hospital for an evaluation) plus right to privacy (he did not want to undergo an evaluation at all) trumped the restriction of rights which would have resulted from forcing the applicant to go through with his request of reviewing the incapacity. There seems to be no evidence that the domestic authorities explained these options to the applicant. Second, the European Court of Human Rights did not specify any of the grounds under Article 8(2) on which it relied when finding that the interference with the applicant's private life was 'necessary in a democratic society'. Probably the Court had in mind that the interference was justified for the prevention of disorder or crime, for the protection of health or morals or for the protection of the rights and freedoms or others. It is difficult to see any plausible argument under any of these heads. Of additional curiosity is why this case was not examined under Article 5, where the Court could have found that the detention for forced incapacity examination did not meet the standards of detention of Article 5 (see the case of *Nowicka v. Poland*, discussed above in this chapter).

8. Concluding remarks

Legal incapacity and guardianship proceedings in many countries of the Council of Europe are problematic as they do not afford the adult in question procedural safe-guards. Issues under Article 6 ECHR include imprecise legal definitions of incapacity, the appropriateness of a one-size-fits-all legal approach to capacity, and the availability of a range of legal (and non-legal) measures to protect people who lack capacity to make certain decisions at

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[350] *Matter v. Slovakia*, op. cit., paras. 71–2.

some points in the lives. Further procedural issues involve notice of guardianship proceedings, adequate incapacity examinations which do not equate diagnosis with incapacity, the appropriateness of forced psychiatric evaluations, the right to be heard in person during incapacity proceedings, the right to be represented by a lawyer who takes an active part in representing the adult, the adequacy of evidence presented to the court and the disclosure of documents to the adult and that person's lawyer in order to guarantee a fair trial. The right to appeal findings of incapacity, the right to have an opinion about who will exercise decision-making, and the right to effectively challenge the decisions a substitute decision-maker are also relevant. Further, a regular review of the necessity of the legal measure will also be increasingly relevant, especially for people with fluctuating mental disabilities. The Council of Europe Recommendation No. R(99)4 has started to assist the Court to give relevance to fair trial and privacy rights in the context of substitute decision-making and it is hoped that the Court will continue to cite the Recommendation and other international instruments with authority.

Some countries' civil codes and civil procedural codes will require significant re-writing to bring them in line with the basic guarantees set forth in the Recommendation No. R(99)4 and given legal force by an increasing number of cases to the ECtHR. Ironically, given the extraordinarily huge numbers of people affected across Europe, the Court will not be loaded with applications. This has more to do with practical and legal difficulties by people under guardianship to bring cases in domestic courts and to the European Court. The Court is encouraged to use its pilot judgment procedure in appropriate guardianship cases in order to send clear signals to domestic authorities that legislative revisions are necessary in order to secure Convention compliance.

Chapter 4: The Expressive, Educational and Proactive Roles of Human Rights: an Analysis of the United Nations Convention on the Rights of Persons with Disabilities

This chapter was published as a chapter in the book *Rethinking Mental Health Laws*, Bernadette McSherry and Penelope Weller (eds), Hart Publishing, 2010

1. Introduction

Addressing dignitaries on the day the United Nations Convention on the Rights of Persons with Disabilities (CRPD)[351] opened for signature, Louise Arbour the then United Nations High Commissioner for Human Rights said:

> *At the time of the adoption of the Universal Declaration of Human Rights, Eleanor Roosevelt famously asked: "Where do human rights begin?" and answered "In small places, close to home". This is as true in the area of human rights and disability as with any other area of human rights.*[352]

People with psycho-social (mental health) disabilities[353] are among those who suffer most from the compliance gap between lofty declaration and rights

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[351] Opened for signature 13 December 2006, GA Res 61/106, UN Doc A/Res/61/106, entered into force 3 May 2008.

[352] L Arbour, Opening address of the High Level Dialogue on the day of the signing of the Convention on the Rights of Persons with Disabilities and its Optional Protocol: From Vision to Action: The Road to Implementation of the Convention, 30 March 2007.

[353] I use the term 'psycho-social disabilities' to mean people labelled or living with mental health problems. The Convention says that '[p]ersons with disabilities include those

reality. This chapter attempts to suggest how the CRPD, an international human rights treaty agreed unanimously by the global community, may serve as an innovator of change, in small places, close to home.

The chapter examines the CRPD by applying Sandra Fredman's framework of the expressive, educational and proactive roles of human rights.[354] In doing so, it seeks to analyse the values which the CRPD expresses, the forms of communication it encourages, and the range of actions it demands. 'Groundbreaking' and 'landmark' are among the adjectives which have been used to describe the CRPD. It is both of these and more. This is the first human rights treaty to be adopted in the twenty-first century, and it was negotiated more quickly than any other human rights treaty in history, taking four years from start to finish. It involved the greatest level of participation from civil society of any human rights treaty throughout its negotiating process and benefited from being the first human rights treaty to be the subject of an extensive and coordinated internet lobbying campaign.[355] It is the first to oblige States Parties to take measures to eliminate discrimination 'by any person, organization or private enterprise',[356] thus taking international human rights law into the private sphere for the first time. It is by far the longest and most detailed 'status' based treaty, perhaps making it more likely that it will be implemented.[357]

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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'. The global disability communities fought to have the phrase 'psycho-social' instead of 'mental', but the latter prevailed. There is a significant difference in the terminology used by the Convention and that used by the disabilities communities and other human rights instruments. Prior to the Convention, 'mental disability' had clumsily been the umbrella term including both people with psycho-social (mental health) disabilities and people with intellectual disabilities.

[354] S Fredman, *Human Rights Transformed: Positive Rights and Positive Duties* (Oxford, Oxford University Press, 2008) 32.

[355] See, eg,; comments made by K Annan, UN Secretary General, *Secretary General Hails Adoption of Landmark Convention on Rights of People with Disabilities* UN Press Release, 13 December 2006, Ref SG/SM/10797, HR/4911, L/T/4400, available at www.un.org/News/Press/docs/2006/sgsm10797.doc.htm.

[356] CRPD, Art 4(1)(e).

[357] The CRPD comes in at 9,954 words excluding its title, compared with the other UN treaties protecting the rights of other people due to their 'status': Convention on the Rights of the Child (Adopted by General Assembly resolution 44/25 of 20 November 1989) contains 7,559 words, the International Convention on the Elimination of All Forms of Racial Discrimination (Adopted by General Assembly resolution 2106 (XX) of 21 December 1965) contains 4,739 words, and the Convention on the Elimination of All

This chapter suggests that the CRPD has the potential to become a transformative international legal instrument which innovates domestic politics and as much as policies.[358] The first part of the chapter argues that the CRPD embodies the expressive role of human rights by encouraging actors to rethink assumptions, evaluate positions and shift existing concepts or paradigms. The global community has agreed on the values to which it aspires elevating the CRPD into a 'focus for political and grass-roots campaigning, giving a specific and authoritative legitimacy to demands for their fulfilment'.[359]

The second part of the chapter addresses the ways in which the CRPD embodies the educational value of human rights. If the expressive value of human rights is about thinking, the educational value is about talking. The CRPD sets up and encourages communication horizontally: between organisations in the same country, between government departments, between non-governmental organisations (NGOs) across borders and between various states. It encourages information flow vertically: between people with disabilities and their NGOs and the authorities within a state, and internationally between the treaty monitoring body and domestic actors in each state.

The third section of the chapter looks at how the CRPD can be seen as embodying a proactive role of human rights, moving from talking to doing. It does this by outlining how the CRPD creatively sets up domestic policy processes to increase the chances of effective implementation. The CRPD itself obliges States Parties to establish national independent mechanisms to promote and protect the rights of people with disabilities and monitor the implementation of the CRPD. It provides for participation of people with disabilities in the monitoring process at both international and domestic levels, and it obliges States Parties to designate a disability rights focal point at

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Forms of Discrimination against Women (Adopted by General Assembly resolution 34/180 of 18 December 1979) contains 4,427 words.

[358] For an insightful analysis on how the Convention influences and challenges international human rights law, see F Mégret (2008) 'The Disabilities Convention: Towards a Holistic Concept of Rights'(2008) 12 *International Journal of Human Rights* 261.

[359] S Fredman, *Human Rights Transformed: Positive Rights and Positive Duties* (Oxford, Oxford University Press, 2008) 33.

the heart of government to coordinate policy. In setting out the expressive, educational and proactive values of the CRPD, the chapter acknowledges the artificiality of separating these values. Permeation between them is both inevitable and encouraged.

Whilst this chapter does not seek to build upon the scholarship of an expressive theory of international law, it is influenced by the literature. Expressive law theory may help explain a government's willingness to ratify and implement treaties.[360] Alex Geisinger and Michael Stein, for example, suggest that states operate a 'need-reinforcement principle' by which states ratify international treaties to signal attraction to a group of states, and over time the group collectively develops shared values.[361] This version of expressive international law works on the assumption that desire to be seen as a member of an international club is the key reason why states ratify treaties. There is little empirical evidence to back up this assertion, and it would be interesting to conduct research to gather data from civil servants and diplomats who were members of the Ad Hoc Committee which negotiated the CRPD. Expressive law theory takes us only so far, as it accords insufficient weight to the dynamics of domestic politics during treaty negotiation, the decision to sign and ratify which is negotiated across ministries, and any governmental department's genuine willingness to implement the provisions. In terms of international disability politics, , the supposition put forward in this chapter is that it is not a state's desire to be a member of a club which drives CRPD ratification, but rather the pressure from people with disabilities – including within government by politicians and civil servants with disabilities, NGOs of and for people with disabilities, academics and the media. People with disabilities constitute a sizeable voting minority: all

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[360] For an expressive law analysis of a specific disability law provision, see MA Stein, 'Under the Empirical Radar: An Initial Expressive Law Analysis of the ADA' (2004) 90 *Virginia Law Review* 1151.

[361] A Geisinger and MA Stein, 'A Theory of Expressive International Law' (2007) 60 *Vanderbilt Law Review* 75, 111.

incumbent governments want to be re-elected and the sensible ones will have figured out that ratifying this treaty may earn them votes.[362]

An expressive theory of law is a holistic one in which, although not explicitly stated, the three elements – of thinking, talking and doing - are inextricably linked. Alex Geisinger and Michael Stein nearly go as far when they suggest that the '[l]egal process provides not just focal points for cooperation, but also an iterative process of norm development and entrenchment that carries with it strong influence on the behaviour of States'.[363] Thus the development of law, including international law, can itself be a 'paradigm shift'. Additionally it can set up processes through which ideas are developed and action is taken. As an example of how these three elements are cyclically linked, the CRPD arose from an interaction of new ideas, discussions among and between NGOs and state officials, and action through negotiations and drafting, being continually influenced by communication with others, adjusting ideas to reach compromise positions, and so on. Having said that, it is possible that ideas alone instigate conversations. As one public policy theorist has suggested, 'discursive power can determine the very field of action, including the tracks on which political action travels'.[364] The CRPD is inspiring not because it codifies a pre-existing reality, but because it articulates a shared reality which has yet to be explained. It is this new reality of disability rights to which the chapter now turns.

2. Expressive value of human rights: thinking

The CRPD succinctly explains the reason for its existence. It is that all existing human rights treaties apply equally to persons with disabilities,[365] yet 'despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society

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[362] The caveat is that people under guardianship in many countries are prohibited, through the denial or restriction of their legal capacity, from voting. Art 12 (legal capacity) and Art 29 of the Convention compel legislative reform.

[363] A Geisinger and MA Stein, 'A Theory of Expressive International Law' (2007) 60 *Vanderbilt Law Review* 75,118.

[364] F Fischer, *Reframing Public Policy: Discursive Politics and Deliberative Practices* (Oxford, Oxford University Press, 2003) viii.

[365] CRPD, preambulatory para (d).

and violations of their human rights in all parts of the world'.[366] It is worth pointing out that every single member state of the United Nations agreed with this proposition when they voted unanimously in the General Assembly to adopt the CRPD, signalling a globally-agreed consensus on a new understanding of disability.[367] The 'paradigm shift' championed by the CRPD seeks to move societies away from viewing people with disabilities as passive objects of treatment, management, charity and pity (and sometimes fear, abuse and neglect), towards a world view of people with disabilities as active subjects of human rights and dignity.

The then United Nations Secretary General, Kofi Annan, described the adoption of the CRPD as, 'the dawn of a new era -- an era in which disabled people will no longer have to endure the discriminatory practices and attitudes that have been permitted to prevail for all too long'.[368] In promoting a shift of attitudes, the CRPD embodies the expressive value of human rights, 'signalling the values a society stands for'.[369] Human rights activists celebrating the adoption of the CRPD soon turned their attention to ratification and implementation, encouraging states to do the same. In her speech on the day of the CRPD's entry into force, to which this chapter has referred above, Louise Arbour set out the urgent need for domestic law reform. In a direct message to her audience of ambassadors she injected a sense of urgency by saying that '[w]e need to get moving on the implementation now, which means transposing the provisions of the CRPD into national laws. Changes to the law help speed up changes of attitude'.[370] In her speech, Arbour hinted at the transformative potential of the CRPD. By doing so she addressed a goal of the expressive value of law, which scholars have claimed seeks to 'affect preferences and behaviour by altering social

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[366] CRPD, preambulatory para (k).

[367] The Convention on the Rights of Persons with Disabilities and its Optional Protocol was adopted unanimously by the United Nations General Assembly on 13 December 2006.

[368] UN Press Release: *Secretary General Hails Adoption of Landmark Convention on Rights of People with Disabilities* UN Press Release, 13 December 2006, Ref SG/SM/10797, HR/4911, L/T/4400, available at www.un.org/News/Press/docs/2006/sgsm10797.doc.htm.

[369] S Fredman, *Human Rights Transformed: Positive Rights and Positive Duties* (Oxford, Oxford University Press, 2008) 32.

[370] UN Press Release, *Arbour Welcomes Entry into Force of "Ground-breaking" Convention on Disabilities*, 4 April 2008 , available at www.unhchr.ch/huricane/huricane.nsf/view01/1AD533A6AB95F873C1257421003A8DA8?opendocument.

perceptions and conventions'.[371] In seeking to adjust social perceptions, the CRPD contains a list of principles, which the next section analyses.

A. Articulated Principles

The CRPD lists several principles which flesh out the specificities of the paradigm shift. This itself is innovative, the CRPD being the first international human rights treaty to explicitly list a set of guiding principles. Art 3 of the CRPD sets these out:

a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

b) Non-discrimination;

c) Full and effective participation and inclusion in society;

d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

e) Equality of opportunity;

f) Accessibility;

g) Equality between men and women;

h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Principle (b) on non-discrimination, (c) on participation and inclusion in society, (e) on equality of opportunity and (g) on gender equality are what Gerard Quinn calls the 'legacy values of human rights theory and law'.[372] They are not disability-specific and could apply to disability as they could to, for example, women, persons of ethnic minorities or any other discriminated against 'group'. However, when applied to people with disabilities these regular human rights principles become quite revolutionary. One only has to

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[371] M Stein, and J Lord, 'Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities' in OM Arnardóttir and G Quinn, (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Leiden, Martinus Nijhof, 2009).

[372] G Quinn, 'Resisting the 'Temptation of Elegance' Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?' in MO Arnardóttir and G Quinn (eds), *The United Nations Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Leiden, Martinus Nijhof, 2009).

do a quick internet search to find out about how women and girls with disabilities fare much worse than those without disabilities, or men and boys with disabilities. Similarly, the ways in which persons with disabilities are prevented solely because of their disability from participation and inclusion on an equal basis with others has been well documented. It is of interest to note that the principles firmly reject a 'best interests' or protection approach, a principle contained in the United Nations Convention on the Rights of the Child,[373] and one which is applied in domestic laws throughout the world to provide a legal basis in substitute decision-making for those assessed as lacking functional capacity to make particular decisions. More dubiously 'best interests' is a feel-good vehicle for those making decisions which ignore or override the choices of children and adults with disabilities who have functional capacity to make such decisions.

The CRPD is silent on how the principles laid out in Art 3 are to be used, but the accompanying United Nations website asserts that the principles 'underlie the CRPD and each one of its specific articles'.[374] This can be understood to mean that the principles represent the moral basis of the CRPD, explaining the reasons for the CRPD's existence, and providing guidance for national authorities, courts and the treaty monitoring body on how to interpret the CRPD. The principles cut across all substantive CRPD rights so that, for example, the right to education for children with disabilities in Art 24 read in conjunction with the principle of non-discrimination as set out in Art 3 may well be interpreted to mean that education shall not be denied to Roma children with disabilities, or to girls with disabilities. Art 24 may also be interpreted to mean that discrimination against children with a particular disability is also prohibited – thus the right to education applies equally to *all* children with disabilities, which 'include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various

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[373] United Nations Convention on the Rights of the Child, Adopted by General Assembly Resolution 44/25 of 20 November 1989, Art 3(1).

[374] United Nations Enable, *Guiding Principles of the Convention*, at www.un.org/disabilities/default.asp?navid=14&pid=156.

barriers may hinder their full and effective participation in society on an equal basis with others'.[375]

The two disability-specific principles are Principle (a) which restates autonomy and the right to make one's own choices, and Principle (d) which celebrates persons with disabilities as part of humanity. These principles may be useful when interpreting controversial or ambiguous topics which were subject to heated debate by the Ad Hoc Committee negotiating the CRPD.

B. Silence as expression

An example of a controversial topic on which the CRPD has no explicit provision for or against, is forced psychiatric treatment of persons diagnosed/labeled with a mental illness. Such treatment is lawful in domestic legislation in most countries. The global disability movement fought hard for the CRPD to include an explicit prohibition against forced psychiatric interventions, and the text is quite clear on the prohibition of detention, with Art 14 stating that 'the existence of a disability shall in no case justify a deprivation of liberty'. Some negotiating states sought a specific exception to the general right to consent to treatment so as to explicitly allow forced psychiatric treatment. Instead, the CRPD is silent on psychiatric treatment.[376] Instead, Art 25 on the right to health places an obligation on States Parties to '[r]equire health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent'. The principle of consent to treatment is phrased as a state obligation rather than an individual right and the word 'consent' remains undefined, leaving open the proposition that consent includes a person's current functional capacity, or previous functional capacity during which a future wish was expressed (including in the form of an advance directive).

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[375] CRPD, Art 1 – Purpose.

[376] I am grateful to Professor Amita Dhanda for enlightening me about the potential implications of the Convention's silence on forced psychiatric treatment: see A Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?' (2007) 34(2) *Syracuse Journal of International Law and Commerce* 429 and Annegret Kämpf, this volume, ch 6.

In analysing the range of possible interpretations of the CRPD, their politically palatability and operational viability, those interpreting the CRPD may want to utilise the expressive value of human rights. This would mean, for example, interpreting the substantive articles by giving meaning to the principles of respect for autonomy, freedom to make one's own choices, inclusion in society and acceptance of persons with disabilities as part of human diversity. The gap between the CRPD's values and the current reality of many mental health laws all over the world may be an example of an area where the CRPD is trying to set out a future reality which has yet to be explained. Ambiguity is awkward for policy-makers and for black-letter lawyers, but it represents a triumph of shared norms over policy detail, whereby those negotiating the treaty agreed on the fundamental principles, but were not able -- at that moment in time, on this particular issue -- to find consensus on how these principles should play out in the psychiatric emergency room.

Some English-speaking jurisdictions have introduced mental health laws which contain principles such as measures to minimise the restrictions. These include, among others, the principle of 'least restrictive environment and with the least restrictive or intrusive treatment', 'minimum restriction on the freedom of the patient that is necessary in the circumstances',[377] 'least restrictive environment',[378] and 'minimising restrictions on liberty'.[379] That the CRPD is silent on forced treatment may be viewed as simply naïve, offering domestic policymakers little guidance on the content of domestic mental health legislation, or indeed offering them plenty of room to be creative and progressive, or it may have been simply a political compromise to finalize the treaty. Whichever of these truths emerges, the CRPD is less open to be criticised for hypocrisy, unlike the United Nations Mental Illness Principles which contains a lofty principle on non-discrimination of persons

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[377] Principles for the protection of persons with mental illness and the improvement of mental health care Adopted by General Assembly resolution 46/119 of 17 December 1991, Principle 9(1).

[378] See for example, Mental Health Act 2007 (NSW), s 68(a).

[379] Mental Health Act 2007 (England and Wales), s 8, which inserts into the Mental Health Act 1983 (England and Wales), s 118(2B)(c) compelling the Secretary of State to ensure this principle is addressed when preparing a statement of principles for the Code of Practice.

with mental illness,[380] and goes on to list five exceptions to the right to consent to treatment without offering any legal or moral justifications for the exceptions.[381]

The law's communication process has been described as creating 'a normative framework, a vocabulary and a set of open concepts to structure normative discussion'.[382] The CRPD's silence on forced psychiatric treatment provides space and time for reflection and communication, perhaps demonstrating the interconnectivity between the expressive and the educational roles of human rights.

The CRPD's existence is predicated upon the supposition that, 'the typical welfare response [...] of maintaining rather than empowering persons with disabilities has been relatively immune from pressure to change'.[383] However strong the vision and rhetoric of the CRPD, governments and other actors may find themselves stuck in repeating the behaviours of the past, thwarting change. A filtration of ideas from the grassroots disabilities movement is a good start, but ideas alone will be insufficient to ensure an internalisation of a new disability politics. States' inability or unwillingness to accord persons with disabilities sufficient power to set, implement, monitor and adjust policies was one of the reasons the CRPD was needed. It also represents the greatest risk that it will remain unimplemented. Empowering individuals with disabilities can be achieved by the inclusion of CRPD beneficiaries into the domestic policy cycle. This means moving beyond the rhetoric of paradigms and principles, and engaging vigorously and respectfully with those who hold opposing views to unleash the CRPD's potential.

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[380] Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, Adopted by General Assembly Resolution 46/119 of 17 December 1991, Principle 1(4).

[381] Principles for the protection of persons with mental illness and the improvement of mental health care Adopted by General Assembly resolution 46/119 of 17 December 1991 Principle 11(1)'

[382] W van der Burg, 'The Expressive and Communicative Functions of Law, Especially with Regard to Moral Issues' (2001) 20 *Law and Philosophy* 31.

[383] G Quinn, 'Resisting the 'Temptation of Elegance' Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?' in MO Arnardóttir and G Quinn eds, *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Leiden, Martinus Nijhof, 2009).

3. Educational value of human rights: talking

The playwright and political activist Harold Pinter was once asked a question on the actions which individuals who feel compelled to do something about injustices should take. He answered, '[t]o speak. The appropriate response is simply to look for the truth and tell it'.[384] If the expressive value of human rights aims at seismic shifts in societal thinking, then the educational role of human gets us talking, speaking truth to power. The adoption of the CRPD provides closure on an intensive global conversation about the notion of disability, the rights of people with disabilities, and the duties on states and others towards them. It is a dusk as well as a dawn.

A substantial amount of time and resources will need to be spent in structuring normative discussion on how the CRPD is to be interpreted, on finding new 'institutional champions' at domestic levels,[385] and educating key stakeholders about what the paradigm shift actually means. Stakeholders will hold a variety of views about CRPD interpretation, and those putting forward views may well assume that their own view is correct, and other interpretations are wrong. Appropriate forums to allow communication to take place in a open dialogue will be crucial to exploring the various interpretations out there and persuading each other of the pros and cons of different viewpoints.[386] The public policy theorist Jan Kooiman suggests that communication between stakeholders is crucial because, '[n]o single actor, public or private, has all the knowledge and information required to solve

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[384] Harold Pinter interviewed by Harry Burton, British Library, 8 Sept. 2008.

[385] G Quinn, Resisting the 'Temptation of Elegance' Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?' in MO Arnardóttir and G Quinn eds, *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Leiden, Martinus Nijhof, 2009).

[386] These discussions will need to start at a basic level and those holding discussions should be prepared for unexpected re-opening of the paradigm shift. For example, in December 2008 the author was a co-trainer at a three-day Council of Europe sponsored training seminar on disability rights for staff of various national human rights institutions across Europe. The training schedule had to be adjusted to allow for an unexpected and lengthy debate on why people with disabilities should have the right to vote. Although Art 29(a) of the CRPD unambiguously provides the right of persons with disabilities to vote and stand for election, several participants – who are all charged with monitoring the rights of persons with disabilities – initially laughed at the proposition that persons with mental health problems should have the right to stand for parliament, and after much explanation they remained less than convinced of the merits of the provision.

complex dynamic and diversified problems; no actor has sufficient overview to make the applications or needed instruments effective'.[387] This is as true for disability as it is for any other area of public policy. In this section of this chapter, it is suggested that the CRPD encourages a culture of continuous communication by creating bodies at both the United Nations level and state level, and by placing obligations upon those bodies to specifically seek out the views of persons who have experienced disabilities.

A. Transposing International Norms

Given the stark gap between the text of the CRPD and the reality on the ground, education at various levels clearly needs to take place. The United Nations High Commissioner for Human Rights has called for states to 'transpose international obligations into meaningful programmes for change at the national level'.[388] It is suggested that there are three elements to such a transposition. First, stakeholders need to understand the CRPD's vision and ask themselves 'What are the elements of this aspiration?' In doing so they will reach back to the expressive role of human rights, be aware of the paradigm shift, and conduct an appreciative inquiry into the sort of changes the CRPD envisions. Second, the participants in the conversation will need to assess the current human rights situation of people with various disabilities and analyse the reasons for any gap in compliance, asking the questions 'Where are we now?' and 'What has caused this situation?'. They will have to reach out and hold conversations with a range of groups and individuals, actively listening to their needs and wishes. Third, there will need to be some sort of majority (of whom?!) opinion about the steps which stakeholders need to take in order to make CRPD provisions a reality, in other words they will need to answer questions such as, 'What needs to change?' How are these changes going to be made, by whom, and by when?' In pursuing these discussions, participants may not reach a consensus (although an open discussion certainly makes this more likely), but they may well be able to

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[387] J Kooiman, 'Social-political governance' in J Kooiman (ed), *Modern Governance: New Government-Society Interactions* (London, Sage, 1993).

[388] L Arbour, Opening address of the High Level Dialogue on the day of the signing of the Convention on the Rights of Persons with Disabilities and its Optional Protocol: From Vision to Action: the Road to Implementation of the Convention, 30 March 2007.

better understand each others' positions, explore the reasons underlying deeply-held views, critically appraise their own and others' viewpoints, and find ways of accommodating competing claims.[389]

Taking one of the CRPD's provisions as an example, Art 12 on legal capacity contains two provisions which will require quite significant shifts in thinking, series of conversations, and steps to bring norms and behaviours into compliance. The Article sets out first, that everyone with disabilities has the right to legal capacity, and secondly that those who need support in exercising their legal capacity to make decisions get such support. Recognising that '[r]especting the legal capacity of persons with disabilities is fundamental not only as a right in itself, but also as a basis to protect other human rights', Louise Arbour went on to set out the challenge of implementation:

> *What do these provisions mean for lawyers, for notaries, for institutions, for support-oriented organizations, for justice departments, for courts? To make this right a reality, it will be important to identify good practices in legislative and policy approaches and to examine how these rights and obligations can be incorporated into different legal and developmental contexts.*

Let me give some examples about the educative value of the CRPD in this regard. During 2008 and 2009 my colleagues at the Mental Disability Advocacy Center (MDAC) have been working in Hungary and the Czech Republic with other civil society organisations on Art 12 implementation and advocating at governmental level for the requisite changes. Exchanges of opinions and ideas have taken place horizontally, in coalitions of non-governmental organisations (NGOs). MDAC, a legal advocacy organisation which is not a disabled people's organisation, carried out research on the extent to which these two countries' guardianship arrangements complied with international law. Following the publication of those reports, MDAC worked with a range of NGOs including disabled people's organisations, national umbrella organisations, local service providers and small self-help

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[389] On the naivity of consensus, see W van der Burg, 'The Expressive and Communicative Functions of Law, Especially with Regard to Moral Issues' (2001) 20 *Law and Philosophy* 31, 56.

groups. Coalition members reached out to mainstream human rights NGOs. People with disabilities in the coalitions shared their experiences, ideas and concerns. MDAC lawyers listened to these personal testimonies and framed them as legislative issues. In parallel, colleagues were in contact with NGOs and other experts internationally to gain an understanding of the CRPD's provisions. They also identified best practice in other countries such as Canada, evaluated these programmes and adapted them to the different contexts. In parallel, horizontal exchanges also happened across ministries in these countries, and the governments engaged in discussions such as through the European Union's Disability High Level Group which was established partly to act as a forum for countries to share promising practices.

The advocacy coalitions reached out to central government, taking their research on legislative compliance together with their proposals on how to bring law and services into compliance with Art 12. In this vertical exchange of views, government officials in both countries were initially hesitant to work so closely with civil society, but were soon receptive to ideas when it became clear that the NGOs brought CRPD knowledge together with the testimony of people with disabilities, whose rights could be better protected by domestic implementation. Officials also noticed that NGOs have technical assistance which went above and beyond the competencies of civil servants. The NGOs set out in detail how the government could bring laws into compliance with the CRPD. At the time of writing (November 2009), the Hungarian parliament became the first in the world to enact CRPD-inspired root and branch legal capacity reforms (which abolishes plenary guardianship, and introduces supported decision-making), and the Czech government had agreed with the majority of the submissions made by the NGO coalition These examples are provided to demonstrate how NGOs can take a proactive role in encouraging states to transpose international law into the domestic arena. There are examples from other parts of the world too.

B. Bringing New Actors into Disability Rights Discourse

As noted, the educational value of human rights encourages communication between actors, bringing together people holding diverse views who may share common ground at a deeper value-based level. Most people agree on the concept of equality but may differ on how the concept should manifest itself across policy areas. The CRPD encourages such communication, giving primacy to persons with disabilities and their respective organisations.[390] Through its inclusive approach, the CRPD may encourage groups who have not previously done so to work with each other. A small example is lawyers (attorneys as well as academic) in English-speaking jurisdictions. Disability lawyers tend to focus on discrimination-in-employment law, whereas mental health lawyers usually do not cover employment at all, but focus on detention and forced treatment. Perhaps the CRPD will bring these groups together? Another example is of 'mainstream' human rights organisations which have traditionally been slow to recognise that human rights of persons with disabilities is actually a legitimate topic of human rights. Human Rights Watch is among the most respected human rights organisations in the world but until summer 2009 when it came out with a report looking at corporal punishment of students with disabilities in the USA,[391] it has paid little attention to the rights of persons with disabilities. Its Executive Director acknowledged this in 2002, writing that, '[t]here is little doubt that a disability is a "status" entitling one to protection under, for example, the anti-discrimination provision of Art 26 of the International Covenant on Civil and Political Rights. In some cases involving children, the human rights movement has begun to take on the cause of people with disabilities. But an embrace of this broad sector of humanity has barely begun. Remedying this failure is a major challenge facing the movement.'[392] In 2009 Human Rights

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[390] CRPD, Art 4(3).

[391] *Impairing Education*, Human Rights Watch, New York, 2009

[392] K Roth, 'Foreword', in Mental Disability Rights International, *Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo* (Washington, Mental Disability Rights International, 2002). Art 26 of the International Covenant on Civil and Political Rights states: 'All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective

Watch announced that it had obtained funding to start some specific programming on the rights of persons with disabilities, and it is hoped that Human Rights Watch will contribute to raising the visibility and credibility of the rights of persons with disabilities within the 'mainstream' human rights community and their donors.

Seeking out and bringing on board partners was evident when the CRPD was being negotiated by states and NGOs at the United Nations. Louise Arbour has reflected that the process was a 'significant learning process' and one which has 'helped us forge partnerships with new actors beyond our typical human rights partners - in particular persons with disabilities and their representative organizations'.[393] She has pointed out that the involvement of her office in the negotiation process instigated a process of changing the way the United Nations works – from office layout to the choice of technology.

The CRPD has alerted the attention of United Nations officials who had previously not addressed the rights of persons with disabilities. For example, in December 2007, the Office of the United Nations High Commissioner for Human Rights organised a seminar on disability and torture, which was attended by two members of the United Nations Committee against Torture, and Manfred Nowak who holds the mandate of United Nations Special Rapporteur on Torture.[394] Within a year Nowak had produced a report in which he stated that the CRPD 'provides a timely opportunity to review the anti-torture framework in relation to persons with disabilities'.[395] The report cited examples of how persons with disabilities are subjected to neglect, severe forms of restraint and seclusion, as well as physical, mental and sexual violence. A reframing of the anti-torture framework is necessary, Nowak claims, so that ill-treatment which is perpetrated in public institutions as well

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protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.'

[393] L Arbour, Statement to the General Assembly Ad Hoc Committee, 8th session, New York, 5 December 2006.

[394] For more information see www2.ohchr.org/english/issues/disability/torture.htm.

[395] M Nowak, *Interim Report of the Special Rapporteur of the Human Rights Council on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment* 28 July 2008, A/63/175, para 41.

as in the private sphere, begins to be recognized as torture or other cruel, inhuman or degrading treatment or punishment.

In many states across the world, NGOs are using the CRPD as a catalyst to reach out to others, discuss the benefits for their constituents of adopting a human rights based approach, and build constituencies for advocacy. The need to develop one's own and other people's understanding of disability and to bring new actors into the disability rights field should go hand in hand with the attempt to do something over and above CRPD's aims, namely to reduce world poverty.

C. Poverty and Disability

The educational value of the CRPD has the potential to encourage communication to highlight the intimate link between disability and poverty and to implement inclusive poverty reduction strategies. The key actors in these conversations are host governments, donor governments, other donors and civil society organisations, including disabled people's organisations. The statistics are astonishing. The United Nations estimates that approximately eighty per cent of the 650 million people with disabilities worldwide live in developing countries, and of these some 426 million live below the poverty line, often representing the 15 to 20 per cent most vulnerable and marginalized poor in such countries.[396] The drafters of the CRPD wanted funding to flow between States Parties by inserting a provision which recognises 'the importance of international cooperation for improving the living conditions of persons with disabilities in every country, particularly in developing countries'.[397] The CRPD encourages communication between and among states in cooperation with regional and intergovernmental organisations and civil society, in order to, amongst other things, ensure international development programmes are inclusive of and accessible to people with disabilities, facilitate capacity-building and sharing of best practices, cooperate in research, share information, and provide economic and

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[396] A O'Reilly, Th*e Right to Decent Work of Persons with Disabilities*, rev edn (Geneva, International Labour Office, 2007).

[397] CRPD, preambulatory para (l).

technical assistance.[398] That the CRPD is a human rights treaty as well as a development tool may be one of the reasons why so many low- and middle-income countries have swiftly ratified the CRPD.

A recent report of the United Nations Economic and Social Council has found that '[t]here is a strong bidirectional link between poverty and disability. Poverty may cause disability through malnutrition, poor health care, and dangerous living conditions. Case studies in developing countries show that higher disability rates are associated with higher rates of illiteracy, poor nutritional status, lower immunization coverage, lower birth weight, higher rates of unemployment and underemployment, and lower occupational mobility'.[399] More explicitly, disability needs to become a focus for the United Nations' Millennium Development Goals[400] for these goals to stand any chance of being achieved. The United Nations Commission for Social Development 2008 report puts it bluntly:

The high numbers of persons with disabilities who are disproportionately represented among the world's most marginalized groups have a profound significance with respect to the achievement of the Millennium Development Goals, which thus far seems to have gone largely unnoticed in the international discourse on the Goals. The Millennium Development Goals, in fact, cannot be achieved if persons with disabilities are not included in these efforts. We are now at the halfway point to the target date of 2015, yet in The Millennium Development Goals Report 2007,[401] persons with disabilities as a group are not mentioned, and the issue of disability is briefly mentioned twice. The Human Development Report 2006[402] discusses persons with disabilities within the development context of sanitation. It is hoped that current efforts to integrate disability within the United Nations system will

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[398] CRPD, Art 32.

[399] United Nations Economic and Social Council, "Mainstreaming disability in the development agenda", report for the Commission for Social Development, Forty-sixth session 6-15 February 2008.ref E/CN.5/2008/6, 23 November 2007, para. 3.

[400] The Millennium Development Goals are eight goals aimed to be achieved by 2015 that respond to the world's main development challenges: http://www.undp.org/mdg/basics.shtml.

[401] United Nations, Department of Economic and Social Affairs, *The Millennium Development Goals Report 2007* (New York, United Nations, 2007)

[402] United Nations, Department of Economic and Social Affairs, *The Human Development Report 2006* (New York, United Nations, 2006).

increase the importance of persons with disabilities in such reports in the future.[403]

Article 32 of the CRPD is dedicated to international cooperation and highlights action-oriented measures which states can undertake to support inclusive development. The Article ensures that development programmes become inclusive and accessible to persons with disabilities, putting to bed the idea that the only way to increase the wealth of disabled people is by focusing on disability-specific programming. A consequence of the CRPD's insistence that disability be mainstreamed into all development programmes,[404] is that 'once a country ratifies the CRPD, it will need to be reflected in its national development framework such as the Common Country Assessment, United Nations Development Assistance Framework, and Poverty Reduction Strategy Papers. It is through these broad-reaching approaches to development that the CRPD will become a reality on the ground and in the daily lives of individuals'.[405] Thus the CRPD sets up a communication process among people leading on different policies. The treaty's focus on poverty reduction may well have a direct impact on domestic implementation, as well as on the methods with which international and domestic actors communicate with each other. Boosted communications in the mainstream will result in persons without disabilities being exposed to those with disabilities. Such exposure may help reduce stigma and discrimination against persons with disabilities.

Prerequisites to rebalancing global inequalities by redistributing financial and informational resources include elements of the educational value of human rights: willingness by states to share information with other states, an appreciation by development agencies of the damage caused by inappropriate grant-making (such as renovating children's institutions instead of investing into community-based services), an increased effort by United Nations and regional bodies to facilitate exchange, and more transparent processes to

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[403] UN Commission for Social Development (2008) *Mainstreaming Disability in the Development Agenda*, E/CN.5/2008/6, prepared for the Commission's forty-sixth session, 6-15 February 2008.

[404] CRPD Preambulatory para (g) also emphasises 'the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development'.

[405] *Relationship between Disability and Development*, available at www.un.org/disabilities/default.asp?id=33.

allow civil society organisations to participate and hold states to account. Exchanging information, of course, only goes so far. People's lives will change only if action is taken as a result of the information exchange, and it is the proactive value of human rights which this chapter now considers.

4. Proactive value of human rights: doing

Having laid out the expressive value of human rights which presents a new paradigm for the conceptualization of disability, and the educational value of human rights which opens up conversations inside and between organisations and states, it is the proactive value of human rights which turns thinking and talking into action. The pre-existing international human rights landscape applies to people with disabilities, but as the CRPD points out, 'despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world'.[406] The drafters of the CRPD made it their aim to plug the compliance gap between rights and implementation, and they inserted into the text several structural features which make it likely that the CRPD will be implemented to a greater extent than other human rights treaties.

A. Specificity of Action

The drafters were acutely aware that the need for the CRPD was that international human rights treaties and their mechanisms had failed people with disabilities. The CRPD contains a wealth of action points which states will find difficult to ignore. Whereas the United Nations Convention on the Rights of the Child obliges States Parties to take 'all appropriate legislative, administrative, and other measures' to ensure that children are protected against all forms of discrimination,[407] it does not actually specify what these appropriate measures should be.

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[406] CRPD, preambulatory para (k).

[407] Convention on the Rights of the Child, Art 2(2).

The CRPD does not hold back on specificity, making it easier for States Parties to understand their obligations, and for the United Nations Committee on the Rights of Persons with Disabilities, as well as domestic bodies, to hold States Parties to account. The CRPD goes much further than the Convention on the Rights of the Child, obliging States Parties to 'modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities',[408] to refrain from acting in any way which is inconsistent with the CRPD,[409] to take 'all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise',[410] to promote training of professionals and staff working with persons with disabilities about the CRPD,[411] and (quite remarkably) to 'take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes'.[412] States Parties are therefore under a duty to take broad action across government to ensure that rights are protected, respected and fulfilled in public and private spheres and considered in all policies and services.

B. Independent Mechanisms

It is commonly acknowledged in human rights that it is easy for states to ratify treaties, because they need not do anything about implementation, placing at risk the potential of international law to bring positive changes to people's lives. The CRPD guards against backsliding by establishing an independent body at United Nations level, and by obliging States Parties to establish/designate an independent monitoring body at domestic level. These two mechanisms will be examined in turn.

Despite numerous innovative proposals put forward by a variety of organisations, the CRPD has quite a mundane arrangement at the United Nations level to monitor state compliance. The CRPD establishes a Committee

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[408] CRPD, Art 4(1)(b).

[409] CRPD, Art 4(1)(d).

[410] CRPD, Art 4(1)(e). Note how the CRPD views State intervention into the private spheres as unproblematic.

[411] CRPD, Art 4(1)(i).

[412] CRPD, Art 4(1)(c), emphasis added.

on the Rights of Persons with Disabilities,[413] which consists of twelve experts (increasing to eighteen after eighty ratifications of the CRPD)[414] who 'shall serve in their personal capacity and shall be of high moral standing and recognized competence and experience in the field covered by the Convention'.[415] When nominating prospective members, States Parties are encouraged to 'closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations'.[416] The CRPD calls for States Parties to 'consider' the prospect of achieving 'equitable geographical distribution, representation of the different forms of civilization and of the principal legal systems, balanced gender representation and participation of experts with disabilities'.[417] The members serve for four years, except for six members from the first batch who serve for two years only, ensuring a staggered turnover.[418]

The role of the Committee is two-fold. First, the Committee receives reports by States Parties on measures taken to implement the CRPD. The reports 'may indicate factors and difficulties affecting the degree of fulfilment of [CRPD] obligations'.[419] These reports must be submitted within two years of the entry into force of the CRPD in each particular State Party,[420] and thereafter every four years.[421] The CRPD uses rather tentative language when it invites States Parties 'to consider' preparing their reports 'in an open and transparent process and to give due consideration' to 'closely consult[ing] with and actively involv[ing] persons with disabilities, including children with disabilities, through their representative organizations'.[422] The Committee will consider these reports, and 'shall make such suggestions and general recommendations on the report as it may consider appropriate'.[423]

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[413] CRPD, Art 34(1).
[414] CRPD, Art 34(2).
[415] CRPD, Art 34(3).
[416] CRPD, Art 4(3), to which Art 34(3) invites States Parties to give due consideration when nominating their candidates.
[417] CRPD, Art 34(4).
[418] CRPD, Art 34(7).
[419] CRPD, Art 35(6).
[420] CRPD, Art 35(1).
[421] CRPD, Art 35(2).
[422] CRPD, Art 35(5), citing Art 4(3) on participation.
[423] CRPD, Art 36(1).

Interestingly enough, the CRPD places an obligation on States Parties to 'make their reports widely available to the public in their own countries and facilitate access to the suggestions and general recommendations relating to these reports'.[424] This is worth dwelling on a little. The CRPD is the first United Nations human rights treaty to contain an obligation on States Parties to make widely available to the public either their own report on compliance or the treaty monitoring body's suggestions and recommendations relating to that report. This is another example of how the CRPD pioneers a new participatory politics and promotes a dynamic of domestic discussion and participation. Presumably the obligation to make reports widely available means producing the reports in various formats – for the public without disabilities, and various accessible formats for people with disabilities who require different formats. So the reports would at a minimum have to include: easy-to-read format for children with disabilities, easy-to-read format for adults with intellectual disabilities, large print, Braille, and electronic versions. The public also consists of people without disabilities. One can read into the CRPD an implicit obligation that the government takes the responsibility to translate its report and the Committee's suggestions and recommendations into indigenous languages accurately and promptly, and to issue all of the above-mentioned formats in each of these languages.

The second role of the Committee applies only in relation to those states which have ratified the Optional Protocol to the CRPD. The Committee can receive and consider communications from or on behalf of individuals or groups of individuals subject to its jurisdiction of that state who claim to be victims of a violation by that State Party of any CRPD provisions.[425] The Optional Protocol sets out various procedural rules, including the requirement that the victim(s) must exhaust domestic legal remedies before submitting the communication to the Committee. After considering the Applicant's and the respondent state's positions in a given communication the Committee may make recommendations and suggestions to the respondent state.[426] In addition to dealing with individual communications the Committee can also

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[424] CRPD, Art 36(4).
[425] Optional Protocol to the CRPD, Art 1.
[426] Optional Protocol to the CRPD, Art 5.

instigate an ‘inquiry’ where it receives information ‘indicating grave or systematic violations’ of the CRPD.[427] The Committee can ask a state to include in its periodic reports under Art 35 of the CRPD any measures which it has taken in response to such an inquiry.[428]

The rather mundane international arrangement for monitoring compliance si compensated for by innovative domestic monitoring mechanisms. The CRPD follows a recently-established trend in international human rights treaties to oblige States Parties to establish domestic mechanisms for monitoring implementation. The obvious parallel is the Optional Protocol to the United Nations Convention against Torture (OPCAT) which obliges States Parties to ‘maintain, designate or establish [...] one or several independent national preventive mechanisms for the prevention of torture at the domestic level’.[429] These national preventive mechanisms may be ombudsman offices, national human rights institutions or fresh bodies. States must give them the power to enter places of detention in order to examine the rights of persons deprived of liberty, make recommendations to the authorities on each place of detention and make recommendations on draft legislation.[430]

The CRPD takes this idea and runs with it, obliging States Parties to ‘maintain, strengthen, designate or establish [...] a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present [CRPD]’.[431] In carrying out this obligation states must take into account the Paris Principles,[432] which set out minimum standards for the functioning, composition, financing, guarantees of independence and pluralism, and methods of operation of national human rights institutions. Although the national monitoring mechanisms are seen as quite innovative, during the negotiations of the CRPD, states rejected even more creative proposals put forward by both the International Disability

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[427] Optional Protocol to the CRPD, Art 6.

[428] Optional Protocol to the CRPD, Art 7(1).

[429] Optional Protocol to the UN Convention against Torture, Art 17.

[430] Optional Protocol to the UN Convention against Torture, Art 19.

[431] CRPD, Art 33(2).

[432] National Institutions for the Promotion and Protection of Human Rights, United Nations General Assembly resolution 48/134, 20 December 1993.

Caucus (comprising all sorts of disability NGOs) and the grouping of National Human Rights Institutions.[433]

The national independent mechanisms foreseen by the CRPD will in many countries likely be crucial in conjoining the government to focus on effective implementation. The CRPD inventively mandates States Parties to ensure that these independent mechanisms do three quite different things: 'to promote, protect and monitor implementation of the [CRPD]'. To get round the linguistic ambiguity, my reading of this sentence is that the duties to promote and protect refer to the rights of people with disabilities and not to promoting or protecting implementation.

What sorts of activities would fall under these three headings? Promoting human rights of persons with disabilities means anything which 'valourises' the paradigm shift.[434] This would include activities in the public arena and in the corridors of power to promote the ratification of the CRPD (if the state has not already done so), and encouraging ratification without reservations or interpretative declarations which unravel the CRPD. Promoting rights means getting out of the office and meeting key officials to encourage them to take action to ensure the full and effective implementation of the CRPD. Other activities would include awareness-raising campaigns for the general public including delivering messages to the public through the media.[435] It would also include organising training for people working with and caring for people

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[433] For an analysis of these proposals, see G Quinn, 'Resisting the 'Temptation of Elegance' Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?' in MO Arnardóttir and G Quinn eds, *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Leiden, Martinus Nijhof, 2009). These included a direct obligation on the national monitoring mechanism not just to hold the government to account with regard to the Convention, but also domestic disability policies, and that the national body should make legislative recommendations. The proposal for an international monitoring body included a set of facilitative, solution-oriented activities rather than a passive role which receives reports from states parties. It also contained an elaborate mechanism to ensure that the Committee contained experts with disabilities proposed not by states, but by the Office of the UN High Commissioner for Human Rights.

[434] Thanks to Gerard Quinn for this phrase and for encouraging me to delve into domestic monitoring mechanisms.

[435] In the Convention, 'States undertake to adopt immediate, effective and appropriate measures' (Art 8(1)) on awareness-raising, with measures including 'encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention' (Art 8(2)(c)).

with disabilities,[436] and capacity-building of organisations of and for persons with disabilities so that they can better participate in public policymaking on issues which affect them, as envisioned by the CRPD.[437] Promoting human rights means working with education systems to integrate disability into human rights education in primary and secondary schools. It also means encouraging law faculties and human rights institutes to include the rights of persons with disabilities as part of their regular human rights teaching and research.

As already noted, the CRPD places a general obligation on states '[t]o take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes'.[438] So too should an ombudsman office or national human rights institution ensure that in addition to carrying out specific programming to promote and protect the rights of persons with disabilities, they integrate and mainstream disability into all areas of existing work. For example, they need to promote disability rights within thematic areas such as the prevention of torture, promotion of sexual and reproductive rights, freedom of expression, election monitoring, domestic violence and hate crime. Mainstreaming also means dealing authentically with double (and treble, and more) discrimination by ensuring that people with disabilities feature as part of work regarding all discriminated-against groups: women, refugees, people of ethnic or religious minorities, lesbian, gay, bisexual and transgender people, children and young people, elderly people, poor people, detained people and so on. The national monitoring mechanisms need not do this alone; they can call for assistance from sister organisations abroad, working in concert to share practices and to develop ideas.

So much for promoting rights. Protecting rights has more of a hard-edged feel. This may include providing legal advice and assistance to individuals and – depending on the mandate of the independent mechanism – representing them in domestic courts or before the United Nations Committee on the

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[436] CRPD, Art 4(1)(i) requires states 'to promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights'.

[437] CRPD, Art 33(3) – this is addressed below.

[438] CRPD, Art 4(1)(c).

Rights of Persons with Disabilities in individual complaints under the Optional Protocol. The independent mechanism could seek to advance jurisprudence by piggy-backing on litigation by intervening as a friend-of-the-court by submitting an amicus curiae brief. Protecting rights means reacting in a speedy and appropriate manner to cases revealed by the media. It means vigorously holding governments to account and ensuring that independent bodies are seen and heard to be doing so. It also means travelling the breadth and width of the country to monitor the rights of people with disabilities where they live, including in places of detention such as psychiatric facilities and social care institutions, as well as in smaller group homes. There is an inevitable crossover here between the role of the CRPD independent mechanisms, and the national preventive mechanism of places of detention under the Optional Protocol to the United Nations Convention against Torture (OPCAT), noted above. Coordination between the two bodies will be necessary, as will cross-fertilisation of skills and experience. In some countries they will be different departments of the same Ombudsman's office or national human rights institution, in which case cross-departmental cooperation is called for..

If the independent body is doing its job properly, it will come head-to-head with governmental authorities. Part of being an independent human rights structure means speaking truth to power. In the area of human rights, truths can be uncomfortable, and some governments go to great lengths to crush criticism. It is vital that legislation protects the independence of national human rights structures to prevent their budgets being slashed by government, to prevent summary dismissal of staff, or raiding of premises.

The third function of the national independent body as set out in the CRPD is to monitor the implementation of the CRPD. This is an unusual task, unparalleled in international human rights law. It is quite remarkable that states negotiating the CRPD agreed that they would each establish and finance a body at arms-length to government with the mandate to monitor how well the government is implementing the CRPD. Such a task will be challenging even for well-established independent mechanisms. The CRPD is detailed and complex and most existing national human rights institutions are already overloaded even without this significant additional mandate.

Monitoring the implementation of the CRPD will mean carrying out an array of concrete activities distinct from those falling under the headings of promoting and protecting the rights of persons with disabilities. The first activity when monitoring anything is likely to be to establish the current reality. Each national independent mechanism will have to analyse how national laws and policies compare with the CRPD and publish a base-line report which highlights areas on which the independent body needs to focus, and, flowing from this, a work plan with measurable objectives. Monitoring CRPD implementation also means tracking draft legislation which has or ought to have an impact on people with disabilities, analysing it through the lens of the CRPD, and coming out with a view as to its CRPD compliance. A legislative scrutiny role such as this will feed into or from a parliamentary human rights committee (where such a body exists).

Conducting analyses of actual and draft laws and policies for Convention compliance requires staff working for the independent mechanism to have a high level of understanding of the CRPD, the skills to conduct such analyses, and the resources to ensure that analyses are available in a variety of formats. In building its own capacity such a mechanism might want to draw on the expertise of disabled people's organisations, other NGOs and academics. The independent mechanism will need to develop and adopt indicators or precise standards against which laws or practice can be measured. A useful early task for the United Nations Committee on the Rights of Persons with Disabilities is to develop – with the participation of persons with disabilities and their NGOs – a reporting template with basic indicators of compliance, and make it clear that they expect States Parties to use this template when compiling their reports under Art 35 of the CRPD. This will help the national independent mechanisms to carry out their baseline analyses, and to repeat these periodically so that information is tracked through time. Assessing compliance at various points in time is a vital tool to be able to comment on whether a particular state is, to the maximum of its available resources, progressively realizing the economic, social and cultural rights set out in the CRPD.[439]

A compliance analysis requires data. The lack of meaningful data and statistics is a major problem in some countries where governments fail to collect and collate national data on disability rights issues, such as (if we are analyzing compliance with Art 12 of the CRPD), how many people in a particular country have been deprived of legal capacity. States Parties are obliged by the CRPD to 'collect appropriate information including statistical and research data to enable them to formulate and implement policies to give effect to the present CRPD'.[440] The data should be disaggregated, so as to monitor potentially discriminatory practices, and the independent monitoring body would be wise to ensure that it makes its expectations clear at the outset, so that the government can start collecting the appropriate data.

Evaluating policy implementation is no easy task, and the national monitoring body – as well as the United Nations Committee on the Rights of Persons with Disabilities itself – will need to be well-resourced. Difficulties which these bodies may face include evaluating several initiatives in parallel; dealing with governmental 'initiativitis' whereby policies change quickly without proper evaluation or sometimes explanation; evaluating policies serving multiple policy objectives which rely on the input of various departments, services and organisations; and dealing with the incredible breadth of legislation and policies which implement the CRPD: from inclusive education of children with visual disabilities to the disability inclusivity of international aid, from accessibility of police stations, to the sexual and reproductive rights of adults with intellectual disabilities in group homes. The scope of the topics covered by the CRPD could easily become overwhelming for those responsible for monitoring and evaluating its implementation.

The United Nations Committee on the Rights of Persons with Disabilities will need to be the watchdog of watchdogs, monitoring the performance of the

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[439] CRPD, Art 4(2). It is not clear which of the CRPD rights fit into the seemingly neat box of 'economic, social and cultural rights'. For a discussion of this point, see F Mégret, 'The Disabilities Convention: Towards a Holistic Concept of Rights'(2008) 12 *International Journal of Human Rights* 261, 265-266.

[440] CRPD, Art 31.

national monitoring bodies, as well as compiling and sharing information about 'best practices' among them. To give meaning to the proactive role of human rights, the national monitoring bodies should ensure the participation of people with disabilities, as well as draw on the expertise of people within their own country and gather information from abroad. In combining information-sharing with carrying out concrete activities, such bodies will demonstrate the connectivity between the educational role and the proactive role of human rights.

C. Participation by People with Disabilities

One of the CRPD's principles is '[f]ull and effective participation and inclusion in society'.[441] Specifically the CRPD guarantees participation in political and public life by reaffirming the right to vote and stand for office.[442] Participation in public life, however, means more than voting every few years. The CRPD sets out the right to participation in strong terms, and locates this obligation in Art 4(3) on general obligations:

> In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

As noted above, the duty on the state to ensure participation of persons with disabilities in legislative and policy reforms is extended to the process for states to nominate candidates for the United Nations Committee on the Rights of Persons with Disabilities. When nominating their candidates, 'States Parties are invited to give due consideration' to consulting with and actively involving persons with disabilities through NGOs.[443] When States Parties elect

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[441] CRPD, Art 3(c).

[442] CRPD, Art 29.

[443] CRPD, Art 34(3).

the members of the Committee they are asked that consideration be given to the 'participation of experts with disabilities'.[444]

The CRPD guarantees that persons with disabilities and their organisations are involved in monitoring its implementation.[445] This means that the domestic independent monitoring bodies (discussed in the section above) must find ways of reaching out to people with disabilities and including them in their work. Participation of persons with disabilities in the monitoring of the CRPD will likely result in the monitoring being more relevant, accurate and sensitive to the needs of those whose rights the CRPD aims to advance.

Across the world, people with disabilities have been denied access to information and therefore denied power. Those in position of influence and wealth (for example, disability service providers, psychiatrists, lawyers, family members and carers, not to mention pharmaceutical companies) have traditionally been the policymaking power players, lobbying governments to adopt policies which are professionally and financially beneficial. The CRPD is premised on the belief that 'persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them',[446] and in doing so the treaty seeks to repatriate power towards those who have most to gain from Convention implementation. The CRPD organises this power redistribution by creating a general obligation to ensure participation, a general obligation which should be read into each CRPD provision. The general obligations need also to be read into the various bodies which the CRPD establishes and which are referred to in this chapter, namely the Conference of States Parties to the Convention,[447] the Committee on the Rights of Persons with Disabilities,[448] the focal point(s) in the domestic executive structure,[449] and the national independent monitoring bodies,[450] in which '[c]ivil society, in

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[444] CRPD, Art 34(4).

[445] Art 33(3) says that, '[c]ivil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.'

[446] CRPD, preambulatory para. (o).

[447] CRPD, Art 40.

[448] CRPD, Art 34.

[449] CRPD, Art 33(1).

[450] CRPD, Art 33(2).

particular persons with disabilities and their representative organizations, shall be involved and participate fully'.[451]

An insistence that people with disabilities and their NGOs participate in monitoring the CRPD's implementation makes it more likely that implementation will actually happen. It is also more likely that the United Nations Committee on the Rights of Persons with Disaiblities and the domestic independent monitoring bodies receive relevant, informed and accurate information from civil society so that they in turn can provide specific, measurable and time-bound objectives for States Parties to bring their laws, policies and practices in line with CRPD requirements. The CRPD's insistence on ensuring the participation of persons with disabilities suggests a post-hierarchical politics, one in which there is greater transparency, ownership of results, and likelihood of implementation.

Research has suggested that participation allows for a greater and more varied set of voices to be brought into decision-making processes in order to counteract the dominance of previously more powerful voices. It has also indicated that participation increases the effectiveness of service delivery. A group of British researchers puts it succinctly in observing that, '[e]ffective governance requires an informed, engaged citizenry which votes in elections, participates in decision making and works with service providers in designing, delivering and monitoring services'.[452] In other words, participation in CRPD processes goes beyond superficial attempts at political correctness: it is beneficial for persons with disabilities, and for politicians and civil servants too.[453]

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[451] CRPD, Art 33(3).

[452] SR Andrews, R Cowell, J Downe, S Martin, and T Turner, *Promoting Effective Citizenship and Community Empowerment*: *A Guide for Local Authorities on Enhancing Capacity for Public Participation* (London, Office of the Deputy Prime Minister, 2006).

[453] For a discussion on participation in the mental health arena, see O Lewis, and N Munro, 'Civil Society Involvement in Mental Health Law and Policy Reform' in M Dudley, D Silove, and F Galeeds, *Mental Health and Human Rights*, (Oxford, Oxford University Press, forthcoming 2010).

D. Co-ordinating Implementation

As well as establishing independent mechanisms at the domestic and international levels and insisting on the participation of people with disabilities at both those levels, the CRPD demands executive coordination of implementation at both intergovernmental and governmental levels.

The CRPD is the first United Nations human rights treaty to require the States Parties to 'meet regularly in a Conference of States Parties in order to consider any matter with regard to the implementation of the present CRPD'.[454] The Conference can be convened however regularly the States Parties decide, but no less regularly than every two years.[455] Although most other treaties have a provision for calling a Conference of States Parties, the CRPD is the only one to mandate its Conference to consider implementation.[456] Early indications are that the Conference of States Parties to the CRPD will be held more or less annually, and will be inclusive of civil society organisations.[457] The Conference of States Parties is serviced not by the Geneva-based Office of the High Commissioner for Human Rights (which services the Committee on the Rights of Persons with Disabilities), but by the Department for Economic and Social

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[454] CRPD, Art 41(1) CRPD.

[455] CRPD, Art 41(2) CRPD.

[456] Although a Conference of States Parties is envisioned in Art 51 of the International Covenant on Civil and Political Rights (adopted by General Assembly resolution 2200A (XXI) of 16 December 1966), Art 29 of the International Covenant on Economic, Social and Cultural Rights (Adopted by General Assembly resolution 2200A (XXI) of 16 December 1966), Art 29 of The Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (Adopted by General Assembly resolution 39/46 of 10 December 1984), Art 50 of the Convention on the Rights of the Child (Adopted by General Assembly resolution 44/25 of 20 November 1989), Art 90 of the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (Adopted by General Assembly resolution 45/158 of 18 December 1990), Art 34 of the Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (Adopted by General Assembly resolution 57/199 of 18 December 2002), all of these treaties limit the formal mandate of such a conference to a consideration of proposed amendments to the treaty by states parties. Curiously neither the International Convention on the Elimination of All Forms of Racial Discrimination (Adopted by General Assembly resolution 2106 (XX) of 21 December 1965) nor the Convention on the Elimination of All Forms of Discrimination against Women (Adopted by General Assembly resolution 34/180 of 18 December 1979) do not contain provision for a Conference of States Parties.

[457] The second Conference of States Parties was held over three days in September 2009. The agenda included panels, dialogues and side events, all discussing the subject 'Legislative measures to implement the Convention on the Rights of Persons with Disabilities'. There was significant participation of NGOs.

Affairs based in New York. This reflects, perhaps the fact that the Conference is governmental, whereas the Committee is supposed to be independent.

The CRPD encourages states to talk to each other and (possibly) make decisions on implementation, through the Conference of States Parties. . At the domestic level, it requires that States Parties, 'designate one or more focal points within government for matters relating to the implementation of the present CRPD'.[458] The purpose of the focal points is to coordinate action across ministries, departments and agencies to deliver a coherent disability policy. Central government has a duty under the CRPD to ensure that its provisions are implemented everywhere within the state's jurisdiction, (even in federal states). It has a further duty to coordinate action across local and regional authorities. The drafters of the CRPD (which were, after all, state representatives themselves) were aware that many of the rights violations suffered by people with disabilities are caused by failures in communication and co-ordination of policy. This proposition is supported by empirical evidence which suggests that a key element in policy implementation failure is that many actors do not talk to each other and do not co-ordinate policy delivery.[459]

That the CRPD sets out how States Parties should organise the executive branch of government in order to implement the treaty is an audacious constitutional masterstroke. The CRPD insists on 'joined-up' government, a new concept for many countries which govern by departmental machine. Governments may like to consider having the following objectives for their disability rights focal point(s):[460]:

> To create an integrated, holistic approach to the development and delivery of disability policy;

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[458] CRPD, Art 33(1).

[459] S Barrett, 'Implementation Studies: Time for a Revival? Personal Reflections on 20 Years of Implementation Studies' (2004) 82 *Public Administration* 249. Barrett suggests that the three other factors deemed to contribute to implementation failure are lack of clear policy objectives; inter- and intra-organisational value and interest differences; and relative autonomies of implementing agencies coupled with limits of administrative control.

[460] Adapted from J Newman, 'Joined-up Government: The Politics of Partnership' in *Modernising Governance: New Labour, Policy and Society* (London, Sage, 2001).

> To overcome departmental barriers and the problems of 'silo' management;
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> To reduce transition costs from overlapping policies and initiatives;
>
> To deliver better policy outcomes by ensuring the participation of and contributions from people with disabilities;[461]
>
> To encourage greater coordination and integration of service delivery among providers at the local level;
>
> To develop innovative approaches to policies and services by eliciting the contributions of various partners;[462] and
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> To increase the financial resources flowing into the disabilities sectors.[463]

A pre-requisite to pursuing joined-up government will be for politicians overseeing these focal points to provide leadership towards Convention implementation. Despite strong political backing, an enabling approach to delivering disability policy may be undermined by the strong traditions of rational planning and the continued centralisation of power associated with mechanical models of the 'policy-action dynamic'. It is crucial therefore that the effectiveness of CRPD focal points is closely monitored by civil society, by the relevant state's independent monitoring body, and by the United Nations Committee on the Rights of Persons with Disabilities.

In many countries the focal points are being set up within traditionally low-power ministries, such as ministries of social affairs, or ministries of employment. In placing the focal points in these ministries, states perpetuate the myth that disability policy is a soft social issue, or that its only aim is to

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[461] This is a requirement under CRPD Arts 4(3) and 33(3).

[462] This could mean facilitating the sharing of promising practices within the country, and importing practices from outside the country – perhaps by working with sister focal points in other countries or via organisations such as the UN or international NGOs.

[463] This could be achieved, for example, by quantifying the needs of persons with disabilities, ensuring that ministries contribute to providing the funding, developing partnerships which can deliver on providing appropriate services. Such partnerships these could, depending on the local circumstances, involve State bodies, quasi-State agencies, private companies, and non-profit organisations.

reduce discrimination in employment. The CRPD is a cross-disciplinary treaty which, of course, does cover public policy areas of employment and social affairs, but goes much broader into policy areas of education, criminal justice, civil justice, family, foreign affairs,[464] international development, home/interior affairs, data protection, data and statistics. Given that the CRPD's main goal is to achieve equality and non-discrimination, it may be more prudent for activists to suggest that the relevant government's focal point is housed by the ministry of justice which, in many countries, has power and authority across a variety of other ministries. It will be interesting to see what the United Nations Committee on the Rights of Persons with Disabilities says about the ideal mother ministry for the focal points.

A further pre-requisite to pursuing a 'holistic' approach of policy co-ordination will be for all actors to be clear about the role of government. Such clarity is needed when coordinating policy, ensuring the participation of persons with disabilities, and delivering policy and services. In hierarchical models of governance, the government sets the agenda, develops the policy and implements it or orders others to do so. In encouraging an alternative politics, the CRPD sets up potential conflicts which will have to be managed. The policy theorists Erik-Hans Klijn and Joop Koppenjan suggest that in a network-like situation, the government may choose not to join in discussions at all.[465] Alternatively the government could communicate with other public agencies and NGOs, or they may choose to play the role of process manager facilitating iterative discussions, or they may choose to be a network builder using their resources and their credibility as legitimately elected representatives of the majority. Klijn and Koppenjan warn that if government is inexperienced (which will inevitably be the case for the majority of CRPD focal points around the world) there is a risk that behaviours will revert to established and safer routines in which 'misunderstandings and conflict

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[464] For example, people entering the United States risk not being allowed in the country if they fail to tick the box certifying that they do not have a major mental illness. Another example is that it could be argued that the Convention requires embassies to be accessible for persons with disabilities, and another example is that embassies act as polling stations, and Art 29 of the Convention requires voting procedures to be accessible.

[465] EH Klijn and FM Koppenjan, 'Public Management and Policy Networks: Foundations of a Network Approach to Governance' (2000) 2(2) *Public Management*, 135.

among actors can prove to be costly in terms of effectiveness and efficiency, but especially with regard to the reliability and legitimacy of governments'.[466] This may be especially the case in countries with active focal points, with civil servants who want to combine the roles of a body which has a political 'opinion' with a more neutral process manager role or a network builder role. In time we will be able to assess how well the focal points manage their new and complex role. It is hoped that the Conference on States Parties will take the lead in sharing promising practices in executive coordination.

The politics of power has inevitably surfaced in this section on the proactive value of human rights. Power exists also in formulating ideas and discussions between stakeholders, so it is a consideration which runs through the expressive, educational and proactive roles of human rights. This section has looked at the structures established at the international and domestic levels to ensure policy coordination and those set up to monitor the implementation of the CRPD. The strong participation of people with disabilities in these mechanisms will re-balance power and ensure that policies and monitoring methodologies are relevant and owned by disability communities. Ownership will happen if governments tacitly acknowledge the disenfranchisement of persons with disabilities and their respective organisations, and ensure that these citizens are empowered to participate in and have the capacity to intervene on an equal basis with others in the policy cycle. The combination in the CRPD of substantive rights coupled with process requirements is unusual in human rights treaties. Its innovative implementation mechanisms may well contribute to closing the gap between rights rhetoric and reality.

5. Conclusion

This chapter has suggested that a way of conceptualising the potential of the United Nations Convention on the Rights of Persons with Disabilities to effectuate social change is through the framework of the expressive, educational and proactive roles of human rights. The interdependence of

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[466] EH Klijn and FM Koppenjan, 'Public Management and Policy Networks: Foundations of a Network Approach to Governance' (2000) 2(2) *Public Management*, 135, 154 .

these roles mirrors the rights enshrined in the CRPD as well as the institutions established by the CRPD at United Nations and domestic levels to ensure implementation. Interdependence itself is a core feature of human rights law and practice. The CRPD is now one of the nine core United Nations human rights treaties, but as Gerard Quinn has suggested, we should think of it 'less as a means for coercing States and more as a powerful tool for enabling its revolutionary insights to percolate into the political process (by 'persuasion' and 'socialisation') and hence transform the political process to the point that justice and rights for persons with disabilities is seen as the primary departure point and not as an annoying distraction'.[467]

Political processes are likely to be transformed if persons with disabilities, their family members and carers, providers of services, governmental authorities, and a range of civil society actors are open to thinking about ideas which may initially be uncomfortable. Political processes are likely to be transformed if people talk to those whose views may have been marginalised and with whom they have previously not talked to or with whom they have vehemently disagreed. And political processes are likely to be transformed if programmes outside their drafters' comfort zones are implemented. In other words, the expressive, educational and proactive roles of human rights may be relevant to this Convention's implicit goal of changing the politics which have marginalised people with disabilities worldwide.

Creative problem solving will mean that policy-makers will have to take risks, and try out programmes to, for example put in place supported decision-making to comply with Art 12 of the CRPD. On such issues the 'correct' thing to do may be to take risks and put in place services for which there are no best practices, but rather promising practices which will have to be evaluated over time. Some of these programmes will work; others will flop. The United Nations Commission for Social Development has lent its weight to the notion of programme experimentation and knowledge-transfer, suggesting that, '[n]ew and innovative thinking and collaboration are required to utilize the

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[467] G Quinn, 'Resisting the 'Temptation of Elegance' Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?' in MO Arnardóttir and G Quinn eds, *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Leiden, Martinus Nijhof, 2009).

CRPD so as to bring the maximum benefit to persons with disabilities and society'.[468] The negotiation process was an example of innovative collaboration, and the resultant text of creative thinking.

The CRPD attempts to redistribute power and creates new forums for stakeholder communication, policy coordination and implementation monitoring. These are all reasons to be optimistic that this Convention, more than others, will be implemented in small places, close to home. Implementation will depend on the genuine willingness of policy-makers to embrace a new kind of politics, an embrace which no treaty can guarantee.

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[468] UN Commission for Social Development (2008) *Mainstreaming Disability in the Development Agenda*, E/CN.5/2008/6, prepared for the Commission's forty-sixth session, 6-15 February 2008, at [30(b)].

BLOCK TWO

Chapter 5: Advancing legal capacity jurisprudence

This chapter was published as Oliver Lewis, "Advancing legal capacity jurisprudence", (2011) *European Human Rights Law Review*, 6, 700-714

1. Abstract [469]

This paper addresses the role of strategic litigation of the right to legal capacity of people with disabilities. It places legal capacity within international human rights law and sets out how it is particularly resonant in the context of disability where its withdrawal leads to arbitrary removal of rights such as right to property, healthcare decision-making, working and voting. The paper examines Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), a treaty which, at the time of writing, had been signed by all 27 Member States of the European Union (EU) and ratified by 18. In addition, the EU has acceded to the Convention, the CRPD being the first UN human rights treaty that has provided this

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[469] Parts of this article were presented at a disability litigation conference on 13 November 2009 at American University, Washington DC, organised by Disability Rights International and the Open Society Foundations. I wish to thank Michael Bach, Lycette Nelson and Gerard Quinn for their incisive comments on an earlier draft.

opportunity.[470] The paper provides a review of European jurisprudence in the area of legal capacity and suggests that litigation can play a valuable role in highlighting the wrongs in guardianship systems, and opening up areas for advocacy and law reform.

2. The emergence of legal capacity as a right

Legal capacity is a construct which enables law to recognise and validate decisions and transactions which a person makes. Jurisdictions differ in their laws, but denial of legal capacity can mean that a person is stripped of the legal authority to make decisions about where and with whom to live, how to manage their own property and finances. Their rights to vote and seek political office are removed, as are their right to join political parties, trade unions and non-governmental associations. Marriage and parenthood are also compromised, as are transactions of an every-day nature: contracting with a utility company or mobile phone firm. Denial of legal capacity locks an individual out from accessing justice systems on an equal basis with others. Legal capacity therefore underpins the enjoyment of a range of fundamental rights.

Two approaches to legal capacity are still widespread in Europe,[471] despite their rejection by international human rights law. Both are based on the now increasingly questioned assumption that the right to legal capacity is dependent upon, or equitable with, requisite mental/functional capacity. The first is the status-based approach in which a medical diagnosis of a mental health or intellectual impairment forms the basis for removing legal capacity. The second is an outcome-based approach which utilises psychiatric assessments in order to cast doubt over the integrity of a person's decision-making process, seeking to prevent decisions which others deem bad or

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[470] See Article 44 of the CRPD which allows for "regional integration organizations" to accede to the Convention, a step which the European Union took on 23 December 2010.

[471] For more on the approaches, see Dhanda, A. (2007) "Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future", 34 *Syracuse J Int'l L & Com*, 429, and Keys, M (2009) "Legal Capacity Law Reform in Europe: An Urgent Challenge", in Quinn, G. and Waddington, L. (eds) *European Yearbook of Disability Law*, Intersentia.

irrational from having a deleterious effect on the person or other people. Once legal capacity is deprived or restricted, the individual is placed under (what many jurisdictions call) guardianship, and decisions are made by a guardian. There are various forms of guardianship: partial (for example decisions can only be made in relation to the person's finances but the individual retains decision-making in other fields such as healthcare), or it can be plenary measure where all legally-relevant decisions are made by the guardian.

Legislation regulating legal capacity can be remarkably broad, allowing for the medical and judicial systems to work together to declare someone incompetent. For example, guardianship is available in Croatia on the basis that the adult "is not able to care for his or her own needs, rights and interests, or who presents a risk for the rights and interests of others".[472] No further guidance is given in law as to what these terms mean or how they are to be assessed.

The effect of these approaches has been to remove decision-making authority from people, rather than provide supports to those who may need such assistance. In Hungary, for example, research which the Mental Disability Advocacy Center carried out revealed that around 67,000 people are deprived or restricted of legal capacity and are "subject to significant, arbitrary and automatic deprivations of their human rights. These include a deprivation of their right to property, to work, to family life, to marry, to vote, to associate freely, and to access courts".[473] Like many jurisdictions in continental Europe, guardianship is the Hungarian law's only legal response to people who require assistance to make decisions. Although legal reforms are taking place, the statute book does not yet contain alternatives such as supported decision-making (where a person or network provides tailored informational and/or interpretation/communication assistance in a structured way), advance directives (where an adult specifies her wishes now to plan for a future time in which she is unable to make such decisions) or powers of attorney (where an

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[472] Section 159 of the Family Act (*Obiteljski zakon*, Official Gazette nos. 116/2003, 17/2004, 136/2004 and 107/2007), cited in European Court of Human Rights judgment of *Krušković v. Croatia*, judgment 21 June 2011, Application No. 46185/08, para. 13.

[473] Mental Disability Advocacy Center (2007) *Guardianship and Human Rights in Hungary: Analysis of Law, Policy and Practice*, p. 6.

adult specifies a person to take decisions at a future time in which she is unable to make such decisions).

The research which has been carried out has suggested that guardianship laws are vague and broad, making it easy for someone to be deprived of their legal capacity.[474] It is MDAC's experience that once a person has been placed under guardianship, access to justice barriers accentuate the difficulty for that person to apply to a court to regain their legal capacity. There are both legal and practical barriers, which interact with a person's impairment and by doing so "hinder their full and effective participation in society on an equal basis with others".[475] The main legal barrier is that once deprived of legal capacity, courts view that person as lacking legal standing to bring cases, blocking the opportunity to initiate any legal action, including an action to have their capacity restored. Other legal barriers include the fact that a person's signature becomes invalid, so that a person is legally unable to grant a power of attorney for legal representation. Another is the excessively short time periods to file an appeal.[476] Practical barriers include a lack of information about appeals and complaints processes, insufficient access to legal advice and representation, legal proceedings taking place without informing or involving the individual, and lack of adjustments in justice systems to accommodate a person's disability.

The functional approach differs from the status-based and outcome-based approaches because, unlike them, it does not label a person as wholly incapacitated or incompetent. Rather, it tests a particular function of a person (for example, making a bank transaction) and assesses whether a person can perform that function. The functional approach theoretically does not take into account the wisdom of the decision made,[477] but in practice it may be all too easy for practitioners to attach a label of incompetence to a person with

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[474] See reports by Mental Disability Advocacy Center (2008) *Guardianship and Human Rights in Bulgaria*, and similar reports with regard to the Czech Republic, Hungary and Russia.

[475] See Article 2 of the CRPD.

[476] For examples of all of these issues, see the European Court of Human Rights case of *Shtukaturov v. Russia*, judgment 27 March 2008, Application No. 4009/05.

[477] For a legislative example of this, see the English and Welsh Mental Capacity Act 2005. One of the five statutory principles listed in section 1 of the Act is that "A person is not to be treated as unable to make a decision merely because he makes an unwise decision."

whose decision they disagree. The approach recognises the need to establish safeguards to minimise the number of people whose decisions are made by others on their behalf (known as "substituted decision-making"); the length of time for which a person is subject to such a measure; and the potential for abuse. Generally, the emphasis is on ensuring that the least restrictive arrangement is put in place.

While the functional approach is an improvement conceptually over the status and outcome approaches to assessing mental capacity as a foundation for legal capacity, it is rooted in the idea that legal recognition of an other's right to legal capacity is dependent on their demonstrating their rationality. "A sound mind in a sound body", claimed John Locke in 1692, "is a short, but full description of a happy state in this World: he that has these two, has little more to wish for".[478] Twentieth century human rights discourse is faithful to this Enlightenment belief in human reason and rationality. The 1948 Universal Declaration of Human Rights proclaims that men are "endowed with reason and conscience and should act towards one another in a spirit of brotherhood".[479] From this perspective, the grandparent of modern human rights law frames the individual as a singularly rationalistic entity, standing "as a person before the law",[480] but not necessarily one who is embedded within it or admittedly dependent on others. "This masterless man," notes Gerard Quinn ironically, "this atom colliding in beneficial ways with other atoms – is rational".[481]

At the international level a significant rhetorical shift has been taking place, one which moves towards an embrace of autonomy, self-determination and support. The 1979 Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) sought to close the gender differential in recognition before the law and in the exercise of legal

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[478] John Locke, *Some Thoughts Concerning Education*, 1692.

[479] *Universal Declaration on Human Rights*, adopted by the UN General Assembly, 10 December 1948, Article 1.

[480] *Universal Declaration on Human Rights*, Article 6.

[481] Gerard Quinn "Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD", paper presented at a conference of the Harvard Project on Disability, 20 February 2010.

capacity.[482] It was twenty years later, in 1999, that the Council of Europe's Committee of Ministers issued what remains the most developed international law exposition of the functional approach to legal capacity. In a Recommendation entitled "principles concerning the legal protection of incapable adults" (itself quite a revealing title), the highest political body of the Council of Europe rejects the status-based and outcomes-based approaches in support of a functional approach in which decision-making ability is assessed according to the nature and point in time of the decision which needs to be made.[483] The nature of the decision is important as a person may be able to understand information relating to a dental procedure or buying a loaf of bread, but not that related to heart treatment or buying an apartment. Point in time relates to fluctuating ability throughout our lives – all of us are sometimes more able than not to make certain types of decision, and the capability of people with certain mental health issues may fluctuate.

The 1999 Recommendation sets out a wish-list directed at European governments and is accompanied by an elegantly-drafted explanatory memorandum. Among the recommendations made in the document are that every effort should be made to put in place alternatives to restriction of legal capacity,[484] as well as measures which allow people to plan for future incapacity.[485] The document recommends that there should be no automatic removal of legal capacity. It is recognised that "different degrees of incapacity may exist and that incapacity may vary from time to time", the document states decisively that "a restriction of legal capacity should be possible where it is shown to be necessary for the protection of the person concerned".[486] It is of course very difficult to define such a "necessity", and to operationalise such a

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[482] Article 15(1) of CEDAW accords equality to women before the law, and Article 15(2) goes on to set out a State obligation to "accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity. In particular, they shall give women equal rights to conclude contracts and to administer property and shall treat them equally in all stages of procedure in courts and tribunals." CEDAW, adopted by the UN General Assembly, 18 December 1979.

[483] Committee of Ministers of the Council of Europe (1999), Recommendation No. R(99)4 on principles concerning the legal protection of incapable adults, adopted on 23 February 1999.

[484] Committee of Ministers of the Council of Europe (1999), Recommendation No. R(99)4 on principles concerning the legal protection of incapable adults, adopted on 23 February 1999, Principle 2(4).

[485] Recommendation No. R(99)4 (op cit), Principle 2(7).

[486] Recommendation No. R(99)4 (op cit), Principle 3(1).

system which is based on protection of the self – a notion which is open to moral as well as legal objection. The 1999 Recommendation builds in safeguards to ensure that substituted decisions are taken as thoughtfully and humanely as possible, so that, "the interests and welfare of that person should be the paramount consideration".[487] Decisions should be made taking into account any current or previously-expressed wishes or desires of the adult.[488] (There is nothing to prevent these wishes or desires to then be ignored by the substitute decision-maker: one of the weaknesses of the functionalist approach). The duration of guardianship or other such measure should be limited, the Recommendation insists, and reviewed on a change of circumstances.[489]

Although it has some intuitive appeal over the odious discrimination in the status-based approach and the value-laden outcomes approach, the functional approach is subject to critique from a number of fronts. The standard test of rationality, and its inherent limitations from a social and human rights model of disability is neither questioned or unsettled with this approach. The functional approach is sociologically counterfactual: most of us simply do not take solo decisions, especially important ones like where to live, which medial treatment to choose or where to go on vacation. To the extent that capability assessments are limited to how a human being performs on his or her own without supports, the functional approach is open to accusations of being disablist and sanist. It allows for a person with disability to be classed as incompetent and incapacitated – albeit limited in time and type of decision and with so-called safeguards. It has been shown that labelling a person as incompetent can contribute to stigma and result in deleterious outcomes.[490]

A finding of incompetence may end up being a self-fulfilling prophecy: we lose skills if we do not practice them. If other people take our decisions for us, we will become less talented at taking them ourselves. Stripped of decision-making authority, a person's existence may become, as philosopher Jonathan

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[487] Recommendation No. R(99)4 (op cit), Principle 8(1).

[488] Recommendation No. R(99)4 (op cit), Principle 9.

[489] Recommendation No. R(99)4 (op cit), Principle 14.

[490] See Brian Winick (1995) "The side effects of incompetency labeling and the implications for mental health law" 1(1) *Psychology, Public Policy, and Law*, 6.

Wolff puts it, mundane and dreary, in which "individual life becomes an epiphenomenon of other people's decisions".[491] This raises a question which is key as a matter of moral philosophy and as a matter of law, namely whether there is in practice a bright line between substituted decisions and supported decisions. This question is prompted by the adoption of the UN Convention on the Rights of Persons with Disabilities. The question is hardly one of theory; CRPD-inspired legal capacity law reform discussions are taking place in many European jurisdictions.[492]

3. UN Convention on the Rights of Persons with Disabilities

Legal capacity was fiercely negotiated by the Ad Hoc Committee which developed the text which was adopted as the CRPD by the UN General Assembly in December 2006.[493] Article 12 has five paragraphs which will now be outlined. Paragraph 1 sets out the "right to recognition everywhere as persons before the law", as well as the recognition that people with disabilities "enjoy" (not merely have) "legal capacity on an equal basis with others in all aspects of life" (Article 12(2)). This contrasts to the functional approach which removes a person's legal capacity, at best for a certain transaction and a certain time. The suggestion that all people with disabilities should have legal capacity on an equal basis with others is a radical reframing of legal capacity, elevating the importance for States to ensure that laws respect the autonomy of people with disabilities and people with intellectual or cognitive disabilities and people with psycho-social (mental health) disabilities in particular. Paragraph 2 is phrased as a right, and no exceptions (based on, for example available resources or type or severity of impairment) are listed.

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[491] Jonathan Wolff, "Cognitive Disability in a Society of Equals" in Eva Feder Kittay and Licia Carlson (eds) (2010) *Cognitive Disability and Its Challenge to Moral Philosophy*, Wiley-Blackwell.

[492] At the time of writing, MDAC is engaged in discussions with civil society organisations and/or governments in Bulgaria, Croatia, Czech Republic, Hungary, Iceland, Ireland, Latvia, Lithuania, Moldova, Poland, Portugal, Russia, Slovakia and Spain on legal capacity law reform.

[493] For a history of negotiations on Article 12 of the CRPD, see Dhanda, A. (2007) "Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future", 34 *Syracuse J Int'l L & Com*, 429.

To help put the right to legal capacity into practice, paragraph 3 sets out 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." That people with disabilities "may" need support in exercising legal capacity is, at a basic level, no more than a universal sociological observation: everyone – irrespective of disability – may require some support in exercising their legal capacity. In summary, paragraph 2 rejects the default substitution model which has been imposed on people with disabilities and reframing legal capacity as a universal right. Paragraph 3 sets up a system of societal supports, a natural way which humans make decisions. In a very moving section, the Latvian Constitutional Court stated in the context of legal capacity that "the right to 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."[494]

In this way, legal capacity in the CRPD is a shield which defends us against other people's unwanted decisions, as well as a "sword to forge our own way".[495] Thus, implementing Article 12 of the CRPD can open up "zones of personal freedom" by repatriating the human rights principle of autonomy into a disability-specific document, and in doing so, reversing the erosion of self-determination of people with disabilities in various international legal texts.[496] In this way, the CRPD is a declaration of interdependence: it is

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[494] Judgment of the Latvian Constitutional Court, Case No 2010-38-01, 27 December 2010, para. 7.

[495] Gerard Quinn, "Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 of the UN Convention on the Rights of Persons with Disabilities", paper presented at Harvard Law School, 20 February 2010.

[496] See, for example, General Comment 25 of the UN Human Rights Committee which, without any explanation, restricted voting rights of people with mental disabilities. See also the non-binding "Principles for the protection of persons with mental illness and the improvement of mental health care", adopted by General Assembly resolution 46/119 of 17 December 1991, which sets out notions of consent to treatment, and then proceeds to dilute the notion so as to make it almost meaningless for people deemed to have mental health problems. For a compelling account of the need for the CRPD, see Gerard Quinn and Theresia Degener, The current use and future potential of United Nations human rights instruments in the context of disability, Office of the High Commissioner for Human Rights, 2002.

grounded in liberal individualism and it recognises that all our lives are pursued with others.

The term "supported decision-making" has come to mean that which substituted decision-making is not. It is a cluster of various models and elements which can take various forms.[497] Some essential elements of supported decision-making are that the adult retains full legal capacity and a supporting group or network is recognised (but not imposed) by a court. Supporters are appointed with the consent of the adult, and the relationship is one of trust. Supporters do not make decisions on behalf of the adult but rather assist the adult in reaching his/her own decisions without exercising undue influence and without obtaining undue advantages from the adult's legal transactions or statements. Supporters play a role in providing advice whenever the adult is negotiating a contract, is conducting a legal transaction with an agency/authority or is a participant in court or administrative proceedings. A third party (e.g. a bank) entering into a legal relationship with the adult may contact the supporters to counter-sign the contract, and some registration mechanism of the supporters is therefore required. When counter-signing any document, supporters specify in writing the role that they played, and if the adult enters into a binding transaction without the knowledge of the supporters, the adult and the supporters are entitled to challenge the transaction before a court.[498]

Article 12(4) of the CRPD encourages States to put in place safeguards. The aim of these safeguards is to prevent and remedy exploitation, violence and abuse of, for example, adults who are elderly, have disabilities or who have otherwise been placed in a position of vulnerability.[499] Another type of safeguard is one which ensures that supporters communicate and interpret decisions rather than impose their own views on the adult or communicate

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[497] Anna Lawson and Oliver Lewis (2011) *International developments on the fundamental rights of people with intellectual disabilities and people with mental health problems*, European Union Agency for Fundamental Rights, Vienna.

[498] This is taken from principles developed by Hungarian NGOs in the process of developing legal capacity legislation. See also Robert M. Gordon, "The emergence of assisted (supported) decision-making in the Canadian law of adult guardianship and substitute decision-making" *Int J Law Psychiatry*, 2000 Jan-Feb;23(1):61-77.

[499] Article 16 of the CRPD guards against exploitation, violence and abuse. See also the Committee of Ministers of the Council of Europe (2005) Resolution ResAP(2005)1 on safeguarding adults and children with disabilities against abuse.

their own decisions to third parties. There is some debate, however, as to whether the Article 12(4) safeguard requirement is a deliberate (albeit tacit) acknowledgement of the legitimacy of substituted decision-making, whether the safeguards have reference solely to supported decision-making systems, or whether Article 12(4) exists as a political compromise which enabled the more important paragraphs 2 and 3 to be agreed upon.[500] Some are of the view that Article 12(4) applies to substituted decision-making, whilst acknowledging that the number of people subject to such a system and the amount of coercion and abuse within it should be minimised.[501] An alternative interpretation is that Article 12(4) applies to supported decision-making only and should not be understood to imply the need for substituted decision-making.[502] It may be difficult, however, to envision how people in some situations (e.g. a person in a coma who has not established a prior planning/advance directive document) can be supported to make decisions.

Paragraph 5 sets out financial rights, ensuring 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", adding that no arbitrary deprivation of property is allowed. This paragraph speaks directly to the primary reason in many countries for instigation of guardianship proceedings, namely that a family member wants to legally steal the property of the person with disabilities.

If a protectionist guardianship model amounts to civil death, implementation of Article 12 of the CRPD gives rise to civil life.[503] Encouraging and engraining support networks within communities, as envisioned by Article 12 of the CRPD, may well contribute to a person's sense of subjective as well as inter-subjective well-being and happiness.[504] Scholars and activists are continuing

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[500] Amita Dhanda, 2007, op cit.

[501] See, for example, the reservations to Article 12 of the CRPD entered by Australia and Canada.

[502] See OHCHR (2009), paragraphs. 44-47.· See also United Nations Committee on the Rights of Persons with Disabilities (2009) which instructs States to report on '[t]he existence of safeguards against abuse of supported decision-making models' and does not mention substituted decision-making.

[503] The "civil life" idea comes from Valentin Aichele, head of the German CRPD national monitoring body.

[504] Sissela Bok (2010) *Exploring Happiness: from Aristotle to Brain Science*, Yale University Press, p. 103.

to carry out definitional work on Article 12 of the CRPD, and in time we will be able to assess the distance between the old and the new systems in legislation and practice. Moving from one system to another may give rise to laws which contain elements of two or more approaches to legal capacity. Similarly, legislation may be grounded in one approach but may be operationalised by those at the legal capacity coalface (medical experts, judges, lawyers, bank clerks, family members) in a way which legislators did not intend.[505] One role of legal capacity litigation is to nudge States towards developing better systems by highlighting the failings of systems, and this role is discussed in the next section.

4. Bulldozing away barriers to the life-world

Compliance with the CRPD requires considerable work at a number of levels: law and policy reform,[506] systems development, awareness-raising "throughout society",[507] working on media sensitisation,[508] ensuring accessible justice mechanisms,[509] coordinating policy within government,[510] ensuring independent monitoring implementation,[511] and garnering the participation of people with disabilities and their representative organisations in development and implementation of laws, policies and programmes,[512] and in monitoring.[513] To effectively highlight social injustice and call for reform, litigation should ideally be pursued in parallel to other forms of evidence-based advocacy and capacity-building.

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[505] See Jill Peay, 2003, *Decisions and Dilemmas*, Hart Publishing. This work examines how legal decisions about compulsory medical treatment and the loss of liberty get made by doctors and social workers.

[506] Article 4(1)(b) of the CRPD.

[507] Article 8 of the CRPD.

[508] Article 8(2)(c) of the CRPD.

[509] Article 13 of the CRPD.

[510] Article 33(1) of the CRPD. For more on the entirety of Article 33, see Mental Disability Advocacy Center (2011) *Building the Architecture for Change: Article 33 of the UN Convention on the Rights of Persons with Disabilities*, Budapest, Hungary.

[511] Article 33(2) of the CRPD.

[512] See Article 4(3) of the CRPD.

[513] See Article 33(3) of the CRPD.

Having written in 2002 that guardianship issues “remain under-reported and under-litigated”, significant progress has been made in less than a decade.[514] There is now a substantial body (admittedly not huge) of both research and case-law from which we can draw in order to do some analysis and develop strategies. I suggest that legal capacity litigation can be divided into three clusters. The first cluster chips away at the guardianship edifice, the second decouples legal capacity from subsequent losses of human rights, and the third encourages the State to set up alternatives to guardianship. I focus on the first cluster as these sorts of cases are particularly ripe for the court-room and there is some experience in Europe of litigating them. Before coming to these, I will deal briefly with the second and third clusters.

The second cluster of cases are those which disentangle losses of rights subsequent to deprivation or restrictions of legal capacity.[515] One example is the intimate relationship between legal incapacity and institutionalisation, which litigation can seek to prise apart. Incapacity and institutionalisation are the two main mechanisms which have resulted in the segregation and isolation of people with disabilities from society. In many European jurisdictions the vast majority of residents in long-term institutions have been deprived of legal capacity, with some managers of residential institutions going so far to make deprivation of legal capacity a prerequisite for admission. As uncovered in the Shtukaturov case, guardianship is also used to place a person against their will in a psychiatric hospital, and to sideline safeguards available to people with full legal capacity.

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[514] Oliver Lewis, “Mental disability law in central and eastern Europe: paper, practice, promise”, *Journal of Mental Health Law*, December 2002, 293-303, at 301.

[515] Recommendation No. R(99)4 (op cit) states in Principle 3 that “a measure of protection should not automatically deprive the person concerned of the right to vote, or to make a will, or to consent or refuse consent to any intervention in the health field, or to make other decisions of a personal character at any time when his or her capacity permits him or her to do so.” The Parliamentary Assembly of the Council of Europe (2009) *Access to rights for people with disabilities and their full and active participation in society*, Resolution 1642 (2009), 26 January 2009 states that in line with the CRPD, “people placed under guardianship are not deprived of their fundamental rights (not least the rights to own property, to work, to a family life, to marry, to vote, to form and join associations, to bring legal proceedings and to draw up a will), and, where they need external assistance so as to exercise those rights, that they are afforded appropriate support, without their wishes or intentions being superseded”.

Strategic litigation can play a useful role in decoupling incapacity and institutionalisation. In its March 2008 judgment in Shtukaturov, for example, the ECtHR found that the applicant was detained. This was not a difficult conclusion to draw: the doors were locked and the hospital refused a visit by his attorney. The applicant was detained for seven months. The Court found deprivation of liberty despite the Russian law classifying the hospitalisation as "voluntary" because the applicant's mother/guardian had provided proxy consent to the hospitalisation. In a parallel case brought by the same applicant, in February 2009 the Russian Constitutional Court quashed a provision in mental health legislation which allowed guardians to provide proxy consent.[516] The ECtHR has already dealt with a case in which the applicant was an autistic man not technically under anyone's guardianship. He was assenting (not objecting) to being in hospital but lacked ability by himself to consent to being in the hospital. In this case the ECtHR found that the applicant was detained for the purposes of Article 5 of the ECHR, and therefore safeguards, such as regular court reviews of the necessity of detention, should have been provided.[517]

In the pending case of *Kedzior v. Poland*, the applicant alleges he was restricted partially then deprived fully of legal capacity, his brother was appointed as his guardian, and decided to send the applicant to a long-term social care institution where the applicant was detained.[518] Similar points about the detention of a person under guardianship in a social care institution is made by the applicant in the case of *Stanev v. Bulgaria*.[519] Domestic litigation before the Russian Constitutional Court has resulted in quashing a legislative provision in which a person under guardianship was not subject to

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[516] Russian Constitutional Court decision, 27 February 2009. The Constitutional Court quashed three legal provisions: (1) The Code of Civil Procedure provisions which allowed courts to decide on a person's legal capacity on the strength of one psychiatrist's report and to deny the participation of the person whose legal capacity is in question, (2) The Code of Civil Procedure provisions which allowed courts to deny an appeal against a guardianship order even for people who knew nothing about the initial court proceedings, and (3) The 1992 Law on Psychiatric Assistance provisions which allowed a person deprived of legal capacity to be involuntary detained in a psychiatric hospital solely with the 'consent' of their guardian (even where it's obvious that the detainee has not consented), with the effect that there is no court review of the lawfulness of detention.

[517] *H.L. v. the United Kingdom*, judgment 5 October 2004, Application No. 45508/9992.

[518] *Kedzior v. Poland*, Communicated 7 May 2009, Application No. 45026/07.

[519] *Stanev v. Bulgaria*, admissibility decision 29 June 2010, Application No. 36760/06.

a judicial review of the lawfulness of detention in psychiatric hospitals.[520] Other cases in this cluster include de-coupling legal capacity from the right to political participation,[521] the right to marry,[522] the right to paternity,[523] and right to bring up one's children.[524]

A third cluster of cases contains those which demand alternatives to guardianship.[525] These are cases which seek to put in place the building blocks to establish systems of supported decision-making as alternatives to guardianship. For example, for the CRPD to be implemented, forms of supported decision-making with reasonable accommodations in support structures need to be established, laws need to be put in place which recognise different decision-making statuses through which legal capacity is exercised,[526] and pilot initiatives for supported decision-making need to be established and evaluated. Advance directives and other planning documents need to be legally recognised and utilised. It seems to me that litigation plays a more marginal role here: it may be that with an active judiciary and on legal systems which offer injunctive relief, one could make some headway, but these advances are likely to be made outside the court-room, and for this reason this is all I say on the third cluster.

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[520] Judgment of the Russian Constitutional Court, 19 January 2011, No. 114-O-P.

[521] *Kiss v. Hungary*, judgment 20 May 2010, Application No. 38832/06. See also judgment of the Czech Constitutional Court, 12 July 2010, reference IV.ÚS 3102/08.

[522] See the admissibility decision of *Lashkin v. Russia*, in which the Russian government defended legislation which bars people deprived of legal capacity from marrying: "firstly, it is impossible to establish the genuine will of an incapacitated person who wants to marry; and secondly, mentally ill people often give birth to mentally ill children. Therefore, the law defends the interests of other people. Therefore, the law defends the interests of other people."

[523] *Krušković v. Croatia*, judgment 21 June 2011, Application No. 46185/08. "As a person divested of his legal capacity he is not allowed to institute any proceedings to have his paternity established. In that respect he is entirely dependent on the actions of the competent social welfare centre." at para. 33.

[524] *X v. Croatia*, judgment 17 July 2008, Application No. *11223/04*, in which the ECtHR held that "Under the domestic legislation in force, the applicant, being a person divested of the capacity to act, was not a party to the adoption proceedings, nor was she informed that they had taken place. Only later did the applicant find out that her daughter had been given up for adoption". (para. 20). In finding a violation of Article 8 of the ECHR, "the Court has difficulty in accepting that every person divested of the capacity to act should be automatically excluded from adoption proceedings concerning his or her child, as the applicant was in the present case." (para. 53).

[525] For ideas about how a post-CRPD legal capacity compliant might look like, see Michael Bach and Lana Kerzner (2010) *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*, Law Commission of Ontario.

[526] The word "status" sounds more rigid than it is: the idea is that one can flow between these legal categories as needed.

I return to the group of cases which sculpt a new paradigm by chipping away at the guardianship edifice or – continuing the construction industry metaphor – cases which bulldoze away barriers to the life world.[527] These cases advance Article 12(2) of the CRPD, that everyone has legal capacity on an equal basis with others, and use legal tools to argue that guardianship is an unnecessary or disproportionate constraint on individual freedoms. Courts are not the only arm of the State which should carry out such a demolition job. To fully realise all human rights for people with disabilities, CRPD says that governments must, "take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities".[528] Abolishing laws can be best done through parliament, again emphasising how other forms of advocacy should be carried out to advance legal capacity law reform.

Within this bulldozing cluster I include everything about the guardianship order itself and how someone gets into and out of guardianship. Cases raising procedural issues might challenge the following:

> Insufficiently clear and specific statutory basis for filing an application to restrict legal capacity, low quality of evidence required to restrict legal capacity.
>
> Expert's report recommends the adult is "too mentally ill" to attend court, and the judge proceeds without further scrutiny.
>
> A judge restricts legal capacity in a case where the adult received no or inadequate notification about the pending court hearings, was denied access to information related to the procedures, was not given an opportunity to take part in court proceedings, precluded from presenting and challenging evidence (including calling and cross-examining witnesses), or received no/inadequate State-funded legal representation.

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[527] Gerard Quinn, Harvard paper, op cit.

[528] Article 4(1)(b) of the CRPD.

The guardian has a person with a conflict of interest (e.g. is the director of a residential service where the adult lives), and there is no effective procedure for assessing and preventing and remedying such conflicts of interest.

No effective appeal mechanism to challenge the guardianship (some jurisdictions, for example specify that the adult can appeal within ten days after the court sends notification, irrespective of when the adult receives the notification.), no effective procedure for the adult to challenge the identity of the guardian (e.g. when the guardian is abusive), no complaints mechanism to challenge the guardian's (in)actions (e.g. guardian does not seek wishes of the adult before taking decisions).

Lack of, or ineffective, procedure for regaining full legal capacity.

In jurisdictions with a guardianship law and nothing else, cases need to focus as tightly as possible on demonstrating how a deprivation of legal capacity is never necessary, rather than arguing peripheral points which may result in making a bad system better.

Finally, four points about why litigators should pay attention to legal capacity case selection and presentation, and why establishing an emotional connection between litigant and judge is important. First, legal capacity cases can be perceived as raising dull and technocratic legal issues. Second, legal capacity cases ask judges to confront centuries of civil law (not to mention moral and political philosophy) and/or interpret an international human rights treaty, two tasks which take judges outside their comfort zone. Third, given that people with disabilities have been locked out of justice systems through guardianship and institutionalisation, appellate and higher court judges lack experience dealing with litigants with disabilities which means that there is a significant risk that vigorous legal analysis gets overshadowed by judicial prejudice.[529] And fourth, attorneys can be very bad at lawyering.

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[529] On several occasions I have heard senior jurists say phrases to the effect that this person is so disabled / incompetent / mad that of course they need plenary guardianship. This "need" is universalised so that anyone displaying characteristics of

Attorneys representing people in legal capacity proceedings are often on a list of court-appointed attorneys with no training and little knowledge of the human rights issues involved, or interest in the clients' rights. Often the attorneys' advocacy is minimal: they do not challenge evidence including experts' reports and in some cases even work against their client in agreeing that the person needs to be deprived of legal capacity. Because attorneys do not proceed in a combative or vigorous way, judges are not used to treating legal capacity issues as adversarial proceedings and may resist appointment of experts favourable to the client and admission of non-expert testimony.

5. Jurisprudential tracks

Where are we in terms of the travel of case-law in Europe? There are very few examples of legal capacity litigation available in English.[530] At the time of writing, the UN Committee on the Rights of Persons with Disabilities has adjudicated on no individual complaints,[531] and has issued one set of concluding observations.[532] In its April 2011 concluding observations on Tunisia the Committee states that it is, "concerned that no measures have been undertaken to replace substitute decision-making by supported decision-making in the exercise of legal capacity". It recommends that Tunisia "review[s] the laws allowing for guardianship and trusteeship and take[s] legal and policy action to replace those regimes of substitute decision-making by supported decision-making."

This section looks at legal capacity jurisprudence primarily under the European Convention on Human Rights. Many legal capacity cases pre-date the CRPD, and not all States have ratified the CRPD. Further, the ECHR will remain a key arena for legal capacity-related litigation. The European Court of Human Rights (ECtHR) has made reference to the CRPD, saying that it is the

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the same group such as diagnosis or behaviour "need" plenary guardianship. These stereotypes are a significant barrier not only to litigation, but to law reform.

[530] MDAC's jurisprudence tracker contains major human rights cases concerning people with intellectual disabilities and psycho-social (mental health) disabilities: www.mdac.info.

[531] An individual complaint system is established by an Optional Protocol to the CRPD.

[532] UN Committee on the Rights of Persons with Disabilities (2011) Concluding Observations: Tunisia, Fifth session 11-15 April 2011.

basis for the existence of a European and universal consensus on the need to protect persons with disabilities from discriminatory treatment.[533]

Two provisions of the ECHR can be used to challenge monolithic guardianship systems. The first is to challenge the necessity of guardianship itself, and the second is to challenge all the unfair ways in which guardianship is imposed. In ECHR terms the first of these has been dealt with under Article 8 of the ECHR which sets out the right to respect for private and family life, home and correspondence, and the second under Article 6 of the ECHR on right to a fair trial.

6. Article 8 of the ECHR

A court finding that a person lacks the ability to take decisions will invariably constitute an interference with that person's private life and may amount to a breach of the right to respect for private life, family, home and correspondence under Article 8(1) of the ECHR. Privacy, the ECtHR has found, includes a person's physical and psychological integrity and the guarantee which it affords is primarily intended to ensure the development, without outside interference, of the personality of each individual in his relations with other human beings.[534]

A court ruling that a person is incapable of making any decision will strip that person of the very essence of his or her personal autonomy, human dignity and human freedom. Such a court decision renders a person in some respects a 'non-person', stripped of their identity as an individual human being.[535] Only in the face of compelling evidence and judicial scrutiny could such a determination be made. Such a finding denies the person the right to privacy in virtually every arena of his or her life; it gives third parties access to the person's private papers and medical history; it places severe restrictions on

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[533] *Glor v. Switzerland*, Application No. 13444/04, judgment 30 April 2009. At the time of judgment Switzerland had not even signed the CRPD; this did not prevent the ECtHR commenting on the CRPD's significance.

[534] *Botta v. Italy*, judgment of 24 February 1998, para. 32.

[535] See, *inter alia*, *Pretty v. UK*, judgment 29 April 2002, Application No. 2346/02, para. 62; *Mikulić v. Croatia,* judgment 7 February 2002, Application No. 53176/99, para. 53; *Christine Goodwin v. UK*, judgment 11 July 2002, Application No. 28957/95, para. 90.

the person's ability to enter into social activities and relationships and almost certainly negates any possibility of his or her developing intimate or sexual relationships. Such a decision has the power to strip the individual of the right to refuse medical treatment and most probably render the person liable to forced medication – possibly without the person administering the medication requiring any prior judicial approval. In *Shtukaturov v. Russia*, the ECtHR acknowledged that "the interference with the applicant's private life was very serious", because the applicant was totally deprived of legal capacity for an indefinite period, was fully dependent on his guardian in almost all areas of his life, and could challenge his deprivation of legal capacity except through the guardian.[536]

The point that plenary guardianship is a disproportionate measure is one which has been made by several higher domestic courts across Europe. In June 2009 the Czech Constitutional Court held that the limitation of legal capacity "must be viewed as an extreme measure" and "is a manifest relic of the former regime. The ordinary courts should always consider more moderate alternatives ... by which the aim could well have been achieved. The aim is the protection of competing practical rights or public interests which can be inferred from the constitutional order."[537]

In December 2010 the Latvian Constitutional Court ordered the Latvian government to introduce alternatives to total guardianship, finding both that the aim of guardianship is "safeguarding the rights of the mentally ill person", and that guardianship "significantly restricts a person's right to private life"[538] and is not a proportionate way of achieving this aim.[539] Similarly, the Polish Constitutional Court has held that "most countries are currently departing from the rigid limitation of rights and freedoms of [people with mental

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[536] *Shtukaturov v. Russia*, op cit, para. 90.

[537] Judgment of the Czech Constitutional Court, 18 August 2009 (I. ÚS 557/09), para. 23. Cited in *Stanev v. Bulgaria*, admissibility decision 29 June 2010, Application No. 36760/06, para. 86.

[538] Judgment of the Latvian Constitutional Court, Case No 2010-38-01, 27 December 2010, para. 7.

[539] Ibid, paras. 10 and 11.

disabilities] in favour of more flexible solutions that can match a particular situation".[540]

The Latvian case is clearly a cluster one case (chipping away of guardianship edifice) as it strikes down the offending statutory provisions setting out plenary guardianship from 1 January 2012. The case is also an example of a cluster three case, one which contributes to putting in place alternatives to guardianship, because the Court provides examples of "partial restriction of legal capacity, support in decision-making, personal assistants, observance of previous [planning documents]", going on to observe that "less restrictive measures do exist and they can be used to more effectively achieve the legitimate objective [of safeguarding a person's rights]".[541] In a creative and robust way, the Constitutional Court orders the government "not only to make appropriate amendments to substantive and procedural [legal] provisions, but also to establish the material and institutional structure to successfully operate, provide training for judges and other persons applying the legal provisions and conduct other necessary measures".[542]

Because of the draconian consequences for an individual of such a decision being made, Article 8(1) ECHR places significant positive obligations on States to secure for such persons – to the maximum extent possible – effective respect for their integrity.[543] Such an obligation has as an essential object the protection of the person from arbitrary interference by the public authorities and brings with it procedural obligations to ensure that interferences in

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[540] Judgment of the Polish Constitutional Court, 7 March 2007, ref 24/3/A/2007. In this case the Ombudsman's office applied successfully to the Constitutional Court to revoke the statutory provision which excluded the adult deprived of legal capacity from the circle of people entitled to initiate proceedings to restore capacity or change the scope of the restriction of legal capacity.

[541] Ibid, para. 13.

[542] This case is an example of what can be achieved through strategic litigation. It was initiated by the Latvian advocacy organisation "Zelda" and litigated by its contracted attorney who argued a host of legal arguments, including the ECHR, the *Shtukaturov v. Russia* judgment, and Recommendation No. R(99)4 of the Council of Europe. The breadth of international legal material presented to the Constitutional Court was undoubtedly a factor in the case's success. By litigating the case, Zelda has been invited by the government to the policy table to advise on legal capacity law reform.

[543] See for example, *Glass v. UK*, paras. 74-83.

personal autonomy and all other aspects of the Article 8(1) right are minimised.[544]

An additional procedural component may be able to be read into Article 8 of the ECHR. Any interference with the rights of a person who is adjudged to lack sufficient functional capacity will be considered to be "necessary in a democratic society" (see Article 8(2) ECHR) for a legitimate aim if it answers a "pressing social need" and, in particular, if it is proportionate to the legitimate aim pursued. Although States enjoy a "margin of appreciation", the margin is narrower where the right at stake is crucial to the individual's effective enjoyment of intimate or key rights.[545] In "such a complex matter as determining somebody's mental capacity, the authorities should enjoy a wide margin of appreciation", as they "have the benefit of direct contact with the persons concerned and are therefore particularly well placed to determine such issues".[546] Procedural safeguards available to the individual are especially material in determining whether a State has, when fixing the regulatory framework, acted within the margins: in particular whether the decision-making process leading to measures of interference is fair and such as to afford due respect to the interests safeguarded.[547]

The ECtHR has additionally emphasised that the vulnerable position of a particular group of persons means that some special consideration should be given to their particular needs both in the relevant regulatory framework and in reaching decisions in particular cases.[548] People with mental disabilities are, the ECtHR has found, "a particularly vulnerable group in society, who have suffered considerable discrimination in the past", and as such "the State's margin of appreciation is substantially narrower and it must have very weighty reasons for the restrictions in question" – in this case, a restriction to the right to vote. The Court goes on to say that "[t]he reason for this approach, which questions certain classifications *per se*, is that such groups were

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[544] *Botta v. Italy,* para. 33.

[545] See, for example, *Dudgeon v. the UK*, judgment 22 October 1981, para. 52; and *Gillow v. the UK*, judgment 24 November 1986, at para. 55.

[546] *Shtukaturov v. Russia*, op cit, para. 87.

[547] See *Buckley v. the UK,* judgment 26 September 1996, para. 76; and *Chapman v. UK*, judgment 18 January 2001, Application No. 27138/95, para. 92.

[548] *Connors v. the UK*, judgment 27 May 2004, Application No. 66746/01, para. 84.

historically subject to prejudice with lasting consequences, resulting in their social exclusion. Such prejudice may entail legislative stereotyping which prohibits the individualised evaluation of their capacities and needs".[549]

To this extent, it can be argued that Article 8 of the ECHR creates a positive obligation to ensure that there is a procedure available to people restricted of their legal capacity, so that they are able to challenge significant interferences, such as medical treatment decisions, restrictions on their liberty and significant restraints (even if these interferences fall short of a deprivation of liberty in ECHR terms). The obligation to provide a procedure for challenging such fundamental restrictions should exist even if the applicant does not resist the measures (including medical treatment or detention), since the right to personal integrity protected by Article 8(1) is too important in a democratic society for a person to lose it simply for the reason that she or he is not considered to be resisting.[550] This sort of argument could be made in jurisdictions which provide for no appeal against a guardian's decision by the person under guardianship.

7. Article 6 of the ECHR

Turning now to the right to fair trial, which is the other provision which the ECHR offers in cases which seek to challenge the monolithic guardianship provisions. Admittedly the arguments are similar to those above under the procedural wing of Article 8 ECHR, but there are some helpful jurisprudential principles under Article 6 of the ECHR, and other arguments in mental disability cases under Article 5 of the ECHR (the provision which regulates deprivations of liberty) which we can draw into arguments under Article 6 of the ECHR.

We can say with some certainty that in assessing whether or not a particular measure (e.g. partial guardianship) meets the requirements of fair trial which is set out in Article 6(1) of the ECHR, all relevant factors fall to be considered,

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[549] *Kiss v. Hungary*, Application No. 38832/06, judgment 20 May 2010, para. 42.

[550] See by analogy *H.L. v the UK*, op cit, para. 90; and *De Wilde, Ooms and Versyp v. Belgium*, judgment 18 June 1971, paras. 64-65

including the nature and complexity of the issue before the domestic courts, and what was at stake for the individual in question.[551] These sorts of issues could be bolstered by raising Article 13 of the CRPD, which sets out a wider provision on the right to access justice.[552]

The ECtHR has clarified that when examining fair trial issues for persons with mental disabilities under Article 6 of the ECHR, it will read across from Articles 5(1) of the ECHR (legal criteria for legalising a deprivation of liberty) and Article 5(4) of the ECHR (court review of the necessity of detention).[553] The fundamental requirements of fair trial in legal capacity cases can be summarised to include the following.

A judge must take reasonable steps to ensure that the individual was aware of the application for deprivation of legal capacity,[554] or that the person was being subjected to a forensic psychiatric examination for the purposes of legal capacity proceedings.[555] States should ensure that applicants have the opportunity to present their case effectively and that they are able to enjoy "equality of arms" with the party making the application.[556] The individual must be afforded the right to participate in the proceedings,[557] to present and challenge evidence, and to be heard either in person or, where necessary, through some form of representation.[558]

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[551] *Shtukaturov v. Russia*, op cit, para. 68.

[552] A good example of arguing for the right to a fair trial from both ECHR Article 6 and CRPD Article 13 can be found in a recent UK Upper Tribunal decision which ruled in favour of a person who was detained in a psychiatric hospital and had requested that his mental health review tribunal hearing be held in public, The Upper Tribunal found that he had such a right under Article 6 of the ECHR, "reinforced by Article 13 of the CRPD." *AH v. West London Mental Health Trust and Secretary of State for Justice*, 2011 UKUT 74 AAC, para. 22.

[553] *Salontaji-Drobnjak v. Serbia*, op cit, para. 124

[554] *Shtukaturov v. Russia*, op cit, para. 69

[555] *Shtukaturov v. Russia*, op cit, para. 69

[556] See, among many other examples, *De Haes and Gijsels v. Belgium*, judgment 24 February 1997, para. 53.

[557] In some jurisdictions a doctor can advise that the adult is too mentally ill to attend court, thereby foreclosing the adult's right to participate. See the facts of *Lashkin v. Russia* (admissibility decision 5 January 2011, Application No. 33117/02) in which the ECtHR found that a district court held a hearing about the applicant's legal capacity "in the absence of the applicant, having decided that '... [the applicant's] mental condition prevented him from taking part in the hearing, and, moreover [the applicant's] presence would be prejudicial to his health'."

[558] *Winterwerp v. the Netherlands*, judgment 24 October 1979, para. 79; *Shtukaturov v. Russia*, op cit, paras. 69 and 71; *Salontaji-Drobnjak v. Serbia*, op cit, para. 127.

The question of whether the provision of legal aid is necessary for a fair hearing must be determined on the basis of the particular facts and circumstances of each case and will depend, inter alia, upon (i) the importance of what is at stake for the party in the proceedings, (ii) the complexity of the relevant law and procedure and (iii) the person's capacity to represent him or herself effectively.[559] First, in cases where the consequences could be a severe (or even a 'total') negation of a person's ability to make decisions for him / herself, the importance of what is at stake – deprivation of legal capacity (including subsequent and automatic loss of the right to vote, work, associate, family life, privacy, deciding where to live), mental health detention, forced psychiatric treatment – cannot be overestimated. Second, while it may be possible to envision domestic law and procedures of such elemental simplicity that legal advice and assistance could never be required, legal capacity issues are usually contested legal hearings with expert evidence and these hearings necessitate effective legal representation.[560] And third, given that the person's capacity is what is being adjudicated in such proceedings, there is a clear and self-evident need for representation to protect the person's procedural and substantive rights.

It follows that in cases of this nature there must, at the very least, be a presumption that the measures taken by a State to satisfy its Article 6(1) obligation will include the provision of a lawyer who provides quality legal assistance to the person (not merely a cosmetic nicety in the courtroom) together with a legal aid scheme.[561] Regardless of the individual's wish to participate in the proceedings, where a decision concerning legal capacity is to be taken, the presiding judge (or perhaps an independent and impartial professional with the requisite understanding of the law concerning mental incapacity) should have direct visual contact with the applicant and the opportunity to question him or her. Anything less may be found unreasonable and in breach of the principle of adversarial proceedings.[562] Furthermore, the

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[559] *Steel and Morris v. the UK*, judgment 15 February 2005, Application No. 68416/01, para 59; *Airey v. Ireland*, judgment 9 October 1979, para. 26.

[560] *Megyeri v. Germany*, judgment 12 May 1992, Application No. 13770/88, para. 23.

[561] *Pereira v. Portugal*, judgment 26 February 2002, Appliaction No. 44872/98, emphasised in *Salontaji-Drobnjak v. Serbia*, op cit, para. 127.

[562] *Shtukaturov v. Russia*, op cit, paras. 73 and 91.

court needs to weigh the evidence carefully,[563] and the procedure must take place within a reasonable period of time.[564]

Although States enjoy a "margin of appreciation" as to the means to be used in guaranteeing parties their fair trial rights, the obligation remains that these measures must ensure for all individuals, an effective right of access to the courts for the determination of their "civil rights and obligations" (this is the language of Article 6(1) of the ECHR).[565] Accommodating the needs of persons with mental health disabilities "should not affect the very essence of the applicant's right to a fair hearing as guaranteed by Article 6",[566] and needs to attend to the requirements of reasonable accommodation as specified in the CRPD.[567]

8. The value of litigation

There is a growing body of domestic and European Court of Human Rights jurisprudence on issues related to rights of persons with intellectual disabilities and psycho-social disabilities to retain their capacity and picking up on various rights that are interfered with through restrictions of their legal capacity. But the very restrictions placed on such persons and their frequent isolation from society have meant that the number of people seeking remedies for violations of their rights and the number of attorneys litigating such cases have been relatively small. As the CRPD beds down and people with disabilities become more aware of its provisions and how domestic laws do not meet its standards, litigators are likely to be asked to become engaged in litigating legal capacity cases, in law and policy reform and capacity-building of civil society.

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[563] See the friendly settlement decision in the case of *Dudarevs v. Latvia*, decision 14 June 2011, Application No. 28621/10. A central issue argued by the Applicant was that "the lower court had relied exclusively on the outcome of the medical forensic tests, which had been narrow and had not disclosed the applicant's capabilities, and that the court had failed to assess the other evidence brought before it."

[564] *Matter v. Slovakia*, judgment 15 July 1999, Application No. 31534/96.

[565] *Airey v. Ireland*, judgment 9 October 1979, para. 26

[566] *Shtukaturov v. Russia*, op cit, para. 68; *Salontaji-Drobnjak v. Serbia*, op cit, para. 126

[567] See, in particular the definition of reasonable accommodation in Article 2 of the CRPD, and the prohibition of discrimination (which includes a failure to provide reasonable accommodation) in Article 5 of the CRPD.

Although strategic litigation is especially helpful in shining a light on the wrongs of a system which is not fit for purpose, it has its challenges and limitations. Routes of litigation are often inaccessible, raising serious access to justice questions. Law sometimes provides safeguards which amount to little more than a cosmetic nicety: there is ample evidence now of judicial rubber-stamping of guardianship applications without probing the evidence or questioning the adult concerned.[568] Domestic litigation is constrained by legislation, even in cases where international laws are invoked. Judges' hands are further tied in jurisdictions where there is a binary legal capacity system of plenary guardianship and little else. Judges come with their own cognitive biases against people with disabilities. They adjudicate in systems with embedded concepts such as deficit, best interests, and protectionism where the least restrictive alternative may coexist as the most restrictive.

The cases which have been taken and have been outlined in this paper demonstrate that challenges can be overcome by tenacious litigants and smart litigators. Strategic litigation can yield significant benefits for individual applicants. In the Shtukaturov case, for example, the European Court of Human Rights ordered the Russian government to pay the Applicant 25,000 EUR in compensation for the human rights violations he had suffered. His legal capacity was restored in subsequent domestic proceedings, in which he took part and was able to present evidence.

Strategic litigation enables progressive jurisprudence by encouraging a positive outcome in a particular case. Bringing a case to court plays a human rights documentation role, as judicial findings carry more weight with politicians and the public than reports of non-governmental organisations or indeed national human rights institutions. Courts are seen, in democracies at least, as generally fair and balanced as they have to take into consideration competing factors and weigh evidence presented by at least two sides.

Cases can test the willingness of the judicial system to offer declaratory or injunctive relief to people with disabilities who have historically been

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[568] Mental Disability Advocacy Center (2007) *Guardianship and Human Rights in Hungary: Analysis of Law, Policy and Practice*, and (2007) *Guardianship and Human Rights in Bulgaria: Analysis of Law, Policy and Practice.*

sidelined as holders of rights. As this paper has outlined, legal capacity cases can often be framed in mainstream civil and political human rights terms such as fair trial rights and privacy rights, using concepts such as arbitrariness, disproportionality and discrimination. These claims help challenge the unhelpful view held by many policy-makers and lawyers that disability is inherently a social issue.

Law reform can be instigated on the back of a judgment which finds that a law is not in compliance with international human rights law or otherwise constitutionally faulty, highlighting again the way in which strategic litigation is a tool which is most effectively deployed in conjunction with other advocacy methods. By framing personal misery as a matter of judicial concern, litigation holds to account those who act in an unwanted and unwarranted way in the name of the State (and in many cases, in the name of therapy, care, or one's own protection).

Judgments can be used in various capacity-building and awareness-raising activities, a point which is especially relevant as legal capacity is an area of human rights which rarely hits the headlines. In this way, litigation can engage the media, and therefore policy-makers, taxpayers and voters. It is the only advocacy tool which puts the victim – in other fora conceptualised as helpless and passive – in control of proceedings. Litigation re-balances power by putting the State in the dock. Litigation can have an empowering effect of others similarly situated to the applicant, and can shore up the interest of other potential litigants. It can make available a seat at the policy table, creating an opportunity for the disabilities community to engage in law reform efforts.[569] By enforcing norms, litigation is an element in the iterative process of law reform and review. A judgment can be the catalyst for root and branch reform.

Advancing legal capacity jurisprudence can create a space for a positive reframing of the issues which in time will lead to better laws and better individual outcomes. By forcing a fundamental re-evaluation of positions, strategic litigation can advance the educational and expressive value of human

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[569] See, in particular Article 4(3) of the CRPD.

rights.[570] Pursuing a strategy of bringing cases which chip away at the guardianship edifice in jurisdictions which rely on substituted decision-making systems is likely to yield several specific outcomes which trickle out into law and policy. On its own, litigation may not erode the devaluation of particular differences, but it does provide a basis from which to challenge the power that operates to define some differences as less worthy and deserving of respect and rights than others. It may even spark a more constructive conversation about personhood and the kind of supports which individuals may need to exercise legal capacity on an equal basis with others.

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[570] See Oliver Lewis, "The expressive, educational and proactive roles of the UN Convention on the Rights of Persons with Disabilities", in *Rethinking Rights-Based Mental Health Laws*, edited by Bernadette McSherry and Penny Waller, Hart Publishing, 2010.

Chapter 6: *Stanev v. Bulgaria*: On the Pathway to Freedom

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“I’m not an object, I’m a person. I need my freedom.”

Rusi Stanev, to his attorney Aneta Genova, before the European Court of Human Rights Grand Chamber hearing in his case, February 2011

1. Introduction

In this article, I suggest that the January 2012 judgment of the European Court of Human Rights (ECtHR) in *Stanev v. Bulgaria*[571] takes us a few steps along the path towards freedom. Rather like a Franz Kafka novel, the judgment is a story about an ordinary person who became entangled in a web of antiquated laws and perverse processes, and who ended up in a grotesque situation from which he found it impossible to extricate himself. Rusi Stanev, the applicant, is an extraordinarily tenacious man who faced State absurdity and abuse, and who risked retribution by putting Bulgaria in the dock at the ECtHR in Strasbourg, and won. His life and his case are unique, but his is the voice of millions of others’ that we will never hear. They are – like he was – locked away and silenced.

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[571] *Stanev v. Bulgaria*, App. No. 36760/06, Eur. Ct. H.R. (2012). Also see the admissibility decision of June 29, 2010.

On December 10, 2002, when he was 46-years old, an ambulance picked up Rusi Stanev at his home where he lived alone. He was bundled inside and driven 400km to an institution for "adults with mental disorders." His transfer into the institution was arranged through an agreement by a municipal official acting as Mr Stanev's guardian (the guardian had never met Mr. Stanev and signed off on the institutional placement a mere six days after becoming his guardian) and the institution's director. It was arranged on the basis that Mr. Stanev had a diagnosis of schizophrenia and that his relatives did not want to care for him. Mr. Stanev knew nothing about this agreement and did not want to leave his home. No one told him how long he would stay in the institution, or why he was being taken there. Two years earlier, the Ruse Regional Court had restricted his legal capacity. He was not notified about or allowed to participate in the proceedings that led to this determination. Once under guardianship, Mr. Stanev was prohibited by law from making any decisions about his own life.[572] He had unsuccessfully appealed the court decision a year later. In 2005, the director of the institution was appointed Mr. Stanev's guardian.[573]

Mr. Stanev filed his application to the ECtHR with the assistance of the Bulgarian Helsinki Committee and the Mental Disability Advocacy Center, two non-governmental organizations, on September 8, 2006. There was an oral hearing before a seven-judge Chamber on November 10, 2009, and the Chamber issued its admissibility decision on June 29, 2010. On September 14, 2010 the Chamber relinquished the case to the Grand Chamber, which is the ECtHR's highest body comprised of seventeen judges. On February 9, 2011, an oral hearing took place before the Grand Chamber, and the judgement was issued on January 17, 2012, some six years and four months after Mr Stanev filed his case.

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[572] Mental Disability Advocacy Center, Guardianship and Human Rights in Bulgaria: Analysis of Law, Policy and Practice, (2007), *available at* http://mdac.info/sites/mdac.info/files/English_Guardianship_and_Human_Rights_in_Bulgaria.pdf.

[573] For more on these situations of conflict of interest, *see* MDAC 2007, comments under indicator 11 at p. 42: "The guardian should not have a conflict of interest with the adult, or the appearance of such a conflict."

The Grand Chamber held that Mr. Stanev had been deprived of his liberty under Article 5 of the European Convention on Human Rights (ECHR) because he was under constant supervision in the institution and was not free to leave without permission. The Court found a violation of Article 5(1) of the ECHR because his detention was not based on his mental health status (which remained largely irrelevant to his placement) and that there was no need to detain him. The Court also found a violation of Article 5(4) of the ECHR (which sets out the right to a court review of detention) because the Bulgarian law allowed Mr. Stanev no opportunity to have the lawfulness of his detention assessed by an independent judicial body; as a person whose legal capacity had been stripped, he had no legal standing to litigate. The Court also found a violation of Article 5(5) of the ECHR (which sets out a right to domestic compensation for a violation of Article 5). Of global jurisprudential significance, the Court found that the conditions of the detention were "degrading," in violation of Article 3 of the ECHR. Although the Court found a violation of the right to a fair trial under Article 6 of the ECHR because Bulgarian law provided no mechanism for Mr. Stanev to seek restoration of his legal capacity, the Court, by thirteen votes to four, declined to look into the substance of the complaints about the deprivation of legal capacity, argued by the applicant under Article 8 of the ECHR (which sets out the right to respect for private and family life, home and correspondence). The judgment contains two partly dissenting judgments, both of which depart from the majority on the Article 8 point. The Court awarded Mr. Stanev compensation of €15,000.

This article does not address each of these findings in turn, as it is impossible to do justice to the entirety of the 65-page judgment and partly dissenting opinions. Instead, the rest of this article highlights three substantive issues. The first section looks at the Court's treatment of the living conditions in the institution, the second section examines the Court's discussion of whether Mr. Stanev was deprived of his liberty, and the third section looks at the Court's (mis)handling of Mr. Stanev's legal capacity complaints. I then offer some conclusions.

2. Living conditions were degrading

The social care institution in which Mr. Stanev found himself was "accessible via a dirt track from the village of Pastra, the nearest locality 8km away,"[574] in a village located in a "secluded mountainous area (some 800 m above sea level), near a hydroelectric power station,"[575] in southwest Bulgaria. Mr. Stanev was placed in Block 3 of the home, which was "reserved for residents with the least serious health problems, who were able to move around the premises."[576]

A BBC journalist had visited Pastra in December 2002 and found that some of the residents "had no shoes and socks although it's minus ten degrees [Celsius] outside." The journalist reported that "[o]ne in ten residents did not survive the past year – and there is no reason to expect it to be any different this year."[577]

It was not just the BBC that visited the institution. Of huge significance for Mr. Stanev's international litigation given its documentary credibility, a delegation of the European Committee for the Prevention of Torture (CPT) carried out a periodic visit to Bulgaria in December 2003. Their mission included a trip to the Pastra institution. The CPT found that in Blocks 1 and 2 the temperature at midday at the time of the visit in December was twelve degrees Celsius. In Block 3, where Mr. Stanev was held, the CPT found "somewhat better heating," although "residents indicated that it had been on all the time since the delegation's arrival."[578]

The residents' clothes were bundled together and handed out randomly to the residents, a situation about which the ECtHR commented "was likely to arouse a feeling of inferiority in the residents."[579] The CPT documented that residents had

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[574] *Stanev* at para. 19.

[575] "Report to the Bulgarian Government on the visit to Bulgaria carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 16 to 22 December 2003," CPT/Inf (2004) 23, 24 June 2004, para. 22. (hereinafter "CPT report").

[576] *Stanev* at para. 20.

[577] Karen Allen, *Mental health travesty in Bulgaria*, BBC NEWS, December 16, 2002, http://news.bbc.co.uk/2/hi/health/2579865.stm.

[578] CPT report at para. 26.

[579] *Stanev* at para. 209.

access to the bathroom once a week, and that the bathroom to which Mr. Stanev had access was "rudimentary and dilapidated."[580] The CPT also found that:

> *The so-called "toilets", also located in the yards, represented decrepit shelters with holes dug in the ground. The state of these facilities was execrable; further, walking to them on the frozen, slippery ground was potentially dangerous, especially at night. Residents visibly used the surrounding outside area as a toilet.*[581]

As well as the BBC and the CPT, Amnesty International also visited the Pastra institution one year earlier. Amnesty's report is more graphic than the CPT's. They found that the toilet:

> *[...] was some 30 metres away along a snow-covered path in an outhouse. Faeces blocked the hole in the ground and covered the snow around the outhouse. In block number two there were three rooms on the first floor, with one, four and seven beds respectively. Some beds had no mattresses and a few did not even have spring frames but only flat metal bars. When asked how the residents sleep in such beds the orderly replied to an Amnesty International representative that they put their coats across the metal bars and then lie on top. The orderly also explained that lights are centrally controlled and switched off at midnight. The residents were ordered to rise at 4am. When questioned about the rationale for such early awakening he stated: "Just so! Sometimes it can vary. It depends!" This was a clear admission of abuse of power by the staff.*[582]

The CPT found that there was one TV set owned by one of the residents, but generally that, "[n]o therapeutic activities whatsoever were organised for the residents, whose lives were characterised by passivity and monotony."[583] The

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[580] CPT Report at para. 27.

[581] *Id.*

[582] Amnesty International, Bulgaria: Far from the eyes of society: Systematic discrimination against people with mental disabilities (2002), *available at* http://www.amnesty.org/en/library/info/EUR15/005/2002.

[583] CPT Report at para. 32.

institution's daily budget for food per person was the equivalent of $0.89.[584] The CPT delegation was so appalled with the situation that at the end of its mission to Bulgaria it made an immediate observation,[585] finding that "the conditions witnessed at this establishment could be said to amount to inhuman and degrading treatment." The CPT urged the Bulgarian government to urgently replace the institution with a facility in conformity with modern standards. Responding to this in February 2004, the Bulgarian government promised that the Pastra institution "would be closed as a matter of priority."[586] This turned out to be entirely vacuous: the Pastra institution remains operational to this day. To highlight the situation, the CPT went back in October 2010, but its report on this mission is not yet public.[587]

In its judgment, the ECtHR relied extensively on the CPT's documentation in finding that the living conditions in which Mr. Stanev was forced to spend approximately seven years amounted to "degrading treatment,"[588] in violation of Article 3 of the ECHR, which sets out the absolute prohibition against torture, inhuman or degrading treatment or punishment. In the international litigation, the Bulgarian government pleaded a lack of financial resources in justifying its inaction in closing the Pastra institution, an argument that the ECtHR found irrelevant as justification for keeping Mr. Stanev in such conditions.[589] Stanev is the first case in which the ECtHR has found a violation of Article 3 of the ECHR in any sort of institution for people with disabilities.

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[584] *Id.* at para. 29: "[t]he daily expenditure for food per resident averaged 1.50 BGL and could go up to 2 BGL when there were donations." According to the history section of www.xe.com, in December 2002 1.5 BGL was the equivalent to 0.89 US dollars.

[585] In doing so, the CPT invoked Article 8(5) of the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (November, 26 1987) which provides that, "[i]f necessary, the Committee may immediately communicate observations to the competent authorities of the Party concerned."

[586] CPT Report at para. 34.

[587] The CPT carried out a periodic visit to Bulgaria from October 18-29, 2010 and visited the "Home for men with psychiatric disorders in the village of Pastra, Rila municipality." CPT, *News Flash*," November 3, 2010, www.cpt.coe.int.

[588] *Stanev* at para. 212.

[589] *Id.* at para. 210.

3. Liberty was denied

Mr. Stanev alleged that he had been detained for the purposes of Article 5(1)(e) of the ECHR, which sets out an exhaustive set of circumstances when in which the State can legally deprive an individual of their liberty, including for people of "unsound mind." Case-law has fleshed out what this antiquated phrase means, but the ECtHR has never been asked to decide whether a resident of a social care institution was detained for the purposes of Article 5 of the ECHR. Its previous case-law has largely concerned compulsory detention under mental health legislation in psychiatric wards/hospitals, which the Court has generally found acceptable as long as there are safeguards.[590] If Mr. Stanev was detained for the purposes of Article 5(1) of the ECHR, then (according to Article 5(4)) he should have been entitled to have the lawfulness of the detention reviewed by an independent court.

The seventeen judges of the Grand Chamber saw the public policy implications clearly. No one knows how many people with disabilities are in social care institutions, but my estimation is that the figure is upwards of 2.5 million in the Council of Europe region.[591] It appears from the judgment that the Grand Chamber judges did not want to open the proverbial floodgates. At the outset of the discussion on Article 5, the judgment goes to pains to state that, "it is unnecessary in the present case to determine whether, in general terms, any placement of a legally incapacitated person in a social care institution constitutes a 'deprivation of liberty' within the meaning of Article 5(1) [of the ECHR]."[592] The judgment, we are told, does not "rule on the

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[590] For a review of ECHR case-law on this, *see* chapter 2 of Peter Bartlett, Oliver Lewis, and Oliver Thorold *Mental Disability and the European Convention on Human Rights*, (2007).

[591] In 2007, an international study estimated that there were nearly 1.2 million people living in residential institutions for people with disabilities in European Union member states (the study included Turkey, but excluded Germany and Greece for which no data was available). *See* Jim Mansell, Martin Knapp, Julie Beadle-Brown and Jeni Beecham, *Deinstitutionalisation and community living – outcomes and costs: report of a European Study* 26 (2007). My estimate of upwards of 2.5 million is based on the fact that the European Union's 27 countries constitute around 502 million people, and that the number of people in the Council of Europe (which comprises 47 member states including all EU member states) is around 800 million, and that countries in former Soviet Union have higher rates of institutionalisation than western European countries many of which are undergoing a de-institutionalisation process.

[592] *Stanev* at para. 121.

obligations that may arise under the Convention for the authorities in such situations."[593]

That said, The ECtHR found that Mr. Stanev's detention was attributable to the national authorities because he was placed in a State-run institution that did not interview him before the placement.[594] He was not given an opportunity to express his opinion about the guardian's decision, even though he could have given it.[595] He was not transferred to the institution on his request,[596] and the restrictions complained of were the result of the (in)actions of public authorities.[597] The Court found that in the particular circumstances, with many caveats, without making any policy generalities, and only in this case, Mr. Stanev was deprived of his liberty in Article 5 terms.

The particular circumstances included the following findings of fact. Mr. Stanev needed staff permission before going to the nearest village.[598] He had three leaves of absence of about ten days each, which were "entirely at the discretion of the home's management,"[599] and he needed to travel 400km to get home, making his journey "difficult and expensive [...] in view of his income and his ability to make his own travel arrangements."[600] He was returned to the institution without regard to his wishes when he failed to return from a leave of absence in 2006.[601] Furthermore, his identity papers were constantly held by the institution, which, the ECtHR found, placed "significant restrictions on his personal liberty."[602]

The Court found that Mr. Stanev was not at any health risk that might have warranted detention, and that he was "under constant supervision and was not free to leave the home without permission whenever he wished."[603] Having lived in the institution for eight years, the Court found that he was

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[593] *Id.*
[594] *Id.* at para. 122.
[595] *Id.*
[596] *Id.*
[597] *Id.* at para. 122-3.
[598] *Id.* at para. 124.
[599] *Id.* at para. 125.
[600] *Id.*
[601] *Id.* at para. 127.
[602] *Id.* at para. 126.
[603] *Id.* at para. 128.

likely to have felt "the full adverse effects of the restrictions imposed on him."[604] In addressing the subjective aspect of Article 5, the Court noted that Mr. Stanev had actively complained of being in the institution and had attempted to leave legally. For all these reasons the Court found that he had been detained. The question remained: was the deprivation of liberty lawful under Article 5(1) of the ECHR?

Answering this question in the affirmative, the Court stated what I think is the most important sentence in the whole judgment:

> *It seems clear to the Court 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.*[605]

This is the closest the *Stanev* Court comes to a policy analysis. The decoupling of guardianship and other human rights violations is a topic now well-established, and the Court will be presented with more cases in the future which will tease apart the intimate relationship between detention in an institution and deprivation of legal capacity. Because the freshest medical report was two years old when Mr. Stanev was placed into the institution, the Court was convinced that the detention was not "in accordance with a procedure prescribed by law" under Article 5(1)(e) of the ECHR, and it therefore found a violation under this heading.

4. Legal capacity was hardly examined

Mr. Stanev argued that his right to a fair trial (due process rights set out in Article 6 of the ECHR) and his right to respect for private life (Article 8 of the ECHR) were violated as a result of being deprived of legal capacity and being placed under guardianship. As already noted, the ECtHR found a violation of Article 6 on the basis that Bulgarian law did not guarantee with sufficient degree of certainty access for Mr. Stanev to seek restoration of his legal

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[604] *Id.* at para. 129.

[605] *Id.* at para. 154.

capacity.[606] This is a welcome finding, as it is predictable and technocratic. Of more jurisprudential interest is the range of human rights that are automatically compromised as a result of the deprivation of legal capacity.

Mr. Stanev argued these points at considerable length under Article 8 of the ECHR. The Court refused to even entertain these arguments, and thirteen out of the seventeen judges found abruptly that "no separate issue arises under Article 8." One can only speculate as to why the majority decided this way. Perhaps at sixty-one pages, the judges thought that the judgment was lengthy enough, or has covered enough terrain already. Perhaps they simply ran out of steam, or time. Perhaps they were in a rush to clear the backlog of other cases. Alternatively, (although to be clear, they do not put it in these terms), perhaps the Grand Chamber was willing to offer the State a wide "margin of appreciation" and was reluctant to provide broad policy guidance in an area where there is not yet clear common ground amongst the member States (let alone among the judges) on an issue they consider to be a social or moral one, notwithstanding the existence of the UN Convention on the Rights of Persons with Disabilities.[607]

Whatever the reason for the Court's approach, their handing of the legal capacity claims stands in sharp contrast to its existing body of case law.[608] In its 2008 judgment in Shtukaturov v. Russia, the Court established that the "interference with the applicant's private life was very serious. As a result of his incapacitation the applicant became fully dependant on his official guardian in almost all areas of life."[609] In the Shtukaturov case, the applicant was placed under guardianship without his knowledge, and was sent by his guardian to a psychiatric hospital for seven months. In the *Stanev* case, the applicant was sent by his guardian to a social care institution for seven years.

The *Stanev* judgment is appended by two separate partly dissenting opinions, the first by the judges from Belgium and Luxembourg (who are both Vice

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[606] *Id.* at paras. 222-248.

[607] As an analogy see the approach of the Court with regards artificial insemination in *S.H. and Others v. Austria*, Application no. 57813/00, Eur. Ct. H.R. (2011).

[608] For more on guardianship litigation, *see* Oliver Lewis, *Advancing legal capacity jurisprudence*, 6 EUR. HUM. RTS. L. REV. 700-714 (2011).

[609] *Shtukaturov v. Russia,* Application No. 44009/05, Eur. Ct. H.R. para. 90 (2008).

Presidents of the Court, i.e. very senior) and Estonia, and the second by Judge Kalaydjieva (who herself is from Bulgaria and used to work as a human rights attorney). Both opinions regret that the Court failed to investigate the Article 8 claims, with Judge Kalaydjieva correctly identifying legal capacity as "the primary issue" in the case. She notes that the government offered no justification for Mr. Stanev's preferences being ignored, and that "instead of due assistance from his officially appointed guardian, the pursuit of his best interests was made completely dependent on the good will or neglect shown by the guardian."

Judge Kalaydjieva writes that she would have found a violation of Article 8 of the ECHR, stridently setting out that the Bulgarian law "failed to meet contemporary standards for ensuring the necessary respect for the wishes and preferences he was capable of expressing." This language of contemporary standards is, in my view, code for Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD), which sets out that everyone with disabilities should have legal capacity on an equal basis with others, and that the State is required to make assistance available to those who need help in exercising their legal capacity. It should be pointed out, however, that Bulgaria had not ratified the CRPD when the violations took place, so Bulgaria was not legally bound by its provisions.

Judge Kalaydjieva further notes the access to justice argument which was missed in the majority judgment; namely that Mr. Stanev had to rely totally on the discretion of the guardian to initiate legal proceedings to restore his legal capacity, and to get out of the institution. Her insight highlights the way in which guardianship and institutionalisation conspire not only to invalidate a person's will and preferences, but how they segregate people from our societies, exclude them from the political sphere and erase them from our legal consciousness.

5. Conclusions

I would like to make two concluding remarks. First, that the Court should engage with developments in United Nations human rights law. Second, that despite its weaknesses, the *Stanev* judgment is a significant advance in international human rights law.

First, *Stanev* is the latest example of how the ECtHR is unwilling to interpret the ECHR in the light of UN human rights treaties, in this case the CRPD.[610] One frustration is that CRPD provisions do not map neatly onto the ECHR, but the main frustration is that the Court is not even engaging with what the CRPD has to say. The ECHR was written in the late 1940s, and it is likely that none of the drafters had a situation similar to *Stanev* in mind. By contrast, the CRPD is a document adopted in 2006, drafted largely by experts (many of whom were people with disabilities) who knew the features of guardianship and institutionalisation very well. Its provisions – in particular Articles 12 and 19 – speak directly to a *Stanev* scenario.

The ECtHR first cited the CRPD in 2009, three years after its adoption, in the case of *Glor v. Switzerland*.[611] The Court stated that the CRPD represents a European and universal consensus on the necessity of addressing the treatment of people with disabilities. Although these are encouraging words, the Court did not rely on the CRPD in finding in that case for the first time that disability constituted a "status" as a protected ground of discrimination under Article 14 of the ECHR; or that people with disabilities constitute a vulnerable group for whom the State's margin of appreciation to permit differential treatment should be narrow. More surprisingly, in very important judgments concerning the right to legal capacity in 2008,[612] 2009,[613] and 2011,[614] the Court failed even to mention the CRPD, despite legal capacity being a central concern in each of the cases, and a central feature of the CRPD.

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[610] For more on how the ECtHR is unwilling to synthesize UN law into its jurisprudence, see Magnus Killander , *Interpreting Regional Human Rights Treaties*, 7 SUR INT'L J. ON HUM. RTS. 145-169 (Dec. 2010).

[611] *Glor v Switzerland*, Application No. 13444/04, Eur. Ct. H.R. (2009).

[612] *Shtukaturov v. Russia*, Application No. 44009/05, Eur. Ct. H.R. (2008).

[613] *Salontaji-Drobnjak v. Serbia*, Application No. 36500/05, Eur. Ct. H.R. 2009).

[614] *Krušković v. Croatia*, Application No. 46185/08, Eur. Ct. H.R. (2011).

In a 2010 judgment on the right to vote of a person deprived of legal capacity, the Court cited the CRPD in passing but failed to use it in its analysis,[615] and in a case against the UK in the same year the Court mentioned offhand that the amicus curiae brief had cited the CRPD in its submissions.[616]

In a 2010 case concerning a deaf man who died in custody, the Court cited the CRPD early in its judgment, but despite the CRPD's strong language about reasonable accommodation in detention,[617] the Court did not rely on it in finding that "[w]here the authorities decide to place and maintain in detention a person with disabilities, they should demonstrate special care in guaranteeing such conditions as correspond to his special needs resulting from his disability."[618] In a 2011 case about a person with HIV, the Court referenced the CRPD in relation to the prohibition of disability-based discrimination but did not cite it in the main points of the case (for example whether HIV can be considered a disability which, since *Glor v. Switzerland*, is already an established prohibited ground of discrimination under the "other status" provision in Article 14 of the ECHR).[619] It is probably too early to conclude that the Court is being disablist in its approach, and perhaps too early to conclude that it is taking a different approach to that which it took following the 1989 adoption of the Convention on the Rights of the Child (CRC), although a review of the ECHR judgments from the 1990s citing the CRC suggest a Court slightly more willing to weave CRC principles into its judgments than the current bench's treatment of the CRPD.[620]

Second, the *Stanev* judgment is a significant advancement of European and global case law. Writing in 2007, Sir Nicholas Bratza (the President of the seventeen-judge Grand Chamber that adjudicated the *Stanev* case, and the President of the ECtHR itself) observed that since the first major mental

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[615] *Kiss v. Hungary*, Application No. 38832/06, Eur. Ct. H.R. (2010).

[616] *Seal v. United Kingdom*, Application No. 50330/07, Eur. Ct. H.R. (2010).

[617] See Article 14(2) of the CRPD, which states that "if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation."

[618] *Jasinskis v Latvia*, Application No. 45744/08, Eur. Ct. H.R. para. 59 (2010).

[619] *Kyutin v Russia*, Application No. 2700/10, Eur. Ct. H.R. (2011).

[620] *See*, for example, *Costello-Roberts v. the United Kingdom*, Application no. 13134/87, Eur. Ct. H.R. (1993).

health case of *Winterwerp v. the Netherlands* in 1979, "the jurisprudence of the Court in the succeeding twenty years is notable for the almost complete dearth of judicial decisions in this vitally important area." He goes on to explain that, "This gap is a reflection not of adequate safeguarding by member States of the Convention rights of those with mental disabilities but rather of the acute practical and legal difficulties faced by an especially vulnerable group of persons in asserting those rights and in bringing claims before both the domestic courts and the European Court."[621] Exactly so. That Mr. Stanev was able to bring his case to the public attention through the international litigation is due to his tenacity, to non-governmental organisations, and the donors that fund them.[622] No civil legal aid is available in Bulgaria for this type of case, so the vast majority of cases go ignored.

The Stanev judgment has been described in the blogosphere as an "exciting decision," a "huge achievement,"[623] and a "landmark ruling."[624] My colleague Lycette Nelson, who represented Mr. Stanev before the Grand Chamber, describes the judgment as having "enormous significance."[625] The international NGO, Interights, which submitted an excellent amicus brief said on its website that, "there is no mistaking the significance of the *Stanev* judgment, which will benefit tens of thousands of persons with disabilities,"[626] although this seems to miscalculate the number of potential beneficiaries by several million.

It is surely a jurisprudential failure that the Court did not directly address the right to legal capacity, and it is frustrating that the Court is not yet willing or able to offer macro comments about societal exclusion of people with

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[621] Foreword by Sir Nicholas Bratza, in Peter Bartlett et al, *supra*.

[622] Grants to the Mental Disability Advocacy Center by the Open Society Foundations, the Sigrid Rausing Trust, the Trust for Civil Society in Central and Eastern Europe and Doughty Street Chambers all contributed to MDAC being able to work on the *Stanev* case, among others. MDAC sub-granted part of its funding to the Bulgarian Helsinki Committee.

[623] Nell Munro, *Stanev v. Bulgaria*, January 19, 2012, *www.mentalhealthandcapacitylaw.wordpress.com*.

[624] Lucy Series, *Mr Stanev's fine achievement*, January 20, 2012, www.thesmallplaces.blogspot.com.

[625] Lycette Nelson, *Stanev v. Bulgaria: The Grand Chamber's Cautionary Approach to Expanding Protection of the Rights of Persons with Psycho-social Disabilities*, February 29, 2012, www.strasbourgobservers.com.

[626] Interights, *Stanev v. Bulgaria*, on www.interights.org.

disabilities. I share the frustration, but am not yet overly concerned. The Court is not a UN treaty body that comments on government progress and makes recommendations and has a more personable relationship with civil society. Nor is it an international think-tank or an advocacy organization. We are still in the early days of disability litigation: this is a relatively new and unsettled area, in the European legal system, however backward that may seem to we advocates who operate in the CRPD ecosystem. The ECtHR is a judicial body that currently faces a barrage of criticism from governments for overstepping the boundary between national sovereignty and universal human rights. Perhaps these political considerations were at play in the *Stanev* case.

As a judicial body the Court has adjudicated the particular facts of the case. That it has chosen to couch the violations in overly narrow terms does not detract from the significant advances in international law. This is the first case in which the Court has found that a person in a disability institution was unlawfully deprived of liberty. This is the first case that the Court found that the regime and conditions of a disability institution violate the absolute right to be free from torture and inhuman or degrading treatment or punishment.

Franz Kafka once wrote that, “paths are made by walking.” Mr. Stanev’s case clears the path towards freedom, and towards a time when people with disabilities are not objectified by the law, but treated as full and equal subjects of human rights and fundamental freedoms. It is now for others to take action, by carrying out implementation advocacy, raising judicial awareness of disability rights, empowering victims of human rights violations to continue seek justice through the courts, and ensuring the viability of organizations that enable this to happen.

BLOCK THREE

Chapter 7: Disability, healthcare law and ethics

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1. Introduction

Why devote a chapter to disability in a handbook on *medical* law and ethics? It is increasingly recognized that a disability, however defined, cannot automatically be equated with a medical condition, let alone a disease. Instead, a disability is an ‘infinitely but various feature of the universal condition’ (Bickenbach 1999, p. 112) that may arise from a health condition, age or an injury at a certain point in life and leads to long-term impairments. The United Nations *Convention on the Rights of Persons with Disabilities* [CRPD] 2006 embraces the latter approach, and serves as a comprehensive human rights instrument that establishes a wide array of rights for persons with disabilities that also impact medical law and ethics.

Nonetheless, people with disabilities are and remain victims of human rights violations, both within and outside the healthcare sector. Various studies demonstrate that the right not to be discriminated against, as well as the right to (individual or personal) autonomy,[627] are often neglected (Sapey 2010; Bach & Kerzner 2010; Koch 2009). These and other human rights violations affect the health and access to healthcare of people with disabilities (Krahn, Hammond & Turner 2006; Department of Health and Human Services [HHS] Advisory Committee on Minority Health 2011). According to the World Health Organisation [WHO] (2012), '[p]eople with disabilities have less access to healthcare services and therefore experience unmet healthcare needs' (p. 1). They experience poorer levels of health than the general population, and they may 'experience greater vulnerability to preventable secondary conditions, co-morbidities, and age-related conditions' (WHO & The World Bank 2011, p. 10). They are also at higher risk of being victims of violence. As a result, the world is witnessing disability-related health disparities, leading to ill health, the denial of sexual and reproductive health (rights), substandard healthcare, unnecessary institutionalisation, violence and premature death (Yee 2011). Disability is thus also a medical law and ethical issue deserving attention in this book.

Before turning to the relevant legal and ethical theories, and exploring the rights, principles and issues most prominent in the interrelationship between disability on the one hand and medical law and ethics on the other, we will briefly discuss the various meanings of the term disability, and the way this concept was finally defined in the CRPD. In this chapter, we pay special attention to the human rights of persons with disabilities, as defined under the CRPD, within the context of healthcare, and the implications of these rights for medical professionals. Due to the fact that this book entails a separate chapter on mental health, we will not embark on the human rights of people with mental disabilities (see Chapter VII).

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[627] Instead of 'autonomy,' the term 'self-determination' is often used. These terms are mostly used interchangeably. To stay as close as possible to the CRPD and the case law of the European Court of Human Rights [ECtHR], we use the term (personal or individual) 'autonomy' in this chapter.

2. Definition of Disability

Disabilities have traditionally been defined in terms of physical, mental, intellectual or sensory deviations from normality caused by disease, trauma or other health conditions. This reflects the deep-rooted idea that people with disabilities are unhealthy and in need of medical aid. In other words, disability is seen as a problem, one that is inherent to an individual and that needs to be addressed by medical professionals. In the past, healthcare was thus seen as a means to enable people with disabilities to live a humane and dignified life. In addition, and of particular importance from a medical law and ethical perspective, healthcare decisions were made for, but not by, people with disabilities. The concept of 'informed consent,' a leading principle in medical law and ethics (Faden, Beauchamp & King 1986; Manson & O'Neill 2007), was thought not to be relevant for people deemed unable to make autonomous decisions. As a result of judgments by court, and more often informally, people with disabilities were treated as lacking the capacity to make decisions for themselves and as not entitled to autonomy.[628]

This medical model of disability - portraying people with disabilities as persons with problems, objects of care and recipients of welfare - has been harshly criticized over the last few decades (Percy 1989; Barnes 1991; Finkelstein 1990). According to the medical model, a disability essentially denotes an inability to function in the conventional way due to a defect. It was recognized that, although such an impairment can be inherent (such as a patient suffering from a neurodegenerative disease affecting his or her cognitive competences), this is not always the case. Impairments can also be the result of an external factor that has no relationship with medicine at all, like an accident that results in a leg amputation, which leads to impaired mobility. As such, not all disabilities are necessarily medical.

Proponents of the social model of disability argue that the problems of disability should not be centred on individuals, as medically inspired disability programmes are. Rather they should refer to the interaction between individuals and their environment. In fact, many obstacles faced by those with

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[628] See, for example, Lewis 2012.

disabilities are imposed and exacerbated by the physical and social environment, often designed by able-bodied persons who fail to take into account the needs of differently abled persons. Therefore, disability is not merely an individual characteristic, but a social construct that reflects the systematic denial of human rights to a group of individuals deemed less able to function in our society due to individual impairments. Disability and human rights scholars argue that healthcare is used as an instrument to negatively label people with disabilities, withholding them from participating in society as equals, and hindering efforts to bridge the gap between disabled and able-bodied persons (Krahn & Campbell 2011).

So-called social constructionists demand the breakdown of barriers inhibiting people with disabilities from participating equally in society - a demand clearly echoed in the 2001 'International Classification of Functioning, Disability and Health' [ICFDH] (Taket 2012). Despite these demands for equality, policymakers, legislators and the public at large still widely believe that preventive, curative and rehabilitative healthcare measures are the best remedies to reduce the adverse impact of impairments on differently-abled persons (Borg, Lindström & Larsson 2009). Much to the regret of disability and human rights scholars, disability continues to be perceived as a medical and healthcare issue (Shakespeare 2012). Furthermore, medicalization is feared to threaten the dignity of people with disabilities and justify the discrimination they experience on a daily basis, as opposed to offering a means to strengthen and ensure the equal enjoyment of human rights.

This fear is reflected in the CRPD. After long debates at the United Nations[629], it was finally recognized that people with disabilities are entitled to full and equal human rights, despite much resistance amongst representatives of many States to introduce new 'disability specific' rights. The decision to include a definition of disability in the CRPD was also a point of contention amongst its drafters. Opponents argued that any definition would prevent the CRPD from adequately protecting the rights of disabled groups and persons who are most

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[629] See, for example, Quinn 2009 and Trömel 2009.

at risk.[630] For this reason, in combination with the express difficulty of establishing what precisely constitutes a disability, the law of the European Union does not include a definition. Moreover, there were also fears that the absence of a definition in the CRPD would allow States Parties to adopt strict definitions of disability, possibly denying many people with disabilities protection under the CRPD on a national level (Trömel 2009, p. 121). Others were concerned that the absence of a definition would impose costly obligations on States to accommodate differently-abled persons in education, housing, employment and healthcare, and therefore favoured its inclusion (Quinn 2009, p. 102). As a compromise, States agreed to an open-ended definition, stating, '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' (CRPD, article 1). This refers to the group that should at least be protected under the CRPD on a national level. It is important that this definition does not build on a medical model, but rather embraces the social approach to disability. Although the nature of the impairment is not emphasized, the CRPD definition draws attention to problems that may occur 'in interaction' between impairments and environmental barriers.

It should be noted the CRPD definition purposefully states that impairments should be 'long-term.' Such delineation was included to allow States to confine entitlements, such as to social security, additional healthcare insurance, protection against dismissal and the right to personal assistance, to persons with particular impairments.

Prior to the adoption of the CRPD, the question of whether persons who were absent from work due to sickness were entitled to the same level of protection as people who were unable to work due to a disability emerged. According to the European Court of Justice [ECJ], this was not the case: '...by using the concept of 'disability' in Article 1 of that directive, the legislature deliberately chose a term which differs from 'sickness'. The two concepts cannot therefore

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[630] On this issue see the judgment of the European Court of Justice in *Coleman v Attridge Law and Steve Law* [2008] Case 303/06, ECR I-5603.

simply be treated as being the same' (*Chacón Navas v Eurest Colectividades* [2006], ECR I-6467, paragraph 2). Building on the medical model of disability, the ECJ held that a disability was a medical condition more serious than a sickness. The ECJ thus did not pay attention to the fact the reactions of others to a condition, ranging from fear to hostility, can be as disabling as the condition itself. After the EU acceded to the CRPD in 2010, the ECJ adapted its case law, and embraced a combination of the medical and social model. Also the long-term nature of an impairment recognized by the ECJ is now sufficient to determine whether a person is entitled to the protection bestowed to persons with disabilities under the CRPD (joined cases C-335/11 and C-337/11 *HK Danmark (Ring and Skouboe Werge*) decided on 11 April 2013 and *European Commission v. Italy* (case C-312/11) decided on 4 July 2013.

To conclude, though disabilities are - at least from a human rights perspective - no longer defined in terms of mere individual or medical conditions, it is still often thought that 'the solution' to the obstacles encountered by people with disabilities in daily life lies in the medical domain, by treating the disabled individual. Like everyone else, people with disabilities have healthcare needs that may be related or unrelated to their impairments. The latter brings to the fore questions of access; how healthcare is guaranteed to persons with disabilities, and how medical professionals treat people with disabilities within the healthcare sector.

3. Legal and Ethical Theory

A. From Ethics to Law

Medical law and ethics are both normative disciplines focused on human conduct in the field of healthcare. Different from evidence-based sciences, they do not analyze, describe, comprehend or predict human conduct, but seek to prescribe what individuals should do, based on what is considered a form of morally good treatment. The focus of medical law and ethics is on the conduct of medical professionals towards patients.

Since the times of Aristotle, it has been believed that medical professionals should abide by standards of ethical behaviour. These standards, or principles, were meant to inspire and regulate professional conduct. Compliance with these standards was deemed indispensable to guarantee professional behaviour and instil public confidence in the medical profession. Members of the profession themselves defined these standards and their contents. Medical ethics is thus a form of self-regulation, for and by members of the medical profession.

The dominant standards of medical ethics were later summarized into four principles: respect for autonomy, beneficence, non-maleficence and justice (Beauchamp & Childress 2013). These principles were referenced in many professional codes of conduct, both nationally and internationally, and equally applied to medical professionals when caring for 'patients' and 'persons with disabilities,' however defined (Blustein 2012).

However, these principles leave considerable room for interpretation, and make it difficult to determine a universally-ethical action for a medical professional in any specific case. Moreover, ethical principles cannot be enforced by (invoking the power of) the State. Rather, they are supposed to be morally binding on members of the professional group.

The atrocities committed in the Second World War, amongst others, against patients and research subjects with disabilities displayed the shortcomings of medical ethics (Wolfensberger 1981; Annas & Grodin 1995). In response, efforts to draft treaties and establish other legal standards for regulating the behaviour of medical professionals were introduced in the 1950s and 1960s. The focus of these laws and other legal instruments centred on protecting people with disabilities, the underlying assumption being they are unable to exercise their own autonomy.[631] The ethical principle of justice was thus equated with protection, inspired by non-maleficence (from the perspective of non-disabled persons) and denied people with disabilities the freedom of

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[631] See, for example, the *Declaration on the Rights of Mentally Retarded Persons* (UN General Assembly 1971, p. 93) and *Recommendation No. R(99)4 of the Committee of Ministers of the Council of Europe on Principles Concerning the Legal Protection of Incapable Adults* (Council of Europe 1999).

choice and other equal opportunities. The shift from non-enforceable medical ethics to legally binding medical law, in an effort to strengthen the ethical principles and make them enforceable, could not mask the fact that little attention was being paid to beneficence, from the perspective of disabled persons, self-determination by persons with disabilities and non-discrimination.

B. From Pity and Charity to Human Rights

Medical law emerged in the 1950s and 1960s in response to the shortcomings of medical ethics and the lack of enforceable legal standards that would regulate the provision of healthcare compatible with human rights law. Like medical ethics, medical law was first primarily concerned with professional conduct and not with the rights of healthcare recipients, including persons with disabilities. This approach was akin to most of the laws applying to persons with disabilities, who were portrayed as unable to generate incomes and thus in need of welfare. The urge to assist people with disabilities often reflected pity, a self-defined form of beneficence, instead of respect for autonomy (Shapiro 1993). This was particularly true for war veterans (Anderson 2011). It was felt that these patriots, who became disabled while fighting to protect the rights and freedoms at home, were most deserving of compensation. Quota systems were introduced to ensure veterans gained access to employment and better treatment options (Waddington 1996). Introducing quota systems and other forms of segregated treatment for war veterans and other people with disabilities was not considered a breach of the right to equal treatment. It was simply argued that war veterans and other people with disabilities were not the same as others and therefore not always entitled to the same treatment. This notion of equality, where no attention is paid to the context and where in actual fact inequality is perpetuated, is known as formal equality (Ventegodt Liisberg 2011, p. 23; Hendriks 1995).

It was not until the late 1960s and 1970s that people with disabilities complained against these institutionalized forms of pity and charity, and asserted their human rights, notably the right to be treated as equals (Iezzoni

& Long-Bellil 2012, p. 137). Working in sheltered workplaces, enrolling in separate schools and living in institutions became increasingly seen as methods of exclusion and discrimination. It was also acknowledged that by treating people with disabilities like others, not protecting them against discrimination, and only providing them with segregated forms of different treatment, justified by the formal equality model, discouraged integration and inclusion in society. Instead of the formal equality model, a different approach to equality emerged – known as material or substantive equality – that would take into account the context of a person and historical disadvantages, and would be less concerned about the form of treatment but primarily look at its outcomes. As a result, it was acknowledged that treating disabled persons the same as others, not taking relevant factors into account, could constitute discrimination whereas forms of different treatment were not necessarily regarded as incompatible with the prohibition of discrimination (McLean & Williamson 2007). To the contrary, certain forms of different treatment were regarded as indispensable in efforts to contribute to more equality (Hendriks 1995, pp. 40-62).

It took many decades before the call for equal rights for people with disabilities was echoed at the international level, ultimately leading to the adoption of the CRPD in 2006 (Quinn 2009, pp. 93-99). This Convention is based on a number of general principles, including the principles of autonomy and free choice, equality, respect for difference and non-discrimination, participation, inclusion and accessibility (article 3, *CRPD*). Different from the four ethical principles mentioned above, the human rights principles underlying the CRPD stress the need to also take difference into account, as well as the need to break down barriers that prevent people from participating as equals in society.

As previously mentioned, the drafters of the CRPD did not intend to introduce ‘disability specific’ rights. At the same time, it becomes clear from reading the CRPD that its drafters were well-aware that free choice, participation, inclusion and accessibility remained unachievable for many persons with disabilities as long as their human rights were interpreted from the perspective of formal equality. A material equality approach to the rights of people with disabilities is reflected in the general obligation to provide 'accessible information' (CRPD, article 3), to ensure the provision of 'reasonable accommodation' (CRPD, article 5), to raise awareness and combat stereotypes (CRPD, article 8) and to ensure access to the physical environment (including to 'medical facilities'), to transportation, to information and communications (CRPD, article 9). It can therefore be argued that the main goals of the CRPD are to promote the autonomy and equal rights of people with disabilities, instead of confining the goal to protecting people with disabilities against themselves, and in this way, preventing these persons from participating in the life-world. Before examining the CRPD's provisions with respect to medical law and ethics, we set out some of the CRPD's foundational concepts, namely disability-based discrimination and autonomy.

4. Discrimination

A. Definition

According to the CRPD, State Parties are obliged to prohibit all forms of discrimination on the basis of disability, and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds (CRPD, article 5(2)). This material provision has been modelled after similarly-worded provisions in other human rights treaties. It is also seen as elaborating on the general principle of non-discrimination underlying the CRPD (CRPD, article 3(b)). But what is meant by discrimination?

Article 2 of the CRPD sets out that 'discrimination on the basis of disability' is a term covering:

> *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.*

This description is almost identical to the one contained in article 1, paragraph 1 of the *International Convention on the Elimination of All Forms of Racial Discrimination* 1965. It is important to note here that discrimination neither requires the intent to discriminate nor confines itself to a specific addressee. That is, the prohibition to discriminate formulated in the CRPD equally applies to states and their agents (judges, public hospitals, public healthcare providers, etc.), as well as to private persons and organisations (private healthcare providers, churches, nongovernmental organizations, etc.).

However, the CRPD extends this definition so that the denial of a reasonable accommodation is also recognized as a form of discrimination (Waddington & Hendriks 2002), a concept that we return to below.

It follows from this definition that discrimination is generally understood to mean a form of detrimental or some other form of unfavourable treatment because of certain actual or perceived human features ('characteristics') or 'disability.' This allegedly-discriminatory treatment is usually worse, and therefore detrimental or unfavourable in comparison to the treatment received by people with a different type of disability, or without disabilities. Discrimination on the basis of disability is therefore the denial of equal treatment or rejection of equal worth of a person due to his or her disability. The harms that result from discrimination can manifest in the treatment itself (*e.g.,* intimidation) or as a consequence of the way a person is treated (*e.g.,* the denial of a job).

The prohibition of discrimination and, as a corollary, the obligation to treat people equally, are widely-recognized norms under international human rights law. Non-discrimination law emerged in response to forms of detrimental treatment deemed objectionable in a society built on human rights. Treating people less favourably because of particular features was considered unacceptable, because it was argued that they closely relate to human dignity.[632] Thus, discrimination denies the principle that all human beings are equally worthy and merit equal respect and protection. Discrimination is therefore at odds with the core values and principles underlying human rights law, as well as the CRPD.

Discrimination, as prohibited by the CRPD needs to be distinguished from mere 'different' or 'arbitrary' detrimental treatment. Providing information on the effectiveness and side effects of medication in braille for someone who is blind is a form of differential treatment, but would not constitute discrimination. Likewise, providing a sign-language interpreter to a person with a hearing impairment is not a form of discrimination; rather, it can be an obligation within the context of healthcare to ensure the patient receives adequate information and can consent to treatment (*Eldridge v British Columbia* [1997] 3 S.C.R. 624). As previously stated, discrimination implies disadvantageous conduct due to characteristics intimately linked to human dignity, such as gender, race and sexual orientation and gender identity. A person cannot, at least not easily, change these characteristics without significantly changing his or her identity.

For a long time it was contested that the non-discrimination norm applied to people with disabilities. Some felt a disability reflects a human defect unrelated to someone's identity or dignity. Others were concerned that non-discrimination law would make it impossible to introduce measures and policies aimed at protecting people with disabilities, helping them to cope with their impairments and provide them with necessary care and assistance. Others feared that by adding disability as a prohibited ground, the strong protection generally offered through non-discrimination law, would water down protection for all covered groups due to this inflation of grounds. Regardless, these arguments reflect negative stereotypes of people with disabilities and were otherwise defeated (Rothstein 2000). Since the adoption of the CRPD, a human rights instrument with a very high number of ratifications,[633] it can no longer be contested that detrimental treatment or

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[632] Much has been written on the meaning of the concept human dignity. See, for example, McCrudden 2008; Thies 2009; and Aasen, Halvorsen & Barbosa da Silva 2009.

[633] As of 1 February 2014, the CRPD has had 141 ratifications and accessions (and 158 signatories).

other forms of less favourable treatment due to a disability constitutes discrimination, and should, as such, be prohibited and combatted around the world. This also has, as we will argue below, implications for medical professionals.

B. Discrimination and Healthcare

At first glance, it is difficult to see why the prohibition of discrimination on grounds of disability should be concern medical law and ethics, let alone medical professionals. These disciplines, as mentioned above, are traditionally aimed at protecting and promoting justice, autonomy, beneficence and non-maleficence. In an effort to clarify why medical law and ethics should address discrimination and the lack of equal opportunities for persons with disabilities, we will briefly describe the various forms discrimination can take, using the designations outlined in the CRPD.

Direct disability discrimination has – according to the CRPD – ‘the purpose’ to discriminate. This occurs when a law, company policy or an individual, including a medical professional, treats someone less favourably than another similarly-situated person because of that person’s disability. For example, denying people with intellectual disabilities the right to procreate, or refusing to insure a person with a history of coronary disease are forms of direct disability discrimination (CRPD, article 25(e)). Direct discrimination is, from a legal perspective, always forbidden, unless there is an accepted justification for the differential treatment.

Indirect disability discrimination entails differential treatment on the basis of an apparently neutral criterion, with as a result (‘effect’) that (some) people with disabilities are disadvantaged compared to non-disabled persons. Such differentiation becomes discriminatory when no objective justification is provided. Denying dogs entrance to a hospital can lead to indirect discrimination towards people with a visual impairment with a service dog. Under non-discrimination law, not permitting access to dogs constitutes indirect discrimination towards a particular group of disabled persons, unless it can be demonstrated that the presence of dogs in hospitals poses, for example, a threat to hygiene and that this threat cannot be appropriately alleviated without prohibiting service dogs.

Disability harassment, a third form of discrimination, occurs when unwanted conduct related to a disability (actual or perceived) takes place with the purpose or effect of 'nullifying' the dignity of a person and of creating an intimidating, hostile, degrading, humiliating or offensive environment (Weber 2007). One example is refusing children with severe disabilities any form of medical treatment because they pose a burden on society and the healthcare system.

In addition, the CRPD – like the so-called *Framework Employment Directive* (Directive 2000/78/EC) adopted by the European Union in 2000 – recognizes a fourth form of discrimination – or, more precisely, a form of treatment necessary to enable 'the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities' (CRPD, article 1). Reasonable accommodation discrimination takes place in situations where a party covered by non-discrimination law fails to take into account the impairments of a person with disabilities that – in the interrelationship with his or her environment – constitute a barrier for participation and integration on an equal basis. Such is the case where a physician refuses to consult the representative of a person with an intellectual disability, arguing that speaking to the patient's representative would lead to an unjustified breach of the physician's duty to maintain patient confidentiality. The obligation to provide reasonable accommodations (CRPD, article 2) requires the covered party to take reasonable and effective steps or adjustments to remove the barriers that hinder the equal opportunities of the disabled person, unless the covered party, in all reasonableness, cannot be expected to make the adaptations needed, given the disproportionate burden the adaptations impose on that party. It is for States Parties to ensure that this norm is correctly transposed and enforced under national law (*European Commission v Italy*).

C. Multiple Discrimination

Before turning to the principle of autonomy, it is important to emphasise that discrimination not only occurs because of a sole ground, for example a disability, but that there is often a combination or intersection of grounds that cause or contribute to discriminatory reactions by others. This phenomenon is known as multiple discrimination (Fredman 2005). For example, where a person is denied health insurance due to a particular disability, together with his or her weight and age is multiple discrimination.

Non-discrimination case law demonstrates that the nature, type and intensity of discrimination a person experiences is often not merely dependent on a single ground (‘disability’), but on a number of overlapping ‘unfavourable’ grounds, such as, obesity, age, ethnicity, or religious or sexual minority. Such a combination of ‘unfavourable’ grounds makes some people with disabilities more prone to discrimination than others.

In response, it was felt that non-discrimination law should also offer protection against multiple discrimination. The CRPD is the first - and so far the only - international human rights instrument expressly recognizing multiple discrimination (preamble) and also offering protection to two forms of multiple discrimination: against girls and women with disabilities (CRPD, article 6) and against children with disabilities (CRPD, article 7).

The difficulty in addressing multiple discrimination by law does not negate its significance (Hendriks 2010). We wish to shed light on this form of discrimination because of its ethical importance to medical professionals and others responsible for health and healthcare policies and legislation, and because of the unambiguous references in the CRPD.

D. Discrimination and Justice

In conclusion, people with disabilities may face various forms of discrimination, both within and outside the healthcare sector. Medical law and ethics cannot abstain from this issue without undermining the principle of justice. Non-discrimination law, including the prohibition of multiple discrimination, should therefore be an important aspect of medical law and ethics with respect to persons with disabilities, and the way these persons should be treated by medical professionals, including healthcare institutions (Silver, Wasserman & Mahowald 1998, p. 42).

5. Autonomy

A. Definition

Respect for autonomy is both one of the four core bioethical principles (Beauchamp & Childress 2013), including the freedom to make one's own choices, and one of the general principles of the CRPD (article 3, *CRPD*). According to the CRPD, the autonomy of people with disabilities should also be respected in healthcare contexts, as set out in article 25. But what precisely does autonomy mean and how does it differ from the term discrimination (see section IV (A) of this chapter)? Like the term disability, the CRPD neither defines, nor describes autonomy.

The term autonomy is derived from 'auto' (self) and 'nomos' (government or law), thus literally meaning 'self-government'. Under international law, not only people or nations are entitled to autonomy, or self-determination, but individuals have the right to self-government, that is to say the right to determine their own course of life without external pressure. Thus, autonomy is above all a *negative* or non-interference right. It is therefore often associated with, according to Berlin, 'freedom from' interference by others (1958, p. 7). It has increasingly been recognized that autonomy cannot be equated with negative rights, but also requires positive 'freedom': the right to free choice and the right to fulfil one's own potential. Freedom of choice and the entitlement to evolve in a self-chosen way presuppose that choices can be made and are respected. Autonomy is therefore a complex concept, particularly with respect to health and healthcare. Often, choices must be made and individuals are not always in a position to make 'good' ones, due in part to insufficient information, their dependence on others, or a lack of intellectual capacity. Moreover, healthcare providers are bound by legal and ethical standards as well as professional norms, which at times prohibit them from complying with patient's wishes. This sometimes leads to a dilemma between 'professional autonomy' (the freedom of the professional group to set its own norms) and the individual autonomy of the patient.

B. The CRPD and Autonomy

As noted above, autonomy is a foundational concept of medical law and ethics and is examined in more detail in Chapter III on consent. For people with disabilities, autonomous decision-making often boils down to whether the medical professional is willing to respect the person's decision, including the wish not to be treated, as medical professionals tend to associate 'unwise wishes' with symptoms of incompetence. The latter is not self-evident and disrespectful to people with disabilities who may have views different from those of medical professionals. At the same time, many laws allow medical professionals to override a person's consent or rejection of treatment in case of demonstrated 'incompetence' (as decided by that medical professional). Surrogate decisions are, in these cases, traditionally seen as compatible with the principles of justice, beneficence and non-maleficence, provided that they are as much as possible in line with the previously-expressed wishes of the patient and not infringing his or her best interests. Thus, these laws are seen as protecting the health and wellbeing of the patient and doing justice to individual autonomy. As said, however, proxy or surrogate consent (which the CRPD Committee calls 'substituted decision-making') is easily applied to patients with (mental) disabilities for whom particular forms of treatment are deemed necessary. It can be argued that this situation is discriminatory towards persons with (mental) disabilities, as their autonomous will is not respected. This also raises concerns for medical law and ethics, and for the practice and standards of medical professionals, which should conform to international human rights law.

Consent, at the heart of the principle of autonomy, in the context of healthcare is referenced twice in the CRPD. First, there is a prohibition on medical or scientific experimentation without consent (CRPD*,* article 15). This provision targets the horrific experiments carried out on people with disabilities during the Nazi regime (Wolfensberger 1981; Annas & Grodin 1995), or more recently, feeding radioactive material to mentally disabled children in the late 1940s (Welsome 1999). However, the absolute prohibition on experimentation without consent raises a dilemma about research with individuals that are unable to consent, but for whom gaining scientific insights may be essential to enhance treatment options. The second place where consent is mentioned in the CRPD is article 25(d), in providing equal quality in healthcare, which we will explain in more detail below.

If autonomy is to be understood as making one's own choices and having those choices respected, how is this to be applied in the context of healthcare decisions for people with disabilities? A simple answer is that decisions should be made in exactly the same way as for people without disabilities: all persons should be properly informed about treatment options, and the repercussions of refusing treatment. This solution would alleviate many of the discriminatory elements of unwanted treatments, especially but not limited to, the mental health field. This would provide formal equality, but it would leave many people with disabilities vulnerable to exploitation by others if they did not receive any decision-making assistance. Article 12 of the CRPD tackles this issue by setting out two normative premises aimed at strengthening the autonomy of persons with disabilities.

First, everyone has legal capacity, in all domains of life. Legal capacity is the law's recognition of both holding and exercising a right. For example, in certain jurisdictions the law recognizes adults as having the capacity and right to get married, but denies this right to an adult with an intellectual disability by placing him or her under guardianship with restrictions on his or her legal capacity. In the context of healthcare decisions, people with disabilities are similarly denied the right to provide consent or reject a proposed medical intervention.[634] In response, the CRPD sets out the fundamental principle in article 12(2) that people should have legal capacity.

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[634] See, for example, Hammarberg's *Who Gets to Decide?* (2012); and Lewis' *Advancing Legal Capacity Jurisprudence* (2011).

Second, article 12(3) of the CRPD maintains that States must ‘take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’. If a dentist, for example, does not understand a person’s will and preferences, then a patient is entitled to the support necessary in order to make his or her treatment decisions and preferences understood by the dentist.

In doing so, the CRPD aims to ensure that people with disabilities meaningfully participate in society and truly exercise their autonomy. The Committee on the Rights of Persons with Disabilities [CRPD Committee] states that substituted decision-making systems must be *replaced* by systems of supported decision-making, a system recognising that persons with disabilities should be involved in the decision-making process even though they may need assistance, for example to assess the consequences of various treatment options. According to the Committee, States must repeal legislation allowing for systems of guardianship that are incompatible with human rights law and introduce laws ‘which recognize the rights of persons with disabilities to make their own decisions and to have their autonomy, will and preferences respected’ (CRPD Committee 2012a, paragraph 21). Rights including ‘the right to free and informed consent to medical treatment, the right of access to justice, and the rights to vote, to marry and to choose their place of residence’ (CRPD Committee 2013a, paragraph 30) are also mentioned as being at risk under substituted decision-making regimes. In September 2013, the CRPD Committee issued a draft general comment on article 12 of the CRPD. The draft document declared ‘mental health laws that permit forced treatment … need to be abolished to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others’ (CRPD Committee 2013b, paragraph 7). Healthcare is clearly a domain that needs to bring its practices in line with human rights norms.

6. The CRPD and Healthcare

The CRPD emphasizes that people with disabilities have ‘the right to the enjoyment of the highest attainable standard of health without discrimination’

(CRPD, article 25), reiterating the classic formulation of the right to health set out in the 1966 *International Covenant on Economic, Social and Cultural Rights* [ICESCR]. The focus of the CRPD, however, is not on health and healthcare. Instead, the CRPD is based on a number of general principles – as outlined above – including the principles of autonomy and free choice, equality, respect for difference and non-discrimination, participation, inclusion and accessibility (CRPD, article 3). This is not to suggest that the CRPD is irrelevant for medical law and ethics, or that health and healthcare have no importance in achieving these general principles. On the contrary, we argue that the CRPD requires an adjustment of these principles and the approach of medical law and ethics in order to do justice to the human rights of people with disabilities in the healthcare sector.

Different from medical ethics and, to a lesser extent, medical law, the CRPD is not so much focused on regulating the performance of medical professionals, but rather on guaranteeing that people with disabilities, irrespective of the cause, nature or severity of their impairments, and no matter their needs for medical care, actually get the healthcare they need and want. The CRPD thus also emphasizes the importance of autonomy in cases where disabilities may impair the capacity of individuals to make healthcare decisions. We will illustrate this by examining the relevant CRPD provisions.

Article 25 of the CRPD is the longest and most programmatic explanation of the right to health of any of the human rights treaties. It sets out the obligation of States to ‘take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation’ (CRPD, article 25). The drafters of the CRPD (namely the UN Member States) then established six priorities, ensuring that people with disabilities get ‘the same range, quality and standard of free or affordable healthcare and programmes as provided to other persons’ (CRPD, article 25(a)). This includes access to sexual and reproductive healthcare (this is the first time that this has been articulated in international human rights law) and public health programmes. States need to provide healthcare to alleviate, insofar as is possible, someone’s disability. Early identification and intervention, and ‘services designed to minimize and prevent further disabilities, including among children and older persons' are among the actions which fall under this mandate (CRPD, article 25(b)). The Convention emphasizes the provision of healthcare 'as close as possible to people's own communities, including in rural areas' (CRPD, article 25(c)). Articles 25(d) to (f) of the CRPD then set out overarching principles, reiterating the principles contained in article 3. They require the State to ensure that its medical professionals provide equal quality care, which is given 'on the basis of free and informed consent,' an issue to which we return, below. Equal quality should be achieved, according to the Convention, by pursuing actions that may include raising awareness of human rights 'through training and the promulgation of ethical standards' for medical professionals (CRPD*,* article 25(c)).

Article 25(e) of the CRPD reiterates the right to non-discrimination, this time with respect to health and life insurance. Article 25(f) of the CRPD establishes non-discrimination in providing a patient with disabilities healthcare, food and fluids. This is of particular concern, for example, when a person with Down syndrome needs a kidney transplant, given the reported cases where this has been denied based on the person's disability.[635] It is also a concern for end of life decisions and the management of people in conditions such as persistent vegetative state.

The CRPD recognizes health in parallel with the broader notion of independence, a concept that implies autonomy and the obligation to provide support to exercise autonomy. The drafters of the Convention were keenly aware that health can play an important part in reversing the invisibility of people with disabilities. Healthcare systems are unable to do this alone as many determinants of health are not within the realm of control of healthcare. It is widely known that income and other socio-economic determinants have, on a population basis, a greater effect on health than the quality of healthcare. That is not to ignore the importance of essential healthcare at times

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[635] For a review of outcomes, see Martens, Jones & Reiss 2006. For a case that permeated the public consciousness and resulted in a global campaign to provide an intellectually disabled girl with a much-needed kidney transplant, see Change.org 2012.

(Wilkinson 1997). One socio-economic determinant is adequate housing.[636] There is now abundant evidence that poor housing can lead to poor health, and people with disabilities are particularly vulnerable.[637] The right to adequate housing is set out in article 28 of the CRPD on social protection, and appears alongside other essentials of health, such as water, food, clothing, social protection, poverty alleviation and so on. Housing is a prominent issue in human rights literature. It does not mean simply having a roof over one's head, but is framed in terms of access to, and participation in the community. Central to this right is the obligation of States to provide a range of 'in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community' (CRPD, article 19). This provision speaks to the right to habilitation and rehabilitation, whereby health services should be directed towards enabling people with disabilities 'to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life' (CRPD, article 26(1)).

A. When Treatment Becomes Ill-Treatment

Despite the normative clarity of the CRPD on the right to live in the community, some people with disabilities are forced to live in institutions, often for their entire lives, without their consent, and they are unable to challenge the underlying decision. These institutions are often healthcare establishments such as psychiatric hospitals, or social care institutions where people are forced to take psychiatric medication,[638] while being deprived of basic human needs, such as food, heating, water and sanitation (*Nencheva and others v Bulgaria* [2013] appl. no. 48609/06). It should be added that

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[636] 'The Committee encourages States parties to comprehensively apply the Health Principles of Housing prepared by WHO which view housing as the environmental factor most frequently associated with conditions for disease in epidemiological analyses; i.e. inadequate and deficient housing and living conditions are invariably associated with higher mortality and morbidity rates' (Committee on Economic, Social and Cultural Rights 1991, paragraph 8(d)).

[637] See, for example, Tually, Beer & McLoughlin 2011; CRESA, Public Policy & Research & Auckland Disability Resource Centre 2007.

[638] See many of the reports of the European Committee for the Prevention of Torture, Inhuman and Degrading Treatment and Punishment 2013.

this also raises legal and ethical dilemmas for the responsible healthcare providers: what to do when laws prescribe forms of forced treatment, ignoring the consent of the patient, while the conditions under which the patient will be treated amount to inhuman and degrading treatment.

Prior to the adoption of the CRPD, international law on psychiatric treatment was mainly extrapolated from other human rights treaties, such as a 1994 General Comment by the UN Committee on Economic, Social and Cultural Rights [CESCR] on disability (General Comment No. 5). As progressive as this General Comment was in many respects, it is, in retrospect, disappointing that it did not address forced psychiatric treatment. Six years later, the same Committee published a General Comment on the right to health (General Comment No. 14 2000). This document did not examine mental health in any depth, stating that mental health treatment without consent is allowed on an ‘exceptional basis’, without explaining why it is allowed at all, or explaining this exceptional bases (CESCR 2000, paragraph 34). Both of these general comments referred to a non-binding document adopted in 1991 by the UN General Assembly called the ‘Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Healthcare’ [MI Principles]. The MI Principles set ‘the right to be treated in the least restrictive environment, with the least restrictive or intrusive treatment appropriate to the patient’s health needs and the need to protect the physical safety of others’ (principle 9(1)). Also, ‘[n]o treatment shall be given to a patient without his or her informed consent’ (MI Principles, principle 11). The MI Principles then clearly set out five exceptions to this principle, including a scenario where a doctor thinks that that it is ‘urgently necessary in order to prevent immediate or imminent harm to the patient or to other persons’ (principle 11(8)). This watering down of normative standards led Paul Hunt, the then UN Special Rapporteur on the Right to Health, to observe in his 2005 report on disability and the right to health that while informed consent is necessary to provide treatment and ‘is consistent with fundamental tenets of international human rights law’, the combined effect of the ‘extensive exceptions and qualifications’ ‘tends to render the right of informed consent almost meaningless’ (UN Economic and Social Council 2005, paragraph 88).

Paul Hunt's report marked a turn for the mainstream human rights movement, because it pointed out the discriminatory element of diluted standards for treatment concerning mental health. Reiterating that the right to health is subject to progressive realisation (CRPD, article 4(2)), the Special Rapporteur highlighted that 'the international right to health also imposes some obligations of immediate effect' (UN Economic and Social Council 2005, paragraph 34), which includes freedom from non-consensual medical treatment, or as the CRPD puts it, the obligation of States to ensure that medical professionals provide healthcare to people with disabilities on the basis of free and informed consent (CRPD, article 25(d)).

Though clear on informed consent, the CRPD is silent on forced treatment.[639] That is to say, the Convention neither explicitly permits force when someone lacks the capacity to consent to treatment (as most mental health laws around the world currently around permit force), nor does it ban forced psychiatric treatment (Dhanda 2008). The Convention does not define 'informed consent' nor does it offer guidance as to the actions medical professionals should take when, for whatever reason, it is not possible to seek patient consent.

Despite this, others have stepped up to the challenge of filling the void with human rights content. In 2008, Manfred Nowak, the (then) UN Special Rapporteur on Torture, issued a report on torture and disability in which he notes that people with disabilities are subject to treatment without their consent (UN General Assembly 2008). He highlights in particular the effects of 'electroshock treatment and mind-altering drugs including neuroleptics' (UN General Assembly 2008, paragraph 40). Noting that these treatments are often justified against people with disabilities when they would be unacceptable if performed on others, Nowak calls for a review of the anti-torture framework in relation to disability (UN General Assembly 2008, paragraph 40). In 2013, Nowak's successor as special rapporteur, Juan Méndez, presented his report to the UN Human Rights Council on torture in healthcare (UN General Assembly 2013). He goes further than Nowak in observing how ill-treatment is justified by rhetorical devices such as 'best

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[639] See the 'Special Issue: Torture Prevention and Disability' in the *International Journal of Human Rights* (2012).

interests' which are masked as 'good intentions' of medical professionals (UN General Assembly 2013). Méndez's argues:

> *[States should] impose an absolute ban on all forced and non-consensual medical interventions against persons with disabilities, including the non-consensual administration of psychosurgery, electroshock and mind-altering drugs, for both long- and short- term application. The obligation to end forced psychiatric interventions based on grounds of disability is of immediate application and scarce financial resources cannot justify postponement of its implementation. (UN General Assembly 2013, paragraph 89(b))*

Méndez notes that States should boost community-based mental health which meets the needs of people with disabilities and which respects 'autonomy, choices, dignity and privacy.' He advises States to revise laws 'that allow detention on mental health grounds or in mental health facilities and any coercive interventions or treatments in the mental health setting without the free and informed consent by the person concerned' (UN General Assembly 2013, paragraph 89(d)). Moreover, he cites Anand Grover's 2009 report, the 'Right of everyone to the enjoyment of the highest attainable standard of physical and mental health', which discusses various international and domestic laws that enshrine informed consent as a fundamental principle, before observing that it is, 'frequently compromised in the health-care setting' (UN General Assembly 2013, paragraph 29).

The CRPD Committee shares this view in its 'Draft General Comment on Article 12' (2013b). The Committee reiterates the wording of article 25 on the right to health, and points out that:

> *[States are obliged] to require all health and medical professionals (including psychiatric professionals) to obtain free and informed consent from persons with disabilities. In conjunction with the right to legal capacity on an equal basis with others, this also obligates States to refrain from permitting substitute decision-makers to provide consent on behalf of persons with disabilities. (2013b, paragraph 37)*

It makes a further point about patient-doctor communications by suggesting that ‘health and medical personnel should ensure the use of appropriate consultation skills that directly engage the person with disabilities and ensure, to the best of their abilities, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities’ (CRPD Committee 2013b, paragraph 37).

Thus the CRPD outlines some specific operational standards for governments which should be translated into law, and standards for medical professionals as well as others assisting people with disabilities.

B. A Framework for Policy Discussion

The CRPD offers no guidance as to the actions medical professionals must take beyond a non-discrimination approach. It does, however, make a process point about how these issues are to be discussed and decided upon. Article 4(3) of the CRPD imposes on States a general obligation when laws and policies are developed and implemented. In other decision-making processes relating to persons with disabilities, governments need to ‘closely consult with and actively involve persons with disabilities, including children with disabilities through their representative organizations’ (Mental Disability Advocacy Center 2011, p. 19).

7. Conclusions

Medical ethics is traditionally centered on the principles of autonomy, beneficence, non-maleficence and justice. Doctors and other medical professionals ultimately decide how these principles are to be applied in individual cases. These foundational principles are also at the heart of medical law, even though other branches of law also influence medical law, including human rights law. This has, or at least should have, an impact on the way these principles are to be applied in cases of persons with disabilities, how they regulates the behavior of healthcare providers and how they bestow rights on healthcare recipients.

These observations do not deny the fact that many medical professionals care very deeply for their patients, have a profoundly humane approach, and deliver excellent quality care and treatment for people with disabilities. At the same time, it is uncontroversial to state that the human rights of people with disabilities have frequently been disregarded or devalued within the healthcare system. This can be explained by a lack of understanding and cooperation between the human rights and healthcare domains; by discriminatory laws which result in poor practices; and by a lack of inclusion of people with disability in public health and other development programmes.

The fact that people with disabilities have been treated differently for many decades by healthcare laws and medical professionals does not necessarily constitute a form of disability discrimination. Differential treatment can be a good thing, and the CRPD encourages this by obliging States and medical professionals to adjust their practices when they are seen as 'reasonable accommodations' benefitting people with disabilities. However, differential treatment can result in negative consequences, constituting unlawful, direct or indirect discrimination. The advent of the CRPD in 2006 provides an opportunity for people occupying various domains in society, notably in the field of healthcare, to critically assess their engagement with people with disabilities. This is exactly what the current and previous UN Special Rapporteurs on Torture have tried to do by reassessing the international torture framework. They together pointed out how what the international human rights mainstream almost unanimously viewed as acting in someone's best interests, can be challenged as an invasion of autonomy, trivializing the notion of informed consent, and perpetuating inhumane and degrading treatment that sometimes constitutes torture.

A shift in the conceptualization of healthcare for people with disabilities through a human rights lens should be a clarion call to medical professionals, and those who teach and train medical law and ethics, to alter care practices in the name of justice, beneficence and non-maleficence. Such a shift also requires the political will to address some very challenging dilemmas about how to move from a model of proxy consent to one which truly respects the will and preferences of the person with disabilities when accessing healthcare;

how to ensure that support in decision making is not usurped by substitution; how to prevent supporters exercising undue influence; and how to ensure a person with disabilities does not lose out on their right to health because of the (in)actions of their support network.

Medical professionals must abide by their national laws. They are in a difficult position when their national law does not comply with international human rights standards. If this is the case, medical professionals can capitalize on the power and authority of their professional organizations and liaise with patients' rights organizations about how to instigate legal reform that better meets the healthcare needs of people with disabilities – their patients.

It is also incumbent on medical professionals to become acquainted with the current international human rights standards in more depth than is possible to include in this chapter. Training should feature in medical school curricula and continue post-qualification (Iezzoni & Long-Bellil 2012, p. 137). This coincides with recommendations made by the CRPD Committee that training and legislative reforms should be done 'in consultation and cooperation with persons with disabilities and their representative organizations, at the national, regional and local levels for all actors.'[640]

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[640] See the CRPD Committee's concluding observations with respect to Hungary (2012b, paragraph 26). The same recommendations were made by the CRPD Committee for Spain (2011a, paragraph 34); Austria (2013c, paragraph 28); and Tunisia, where the Committee also stated that training should be provided to 'relevant public officials and other stakeholders' (2011b, paragraph 23).

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Chapter 8: Disability, torture and ill-treatment: taking stock and ending abuses

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1. Introduction

This special issue looks at the nexus of torture prevention and disability. While Volume 16, Issue 5 of this Journal focused on 'Torture and the quest for justice' focused on torture and the development of international law, this Special Issue looks at how law can be used to prevent future instances of torture, cruel, inhuman or degrading treatment or punishment. It focuses on a group which has been neglected by torture prevention actors, namely children and adults with psycho-social (mental health) disabilities or intellectual disabilities in places of detention.

This introduction briefly outlines the history of torturerevention and the development of international law focused on people with disabilities. The paper then looks at the segregation and human suffering of detainees with disabilities, the failure of monitoring mechanisms to integrate such places within their regular scheme of visits, as well as impunity and barriers to access to justice which flow from incarceration. The paper then outlines the aims of this Special Issue and provides an overview of the five papers which follow. Lastly, the paper looks ahead and makes four inter-related recommendations to international, regional and national inspectorate bodies, recommendations intended to help increase their effectiveness with regards to preventing torture and ill-treatment against people with disabilities.

2. Torture prevention

Freedom from torture, cruel, inhuman and degrading treatment and punishment has been recognized as an absolute, non-derogable right since the wake of the global human rights movement in the 1950s. There exist today several bodies at regional and country-level, European and global-levels which seek to prevent or remedy torture and other forms of ill-treatment. The UN Committee against Torture sets standards, reviews State compliance and adjudicates as a quasi-judicial body when allegations of torture arise.[641] Others, such the UN Sub-Committee for the Prevention of Torture, are mandated to ensure prevention of torture and ill-treatment by means of periodic visits to "to any place [...] where persons are or may be deprived of their liberty".[642] The logic of this is that detainees are exposed to a heightened risk of abuse,[643] and that such ill-treatment often takes place with impunity and remains unaddressed.[644] Yet, despite the combined efforts of these bodies, non-governmental organisations, and public campaigns, human rights in places of detention all around the world still continue to be violated.

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[641] The UN Committee against Torture was established by the UN Convention against Torture in 1984. See Art. 17-24 of the Convention.

[642] UN Convention against Torture, Art. 4(1).

[643] 'Preventing Torture: An Operational Guide for National Human Rights Institutions', Office of the High Commissioner for Human Rights. Sydney, May 2010. p.4.

[644] Ibid., pp.6-7. In cases where the judiciary lacks independence, complaint mechanisms are ineffective, there is no access to free legal aid and legal assistance for detainees, allegations of torture and ill-treatment are not investigated, and those who breach the law are not punished, there is a heightened risk of impunity.

The Council of Europe's 1950 Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) and United Nations' 1966 International Covenant on Civil and Political Rights (ICCPR), both human rights treaties, include an unconditional prohibition of all forms of torture, cruel and inhuman or degrading treatment or punishment. The mechanisms established by these treaties, however, have proved to lack sufficient effectiveness in preventing torture. The 1984 Convention against Torture (CAT) and the establishment of the Committee against Torture marked the next step of global efforts to prevent and prohibit such abuses and end impunity. Despite this, torture and ill-treatment continued to be carried out. Particularly worrisome was the situation of people who found themselves in situations of vulnerability, including in places of detention. To strengthen efforts in protecting detainees from torture and ill-treatment the Council of Europe established its own torture prevention body in 1989 – the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT). This body's mandate is to carrying out monitoring visits to all places of detention in Council of Europe Member States.[645] The UN established its own monitoring mechanism after the adoption of the Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT) in 2002, which established the Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (SPT). This global body comprised now of 25 members, was established in 2007. Under the OPCAT States Parties must establish National Preventive Mechanisms (NPMs), which are bodies independent from the State whose mandate it is to carry out preventive monitoring visits to places of detention.[646]

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[645] European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), established by the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment. Strasbourg, 26 November 1987.

[646] Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT). New York, 18 December 2002.

3. A disability-specific focus in international law

The UN Convention on the Rights of Persons with Disabilities (CRPD) was adopted in 2006.[647] The treaty sets out basic international human rights norms specifically for children and adults with disabilities, including in the area of torture and ill-treatment prevention and in places of deprivation of liberty. The CRPD gathers in a comprehensive manner rights for people with disabilities, a term which is defined[648] to include people with "mental" disabilities ("psycho-social disabilities" is the term used by the CRPD's treaty bodies and which we use in this paper)[649] and people with "intellectual disabilities".[650]

The preamble of the CRPD refers to the international human rights infrastructure, including the ICCPR the CAT,[651] explaining that, "despite these various instruments and undertakings, persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world".[652] To overcome these barriers the CRPD articulates a philosophy which is set out in its overarching "Principles", which include respecting dignity and autonomy and

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[647] UN Convention on the Rights of Persons with Disabilities (CRPD), New York, 13 December, 2006.

[648] CRPD, Art. 2 says that "[p]ersons 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."

[649] People with psycho-social disabilities are those who experience mental health issues, and/or who identify as "mental health consumers", "mental health service users", "psychiatric survivors", or "mad". These are not mutually exclusive groups.

[650] People with intellectual disabilities generally have a long-term condition that is present at birth or before the age of eighteen. People have greater difficulty than others with intellectual and adaptive functioning as well as carrying out everyday activities such as communicating and interacting with others, managing money, doing household activities and attending to personal care. While the term "intellectual disability" is technically distinct from other "developmental disabilities" these terms are often used interchangeably.

[651] CRPD, Preamble para. (d).

[652] CRPD, Preamble para. (k).

independence,[653] non-discrimination,[654] and the ambition of "[f]ull and effective participation and inclusion in society".[655]

In 2008 the CRPD entered into force and Manfred Nowak, the (then) Special Rapporteur on Torture, issued a thematic report on "Protecting Persons with Disabilities from Torture". He suggested that the entry into force of the CRPD provided, "a timely opportunity to review the anti-torture framework in relation to persons with disabilities."[656] He did so knowing that there was much scope in the CRPD for people working in the torture prevention field, and that discussions needed to take place at that time to ensure a synthesis of standards, and coordinated actions. His observations remain true today.

The provisions in the CRPD which are relevant for torture prevention include the following. Article 15 repeats the classic prohibition of torture, cruel, inhuman or degrading treatment or punishment, and adds a prohibition on medical and scientific experimentation without consent. The second paragraph of Article 15 focuses on prevention, obliging States to take, "all effective legislative, administrative, judicial or other measures" to prevent torture and other forms of ill-treatment. This is a similar provision to that set out in the UN Convention against Torture which also places an obligation on States to prevent torture and ill-treatment, yet falls short of fleshing out operational requirements.[657] Article 16 of the CRPD remedies this shortcoming by setting out in detail the right to be free from exploitation, violence, and abuse. After stating the prohibition, it establishes a State obligation to take, "all appropriate measures" to prevent such abuse, measures which include providing information to people with disabilities, families and caregivers on how to "avoid, recognize and report" such abuse.[658]

Article 16 of the CRPD goes on to include a very far reaching State obligation, that is to ensure that all facilities and programmes designed to serve

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[653] CRPD, Art. 3(a).

[654] CRPD, Art. 3(d).

[655] CRPD, Art. 3(c).

[656] Manfred Nowak (July 2008), *Protecting Persons with Disabilities from Torture*, p. 9, para. 41.

[657] UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. New York, 10 December 1984, Article 2(1).

[658] CRPD, Art. 16(2).

disabilities are "effectively monitored by independent authorities" (a provision which is broader than OPCAT's focus on places of detention).[659] It also obliges States to ensure access to "recovery, rehabilitation and reintegration" of disabled victims of exploitation, violence or abuse.[660] Lastly, Article 16 calls on States to appropriately investigate and prosecute allegations of exploitation, violence and abuse,[661] ensuring justice systems which are accessible to people with disabilities and which provide appropriate adjustments so as to neutralize the effect of someone's impairment or disability.[662]

These innovative provisions are further bolstered by a new provision in international law, one of respect for "mental and physical integrity on an equal basis with others", which is set out in Article 17 of the CRPD. In its concluding observations whereby it examines a particular State's compliance with the CRPD, its treaty body, the Committee on the Rights of Persons with Disabilities (CRPD Committee), has begun to tease out the meaning of Articles 15 and 17. It has noted that Article 17 violations include forced treatment and surgery of people with disabilities,[663] as well as forced sterilisation of women with disabilities.[664] The CRPD Committee has also held that torture and ill-treatment may include, "the use of continuous forcible medication, including neuroleptics, and poor material conditions in psychiatric institutions [...] where some persons have been institutionalized for more than ten years without appropriate rehabilitation services".[665]

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[659] CRPD, Art. 16(3).

[660] CRPD. Art. 16(4). See also CRPD Art. 26 which sets out obligations to provide people with disabilities to services they may require "to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life".

[661] CRPD, Art. 16(5).

[662] CRPD, Art. 13.

[663] UN Committee on the Rights of Persons with Disabilities, Concluding Observations of the Committee: Tunisia, 13 May 2011, CRPD/C/TUN/CO/1, paras. 28-29,

[664] UN Committee on the Rights of Persons with Disabilities, Concluding Observations of the Committee: Spain, 19 October 2011, CRPD/C/ESP/CO/1, paras. 37-38.

[665] UN Committee on the Rights of Persons with Disabilities, Concluding Observations of the Committee: Peru, 9 May 2012, CRPD/C/PER/CO/1, paras. 30-31

4. From detention to the community

Of particular significance to our examination of disability and detention is that the CRPD provides that the existence of a disability "shall in no case justify a deprivation of liberty".[666] The CRPD Committee has hinted as to what this means, by stating that depriving someone of their liberty because of their actual or perceived disabilities is against the Convention.[667] Deprivations of liberty can be short-term and it can happen in psychiatric wards of general hospitals or emergency rooms; and long-term when a person is placed in residential care. There are ample examples documented of people living their whole lives in such institutions.[668] Such institutions are often in remote areas, segregated from society, where ill-treatment takes place with impunity and without any public oversight.

Whenever a person with a disability is detained, says the CRPD, the relevant state has an obligation to provide "reasonable accommodation",[669] a construct which is defined as any "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". [670] The Convention makes clear that a denying reasonable accommodation constitutes disability-based discrimination, which is prohibited.[671]

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[666] CRPD, Art. 14(1)(b) which states that persons with disabilities, "[a]re not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty."

[667] CRPD Committee's Concluding Observations on Spain (op cit), paras. 35-36.; Concluding Observations on Tunisa (op cit), paras. 24-25.; Concluding Observations on Peru (op cit), paras. 28-29.

[668] See "Out of Sight: Human Rights in Psychiatric Hospitals and Social Care Institutions in Croatia", Mental Disability Advocacy Center, 2011, in which MDAC documented that lifelong institutionalization is often the norm in Croatian facilities for people with disabilities. See also monitoring reports of the Hungarian Civil Liberties Union which reveal the same pattern in social care institutions in the Hungarian county of Tolna. 2010-2012.

[669] CRPD, Art. 13.

[670] CRPD, Art. 2.

[671] CRPD, Art. 5.

The Optional Protocol to the UN Convention against Torture (OPCAT) was conceived because places of detention are incubators of torture and ill-treatment. It is hardly surprising that the disability movement has campaigned for many years that disability institutions should be done away with. The independent living movement has consistently called for a social policy of de-institutionalisation and the establishment of services in community-based settings,[672] not merely because of the horrors of what happens inside institutions, but how institutions by their very nature segregate people from our – their – communities.

It is only within the last decade that the mainstream human rights community has embraced the quite obvious notion that desegregation applies in the field of disability on an equal basis to other domains such as race and ethnicity. Article 19 of the CRPD solidifies this concept, providing for the "the equal right of all persons with disabilities to live in the community, with choices equal to others", in order to "prevent segregation from the community".[673] Importantly, there is nothing in the Convention to suggest that the right to live in the community is dependent on the nature of severity of a person's impairment; indeed, the Convention's preamble emphasises the universality of the rights set out in the Convention, specifying the need for rights to be implemented for those "who require more intensive support".[674]

In 2009 and as Commissioner for Human Rights of the Council of Europe, Thomas Hammarberg was one of the first human rights officials to point out that the CRPD, "questions the very existence of these large institutions".[675] Thus community living, with appropriate support, should no longer be described (as the CPT does) merely as "a favourable development", but rather, as an human right established under binding international law.

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[672] There is a rich literature on this. Se, for example Jerry Alan Winter, "The Development of the Disability Rights Movement as a Social Problem Solver", *Disability Studies Quarterly,* 23(1)(2003): 33-61.

[673] CPRD, Art. 19(b).

[674] CRPD Preamble para. (j).

[675] Thomas Hammarberg, "Inhuman treatment of persons with disabilities in institutions", October 2010. See also his extended Issue Paper, "The rights of people with disabilities to live independently and be included in the community", March 2012, CommDH/IssuePaper(2012)3.

In many jurisdictions, a person can be placed in a psychiatric hospital[676] or social care institution[677] because someone else - their guardian – has taken the decision to put them there. Guardianship is a system whereby an expert deems an individual to lack the competence/capacity to make decisions (in the case of total guardianship) or a specific decision (in the case of partial guardianship) and a substitute decision maker is appointed to act on the adult's behalf. Guardianship systems are intended to protect the interests of the person under guardianship and in some jurisdictions the guardian is obliged to respect the wishes of the person and consult them when making decisions. However, the removal of legal capacity deprives people of aspects of their personhood, rendering them prohibited from exercising some fundamental rights, such as the right to work, to marry, to bring-up children, to control their own money or property interests, to associate and join political parties and NGOs, and to make independent decisions about where and with whom they want to live. Even the right to vote and stand for election – emblematic rights of humanity for which people have fought and died – are denied.

Article 12 of the CRPD establishes that everyone is entitled to legal capacity on an equal basis with others, and that States should ensure access to the supports a person may need in exercising this right. Under guardianship people have little access to systems of justice. In many cases complaints systems are non-existent as are lay advocacy services, domestic monitoring bodies do not visit places of disability detention, and there is no state-funded legal advice, assistance and representation available for people under guardianship to challenge their status, and regain their legal capacity. Article 13 of the CRPD sets out access to justice rights including a state obligation to

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[676] See, for example, *Shtukaturov v. Russia*, judgment of the European Court of Human Rights, Application No. 44009/05, 27 March 2008.

[677] See for example, *Stanev v. Bulgaria*, judgment of the Grand Chamber of the European Court of Human Rights, 17 January 2012, Application no. 36760/06, and *DD v. Lithuania*, judgment of the European Court of Human Rights, 14 February 2012, Application No. 13469/06.

ensure their effective role as direct and indirect participants in all legal proceedings.[678]

The social and political invisibility of people detained inside disability institutions results in a heightened risk of ill-treatment taking place. Given the fact that in many jurisdictions these institutions are not – or inadequately or infrequently – monitored, these violations take place with impunity. Silence perpetuates violence.

5. Why monitoring matters

This section explores the pervasive invisibility of persons with disabilities within human rights bodies and monitoring mechanisms in particular. In pitching our critique at such bodies our wish and intention is that they urgently take measures to change tack. The section starts by giving a some examples from our organisations and other bodies to illustrate the human suffering which flows from segregation. Evidence will be provided about how persons with disabilities have been left off the monitoring radar, including by the global leader UN Subcommittee on Prevention of Torture. The section ends by pointing out how the lack of monitoring has contributed to human rights abuses being carried out with impunity in particular when the access to justice of persons with disabilities in places of deprivation of liberty is rendered virtually impossible.

A. Segregation and human suffering

There are no global figures about people with disabilities in institutions, but one study in 2007 estimated that there were 1.2 million children and adults in

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[678] Article 14(2) states that States need to “ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation”.

disability institutions in the European Union.[679] The figure included Turkey (which is not a member of the EU) but not Germany or Greece (for which no data were available: that governments do not count people in such institutions is itself revealing). Manfred Nowak's 2008 report examined the nexus between torture and disability.[680] His is one of the first reports to recognise that people with disabilities in psychiatric and social care institutions are subjected to torture and ill-treatment due to poor living conditions, severe and prolonged forms of mechanical, chemical, and physical restraints, seclusion and solitary confinement, forced medical and psychiatric interventions, as well as the denial of reasonable accommodations (as outlined above and defined in Article 2 of the CRPD). Of critical importance to the development of global understanding of these issues, Nowak pointed out that involuntary confinement and treatment can themselves constitute torture.[681]

Abuses happen everywhere. They often stem from an institutional culture rather than a lack of available resources. Sometimes these abuses are revealed by investigative journalism: in June 2011 BBC reporters uncovered serious physical abuse in a privately-owned social care institution for adults with intellectual disabilities in Bristol, the United Kingdom.[682] Evidently, the residents had been slapped, beaten, pinned down, left outside in the cold, put in the shower with clothes on, and dragged out of their beds. Sometimes abuses are highlighted by UN treaty bodies – but only when NGOs bring evidence before them and invite them to make findings. In 2012 the Committee against Torture (CAT) documented the widespread use of cage beds in the Czech Republic,[683] and in 2011 with respect to Ghana,[684] found that the main psychiatric hospital was severely overcrowded, lacked appropriate treatment and had poor material and hygienic conditions. The CAT also noted

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[679] Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007) "Deinstitutionalisation and community living – outcomes and costs: report of a European Study", Canterbury: Tizard Centre, University of Kent.

[680] Manfred Nowak, "Protecting Persons with Disabilities from Torture", Office of the UN High Commissioner for Human Rights, July 2008, para. 41.

[681] Manfred Nowak (op cit), para. 65.

[682] "Government condemns 'shocking' Winterbourne View abuse". BBC. 1 June 2011. http://www.bbc.co.uk/news/uk-13617196.

[683] UN Committee against Torture, Concluding Observations of the Committee: Czech Republic, 14 May 2012, CAT/C/CZE/CO/4-5 para. 21.

[684] UN Committee against Torture, Concluding Observations of the Committee: Ghana, 15 June 2011, CAT/C/GHA/CO/1, para. 17.

that in lack of alternatives in the community, and that residents were kept in the hospital long after they could have been discharged had these community alternatives existed. As well as investigative journalism and treaty bodies, mechanisms which inspect institutions can also uncover abuses. During its 2009 visit to Ukraine, the CPT visited a psychiatric hospital and found that that staff verbally and physically abused patients.[685]

Non-governmental organisations, however precarious their existence, play a valuable role in scratching beneath the State surface and holding governments to account for their international human rights commitments. Access to justice (a topic which is addressed below) is often compromised for people in institutions and it is only when NGOs support individuals in taking their cases to court that the judiciary has an opportunity to comment on allegations of ill-treatment. Of considerable significance, in February 2012 the Grand Chamber of the European Court of Human Rights held unanimously that the applicant in the case of *Stanev v. Bulgaria* had been subjected to degrading treatment in violation of Article 3 of the ECHR (which sets out the prohibition of torture, inhuman and degrading treatment or punishment) by being forced to live for more than seven years in unsanitary and unlivable conditions, and that domestic law did not provide him any remedy for such violations.[686] This was the first case in which the Court has found a violation of Article 3 in a social care setting.

Mr Stanev was lucky. The European Committee for the Prevention of Torture (CPT) carried out a periodic visit to Bulgaria in December 2003 and visited the institution where Mr Stanev was being held: likely a minor curiosity for Mr Stanev at the time, but a major blessing for his international litigation. The CPT found that the indoor temperature at midday on a December day was 12 degrees Celsius.[687] The residents clothes were bundled together and handed out

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[685] European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, Preliminary Observations: Ukraine, 23 November 2011, CPT/INF/2011.

[686] *Stanev v Bulgaria*, op cit.

[687] Findings on Pastra social care home for "adults with mental disorders", from "Report to the Bulgarian Government on the visit to Bulgaria carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 16 to 22 December 2003", CPT/Inf (2004) 23, 24 June 2004 (hereinafter "CPT report"), para. 26. In Block 3, where Mr Stanev was held, the CPT

randomly to the residents, a situation which the European Court found "was likely to arouse a feeling of inferiority in the residents".[688] The CPT found that residents had access to the bathroom once a week, and that which Mr Stanev had access was "rudimentary and dilapidated".[689] Mr Stanev's case is merely illustrative of abuses which take place in many jurisdictions, the difference being that most other cases do not find themselves before the European Court of Human Rights.[690]

The Mental Disability Advocacy Center supported Mr Stanev throughout his international litigation, and has been involved in this field since its inception in 2002. The organisation has been concerned how in many countries, children and adults are abandoned into institutions in the name of treatment and care, segregated from families, communities, and chances to become active participants of society. As an illustration, again in Bulgaria, a reported 238 children with disabilities died in State-run institutions in the past ten years as a result of neglect, starvation, poor hygiene, and violence.[691] Deaths are not so prevalent in other countries, but the funding structure makes institutionalisation and ill-treatment more likely. In Hungary, for example, the funding available for a parent with disabilities makes often economically non-viable for the family to keep the child: instead the child is placed into an institution where the accumulated costs are far greater than would be necessary to keep the family intact.

As well as its case-work and policy analysis, MDAC staff have conducted monitoring in various countries in the Council of Europe region. While the conditions in some institutions are still alarming, the routine stripping of fundamental human rights is also of grave concern. In Moldova MDAC has found instances of conditions amounting to degrading treatment, such as a

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found "somewhat better heating", although "residents indicated that it had been on all the time since the delegation's arrival." This tells us more about the institution's management cynical attitude to human rights inspectors than it does about the extra pitiful degrees of warmth.

[688] *Stanev* judgment para. 209.

[689] CPT Report on Bulgaria, para. 27.

[690] For an analysis of this case, see Oliver Lewis, "*Stanev v. Bulgaria*: On the Pathway to Freedom", *Human Rights Brief*, American University Washington College of Law, Vol. 19, Winter 2012.

[691] "Neglected, Abused, and Starved to Death", Bulgarian Helsinki Committee, Sofia, 20 September 2010.

lack of toilet paper, sanitary pads, and tampons on the women's wards in a psychiatric institution where women are (on any objective criteria) needlessly forced to spend many months – and in some cases years – locked up against their will. In a number of psychiatric facilities in that country the use of restraint is common. Residents are injected with sedation against their will, restrained with bed sheets, tied to their beds, forced to spend significant periods in isolation rooms, effectively in solitary confinement.

In a long-term institution for people with intellectual disabilities in Kosovo, MDAC has found appalling conditions in the residents' living area. There, residents had no personal belongings. They had no bed sheets, no towels, no toothbrushes, and no soap. Their rooms often had no doors and no curtains. In Croatia, female residents in the institutions visited reported undergoing forcible abortions.[692] MDAC has documented how physical restraints are used arbitrarily. Such restraints include straps (usually leather or canvas) that are fastened with buckles or magnetic locks that cannot be undone without a key, thereby attaching patients to beds. Limbs are restrained by using straps on the shoulders, waist, thighs, hands and feet. In one of the facilities monitored, staff told MDAC that patients were restrained with belts for an average of, "one day or less". The staff member went on to add, "but in exceptional circumstances for two to three days".

B. Off the monitoring radar

In the past few years torture has been at the forefront of global concern, thanks in part to torture being carried out after the terrorist events in the USA on 11 September 2001 as part of the secret rendition program of the US government and the use of unlawful detention and ill-treatment in Guantanamo Bay.[693] This has been uncovered and debated by the media, human rights organisations, national parliaments and inquiries, and the

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[692] "Out of Sight: Human Rights in Psychiatric Hospitals and Social Care Institutions in Croatia", Mental Disability Advocacy Center, 2011.

[693] See for example, Marjorie Cohn, "Introduction to the United States of Torture: Interrogation, Incarceration, and Abuse", Thomas Jefferson School of Law, 3 February, 2011; Richard Jacson, "Language, policy and the construction of a torture culture in the war on terrorism", 2007, *Review of International Studies*, 33, pp. 353-371.

international community. A focus on these scandals has trickled down into the operations of the small and insular UN torture prevention community, which since its beginnings in 2007 has focused on abuses carried out by police, security forces and prison officers in traditional places of detention.

Any piece of work needs to start somewhere. Priorities need to be set. One advantage of starting with police stations and prisons is that these abuses have wide public resonance. Police stations are drilled in our consciousness from a young age via crime programmes on TV and detective novels. The torture prevention community largely emanates form the prison world: it is inevitable that people stay within their comfort zones. Each decision has its down sides, and a focus on prison torture is ill-treatment which occurs in places other than police lock-ups and prisons have been neglected.

One of the “groups” which has been neglected are those who are detained – de jure or de facto – in psychiatric hospitals, psychiatric wards of general hospitals, social care institutions, elderly people’s homes, group homes[694] and nursing homes. Inside these facilities people labeled with psycho-social disabilities[695], intellectual disabilities[696], autism, brain injury and dementias are detained via formal mental health legislation or through a private arrangement by the person’s relative or guardian and the institution or local municipality – as happened to Mr Stanev.

People with disabilities and in particular those with labels of psycho-social disabilities also make up a considerable subgroup of the general prison population, and are often left without any reasonable accommodations and are exposed to human rights violations in the criminal justice system. A 2010 study about the prison population in New South Wales, Australia, for

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[694] Group homes are small, residential facilities located within a community and designed to serve children or adults with chronic disabilities.

[695] People with psycho-social disabilities are those who experience mental health issues, and/or who identify as “mental health consumers”, “mental health service users”, “psychiatric survivors”, or “mad”. These are not mutually exclusive groups.

[696] People with intellectual disabilities generally have a long-term condition that is present at birth or before the age of eighteen. People have greater difficulty than others with intellectual and adaptive functioning as well as carrying out everyday activities such as communicating and interacting with others, managing money, doing household activities and attending to personal care. While the term “intellectual disability” is technically distinct from other “developmental disabilities” these terms are often used interchangeably.

example, has found that 75 per cent of prisoners had mental health problems.[697] Another study from 2007 revealed that 9 out of 10 prisoners in England and Wales met their criteria for at least one "mental disorder".[698]

There is thus a growing body of research evidence of the scale and nature of suffering inside disability institutions, as well as advocacy calling for an end to congregated care itself. With this backdrop the SPT has noted that "an essential element for preventing torture and ill-treatment is the existence of a fully developed system of independent inspection visits to all places where people may be deprived of their liberty".[699] The SPT has not followed its own advice.

Between its first visit in October 2007 and May 2011, the SPT visited a total of 227 places of detention during 13 missions to 12 States. Of those only three were psychiatric facilities[700] and one was to a hospital.[701] This hospital may have a psychiatric ward which the SPT visited, but due to the confidentiality of the report and the vagueness of information published by the SPT, this cannot be confirmed. It is only since May 2011 that the SPT has paid more attention to visiting such facilities.[702] Of considerable alarm, is that SPT has not visited a social care institution in the course of six-year existence.

The tide seems to be turning, if slowly. In its Fifth Annual Report the SPT states that it will visit more facilities where persons with disabilities may be deprived of their liberty.[703] It is also promising that the SPT held thematic

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[697] Leila Kavanagh, Donald Rowe, Jolyn Hersch, Kylie J. Barnett, Robert Reznik, "Neurocognitive deficits and psychiatric disorders in a NSW prison population", p. 1. *International Journal of Law and Psychiatry*, 33 (2010) 20-26

[698] See for instance "Prison psychiatry: adult prisons in England and Wales" *Royal College of Psychiatrists*, College Report CR141, February 2007, p. 15.

[699] See for instance the SPT's 2010 report on Mexico, following its visit in September 2008. UN Subcommittee on Prevention of Torture, Report on Visit: Mexico, 31 May 2010, CAT/OP/MEX/1, para. 12.

[700] The SPT visited two psychiatric hospitals in Mexico between 27 August- 12 September 2008 and one in Paraguay between 10-16 March 2009.

[701] The SPT visited Liberia between 6 -13 December 2010.

[702] In Brazil (mission 19-30 September 2011) the SPT visited one psychiatric hospital, and in Argentina (mission 18-27 April 2012) it visited four psychiatric facilities. The SPT's press release about its visit to Mali mission (5-14 December 2011) stated that such facilities were visited, but numbers were not made public.

[703] UN Subcommittee on Prevention of Torture, Fifth Annual Report, 19 March 2012 CAT/C/48/3 .

discussions at its 16th Session and an internal training at its 17th Session with the involvement of international experts at the intersection of torture prevention and disability. Representatives of the OPCAT Contact Group – a cluster of international NGOs working to assist the SPT – were excluded from the consultation and training itself. The SPT is currently working on a thematic paper on mental health and detention to set its own standards in this area. The SPT is to be commended in taking these steps towards increasing its effectiveness in preventing torture against persons with disabilities, but the lack of transparency is of continuing concern.

Whatever the reason for the SPT's initial focus (and there is no publicly-available explanation), the consequences are unfortunate as they are serious. Whether intended or not, the message conceptually is clear: society values people in disability institutions less than those in prisons. More concretely, the SPT as the global torture prevention leader has silently said that national-level monitoring bodies need not monitor disability institutions. Had the SPT chosen to visit a more holistic set of detention facilities, the trickle-down effect to the national level would have stopped some human rights abuses against people with disabilities, as NPMs would have followed their global master, visited disability institutions in their countries and taken appropriate actions.

C. Impunity and access to justice

Human rights violations are often carried out with impunity in psychiatric and social care institutions, as they are elsewhere. An authoritative UN document has defined impunity as, "the impossibility, de jure or de facto, of bringing the perpetrators of violations to account – whether in criminal, civil, administrative or disciplinary proceedings – since they are not subject to any inquiry that might lead to their being accused, arrested, tried and, if found guilty, sentenced to appropriate penalties, and to making reparations to their victims".[704]

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[704] "Updated Set of principles for the protection and promotion of human rights through action to combat impunity", United Nations, E/CN.4/2005/102/Add.1, 8 February 2005.

The reasons why disability abuses take place with impunity include the following generalisations, to which there are of course exceptions. There is a lack of public monitoring of such institutions (as noted above); there are insufficiently effective complaints systems; access to free legal aid and assistance is absent; professional psychiatric and nursing bodies fail to discipline their members for breaches of law and professional ethics (in human rights language: perpetrators are not punished); and investigative journalists rarely attempt to uncover abuses in disability institutions.

Procedures for reviewing detention mandated by law (for example, under Article 5(4) of the European Convention on Human Rights) are often inaccessible for people in places of detention. As an illustration, the applicant in the *Shtukaturov v Russia* case before the European Court of Human Rights had his legal capacity removed, and as a result he was treated as a voluntary patient (his guardian had voluntarily placed him there, despite the fact that he made it abundantly clear that did not wish to be in the psychiatric hospital). The Strasbourg Court in this case held that even people whose legal capacity has been restricted, has the right to effectively pursue a legal review of the necessity of their detention.[705] Some jurisdictions have complaints mechanisms available for residents as well as patients' rights advocates and Ombudsperson's offices, which can carry out reactive investigations of abuses. In MDAC's experience (no comprehensive data is available) these complaints mechanisms exist in a few jurisdictions only, and such mechanisms have few resources to deal with complaints and to access institutions which may be located many hundreds of miles outside the capital city where the ombudsman office is located. While non-governmental organisations can be helpful in uncovering abuses and helping bring perpetrators to justice, their access to institutions is often at the mercy of the very ministry against which they are advocating.

In Hungary, for example, every resident in a disability institution has the right to launch a complaint to the director, the Ombudsperson's Office,[706] or a

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[705] *Shtukaurov v Russia*, op cit, para 125.

[706] 18. §, 2011./CXI. Ombudsperson Act. Törvény az alapvető jogok biztosáról.

Patient's Advocate.[707] MDAC has seen how in most institutions residents can complain by putting a complaint note into a message box, but the physical accessibility of the box is undermined by the people in the institutions being generally uninformed: uninformed of their rights, of how to make a complaint, and of what will happen if they do complain.[708] During monitoring visits to psychiatric institutions in Moldova, MDAC has spoken to patients who launched a complaint and as a result were forcibly injected with psychiatric medication as punishment.[709]

Prejudicial attitudes towards people with disabilities can also contribute to low reporting. The credibility of persons with psycho-social disabilities is often questioned by the assumption that they are crazy, dangerous or suspicious, while persons with intellectual disabilities are often viewed as children whose claims are highly questionable and can easily be dismissed. Complaints procedures can be particularly difficult to access for persons with multiple or severe disabilities, who might need assistance in communicating their assertions and who are therefore often in the most vulnerable positions. As noted above, Article 13 of the CRPD speaks to these instances, by setting out that people with disabilities should have effective access to justice as direct participants (which presumably includes being the complainant) in all legal proceedings, including at investigatory stages.

Without regular independent monitoring, as well as taking actions to combat impunity and ensuring effective access to justice, including complaints mechanisms for detainees/patients/residents, it is unlikely that abuses will be uncovered, perpetrators held to account, and ill-treatment prevented.

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[707] 94/E, F, K.; 99 § (14), Law no. 1993./III on Social Administration and Social Benefits, Chapter 'The rights of persons receiving personal care in social care home'. (Törvény a szociális igazgatásról és szociális ellátásokról, A személyes gondoskodást nyújtó szociális intézményekben ellátottak jogairól).

[708] Data from Hungarian Civil Liberties Union (TASZ), monitoring reports of social care institutions in Tolna county, 2010-2012.

[709] Unpublished monitoring report to Chisinau psychiatric hospital, December 2010, on file at MDAC.

6. The aims of this special issue

The aim of this Special Issue is to examine the interface between torture, detention and disability. It is our intention that the Special Edition will contribute to the dialogue within and outside the torture prevention community and the disabilities movement, by highlighting key issues and suggesting solutions to entrenched problems. MDAC's work on freedom from torture and ill-treatment aims to contribute to global efforts to prevent torture and ill-treatment against persons with disabilities and in the Council of Europe region in particular. Our work has strengthened the capacity of international, European, and various national inspectorates in an effort to mainstream disability in their work. In particular, we suggest to these bodies to engage with the standards of the UN Convention on the Rights of Persons with Disabilities (CRPD) and ensure that these standards are duly applied in torture prevention and remedying functions.

With the Human Rights Implementation Centre at the University of Bristol (UK) and the Centre for Disability Law and Policy at the National University of Ireland, in November 2011 the Mental Disability Advocacy Center organised and hosted a one-day roundtable discussion entitled, 'Evolving Standards in Preventing Torture and Ill-treatment against Persons with Disabilities', which was funded by Zennström Philanthropies. The seminar brought together experts working at the intersection of torture and ill-treatment prevention and disability.

The objectives of the event were to contribute to the cooperation among key stakeholders to further increase the effectiveness of their work, to highlight the importance of visiting psychiatric and social care institutions, and to discuss evolving standards of the Convention on the Rights of Persons with Disabilities (CRPD) that inspectorates should apply.

The participants of the event included members of the UN Subcommittee on Prevention of Torture (SPT), the European Committee for the Prevention of Torture (CPT) as well as the UN Committee on the Rights of Persons with Disabilities. Representatives of key civil society groups also attended, namely the European Network of Users and Survivors of Psychiatry (ENUSP), and the International Disability Alliance (IDA).[710]

Draft papers were presented by academics and advocates on issues that MDAC had, through a process of outreach to various organisations, identified as unexplored. These included why psychiatric and social care institutions should be inspected at all; why and how mental health service users should be included as inspectors/monitors; the limits and justifications of mental health detention; the link between legal capacity and detention; medical treatment and ill-treatment in psychiatric and social care institutions; the meaning of reasonable accommodation in places of detention; and how inspectorates can promote the right to live in the community. This Special Edition contains some of the papers which were presented at the November 2011 roundtable, and these papers have benefitted greatly from comments from discussants and peer reviewers, all of to whom we are grateful.

7. Overview of papers

Peter Bartlett's paper on "Mental disorder of a kind or degree warranting confinement: Standards for psychiatric detention under the ECHR" discusses the jurisprudence of the European Court of Human Rights with regards to mental health detention. Bartlett analyses the Court's case-law looking at criteria of detention, and provides examples for the status approaches, dangerousness, treatment, least restrictive alternative, and capacity tests. He looks at the CRPD from various vantage points, from detention based solely on disability to other models in which detention is allowed if reasons for it are de-linked from disability. He finds that the line between the two can be rather blurry and could lead us down a slippery slope. Bartlett points out that Article 5 of the ECHR now represents a clear conflict to the CRPD, and that all Council of Europe and EU instruments must recognise the new standards to be applied. Bartlett concludes that in light of the CRPD more guidance is needed in Council of Europe instruments defining appropriate standards regarding detention.

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[710] The authors of this paper also attended: DK coordinated the seminar, and OL chaired.

Anna Lawson's paper "Disability equality, reasonable accommodation and the avoidance of ill-treatment in places of detention: What role for monitoring and inspection bodies?" points out that little attention has been given to disability equality issues in the monitoring of places of detention, although neglect of disability equality considerations in these settings can have serious implications for detainees with disabilities, and can cause suffering amounting to cruel, inhuman or degrading treatment and possibly even torture. The paper focuses on reasonable accommodation duties by plotting the history of the concept, and placing it in the context of ill-treatment in detention. Lawson discusses relevant international case-law and points out serious discrepancies between inspectorate reports and the CRPD's standards. Lawson adds her voice to those calling for an updating of monitoring bodies' standards.

Nell Munro's paper "Define acceptable: how can we ensure that treatment for mental disorder in detention is consistent with the UN Convention on the Rights of Persons with Disabilities?" suggests that the CRPD provides a way forward based on a multi-dimensional assessment of the factors that need to be present in order for the practice of medical treatment in detention to be deemed acceptable. Munro further argues that since people with mental disabilities are rarely empowered to pursue individual complaints, domestic and supranational monitoring bodies have a key role to play in defining standards and ensuring their compliance.

Charles O'Mahony's paper "Legal capacity and detention: Implications for the CPT Standards", considers the implications of the CRPD for the operation of the European monitoring body, the Committee for the Prevention of Torture. O'Mahony suggests that standards should be reformulated to reflect the so-called paradigm shift in thinking on legal capacity as set out in Article 12 of the CRPD. he goes on to posit that the CPT should examine disability detention as an unjustifiable interference with people's legal capacity. O'Mahony introduces the term "clinical guardianship" and suggests an inconsistency with the CRPD, calling for the CPT to direct States away from this form of substitute decision-making and instead towards supported-decision making.

Finally, the paper on “Monitoring those deprived of their liberty in psychiatric and social care institutions: international and national practice” by Judy Laing, Rachel Murray and Elina Steinerte of Bristol University, discusses the importance of monitoring visits to non-traditional places of detention where people with disabilities may be detained. The paper looks at issues pertinent to independent monitoring of psychiatric institutions and social care institutions by international and national monitoring bodies, the obligations of states that are party to the OPCAT, drawing in particular on the experience in the UK. The paper finds that disability institutions are often of secondary importance when it comes to visits and reveals the problems of lack of expertise in monitoring bodies as well as the lack of clearly articulated substantive standards.

8. Recommendaitons for action

Academics, advocates, and activists can and should take distinct action to stop torture and ill-treatment. However, this Special Edition focuses on the role of international, regional and national inspectorate bodies, and to them we recommend the following four inter-related actions.

A. Recognise the range of human rights violations

The jurisprudence of the European Court of Human Rights and the Standards of the CPT establish that admission to a psychiatric or a social care institution can amount to a deprivation of liberty, which can be unlawful. The former UN Special Rapporteur on Torture further recognised that people with disabilities in psychiatric and social care institutions are often subject to torture and ill-treatment due to conditions, treatment, violence, and discrimination. Monitoring bodies at international, regional, and national levels should also now publicly acknowledge these new (to them rather than the victims) forms of torture and ill-treatment which arise in the context of facilities for persons with disabilities.

B. Visit non-traditional places of detention

It is probably true to assert that most people with disabilities around the world have never been visited by any human rights monitoring body. As this paper has illustrated, in many countries, torture prevention actors do not visit psychiatric or social care institutions or psychiatric wards of general hospitals, and do not report human rights abuses being carried out there. Monitoring bodies have for long focused on visiting traditional places of detention, such as prisons and police custody and the recognition of the need to visit other detention facilities only came later – as pointed out by Laing, Murray and Steinerte in their paper in this Special Edition.

As noted above, while the CPT visits a range of non-traditional detention settings, other monitoring bodies, such as the SPT and various domestic inspectorates do not. Inspectorates need to do justice to their mandate by inspecting the full range of places where people can be detained, and this includes psychiatric hospitals, social care institutions, nursing homes and so on. In other contexts it includes immigration centres, deportation custody suites, children's homes and so on. Civil society must play its part to monitor the monitors.

C. Valourise the CRPD

There is a growing need to harmonise the array of human rights standards established by international treaties across UN bodies. While the advantage of having various human rights mechanisms is that particular 'groups' and pressing issues can be discussed, there is also a risk that universalism and a streamlined approach is abandoned as bodies retrench to their silos. Communication and cooperation are crucial.

As Bartlett, Lawson, Munro, and O'Mahony highlight in their papers in this Special Edition, the CRPD not only prohibits torture and ill-treatment, exploitation, violence, and abuse, but it also obliges States to ensure that persons with disabilities enjoy legal capacity on an equal basis with others and are provided with the supports which may be necessary to achieve this in order that everyone can meaningfully participate in the community. Monitoring bodies will themselves benefit from using these standards; indeed anything else opens them to criticism that they are not fulfilling their obligations under international human rights law.

D. Ensure participation

Participation has been described as the "lifeblood" of the CRPD.[711] We suggest that monitoring bodies include people with disabilities (including users and survivors of psychiatry, as well as people with intellectual disabilities) in their work, including in planning, execution, and evaluation of monitoring. The reason for this is that beneficiary participation can enhance the effectiveness of torture prevention work. Mental health service users are experts by experience and have a particular role to play during visits, picking up on ill-treatment which may be invisible to monitors who have not been through the system. In the same way, ex-prisoners can add a depth and range to the quality of any prison monitoring. Mental health service users can establish trust between monitor and patient/resident in a more sophisticated way than those who have not used mental health services, and can often approach residents/patients who are quieter and less open to be interviewed by monitors who are perceived as part of the system. Mental health service users can also provide a positive example to the residents in showing that there is a way out of the system of institutions. The involvement of service users as monitors will mean that resultant reports are more relevant to needs, and because of a connection with civil society and disabled people's organisations, can ensure a connection between the monitoring report and the community.[712]

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[711] "Building the Architecture for Change: Article 33 of the UN Convention on the Rights of Persons with Disabilities", Mental Disability Advocacy Center, 2011.

[712] See Oliver Lewis and Nell Munro, "Civil Society Involvement in Mental Health Law and Policy Reform", in *Mental Health and Human Rights*, edited by Michael Dudley et al, Oxford University Press, 2012.

Chapter 9: Conclusions

1. Introduction

A study of legal capacity and international law is both exciting and frustrating because the developments over the last few years have been so significant yet are constantly being constructed. Chapter 3 was written in 2006 as the UN Convention on the Rights of Persons with Disabilities (CRPD) was being concluded, and the fact that its analysis is in many ways so speculative is testament to how far the CRPD has shifted the tectonic plates of international disability rights law. The time and effort and sheer word-count which the international human rights community has spent on the right to legal capacity in the drafting of the CRPD, and in its implementation since then, is testimony to disability activists and inspired diplomats who have ensured that whatever debris the tide may bring in, legal capacity is anchored firmly in the CRPD's port.

The achievement of the text can hardly be overstated, yet there is something puzzling about the clunkiness of the Article 12 wording, the many reservations and interpretive declarations entered by States, the feedback from many

States on the CRPD Committee's draft general comment in 2014, and the Committee's decision to ignore the criticism and to persist within its comfort zone of high principle. The passion on all sides demonstrates what a contested field legal capacity really is, however ultimately simple its premise.

This book has argued that Article 12(2) – the right to legal capacity in all areas of life and throughout a person's life – is the CRPD unplugged. It is the reduction of all the Convention stands for, because stigma and discrimination in all other human rights areas (education, employment, political participation and so on) flow from the notion that it is acceptable to categorize people as the other – *les autres* – and suspend some of their rights, as the introductory chapter pointed out. The others, people different from ourselves, need our protection, our intervention and our wisdom. We law-makers write the laws that cast people as other. We psychiatrists assess their capability and deem them not to pass the test. We judges adjudicate according to rules and strip them of their rights, for their own protection and in their best interests. We guardians take decisions which may authorise unwanted medical interventions on these mad others (and deny healthcare from haplessly incapable others). We society banish the undesirable others to institutions, out of our collective sight and mind. We create the unseen and then block their access to justice.

Set against these prevailing powers, it is noteworthy that during the short life-course of this book, the global community has established that these unseen others have rights and entitlements under binding international human rights law. People deprived of their legal capacity have been the subject of global meetings in New York and Geneva, and Europe-wide meetings in Brussels and Strasbourg. That sentence could not have been written a decade ago.

This chapter provides answers to the two research questions set out in chapter 1. The next section of this chapter, the findings, takes a heli-view approach by trying to make sense of the work as a whole in relation to the two research questions, rather than repeat in a linear fashion the conclusions of each chapter in turn. The third part of the chapter sets out the research limitations, and the fourth section posits future research questions arising from the book.

The fifth section suggests some policy implications for the main stakeholders of this book – governments, litigators, courts, international human rights mechanisms and mental health professionals. The chapter finishes with a sixth section that revisits the whole purpose of the human rights project which is ultimately to prevent violence and war by encouraging people to talk with each other.

Human rights norms convey both a certain vision of the future and offer normative process guidelines about how to get there. It is ultimately up to us all, whatever role we have, to have critical conversations, share stories, and take some action to repatriate the right to decide to people who have had that right removed.

2. Findings

Chapter 1 set out the primary research questions of this book. They were:

1. What are the human rights consequences of guardianship laws?
2. To what extent does international human rights law recognise the right to legal capacity of people with mental disabilities?

The first research question asks about the human rights consequences of guardianship laws. One part of the answer is contained in chapters 5 and 6 where the case-law of the ECtHR has been analysed. These cases derive from the guardianship regimes of several countries in the Council of Europe region, and the cases themselves illustrate the human rights impact on the people affected. They include procedural violations which the Strasbourg court usually bundles up into the right to fair trial (Article 6 of the ECHR), and the right to privacy under Article 8 of the ECHR), both analysed in chapter 3, written at a time before the main ECtHR cases in this field were decided, starting with *Shtukaturov v. Russia* in 2008. Chapter 5 sets out a critique of the ECtHR's handling of guardianship cases where the human rights implications of the deprivation of legal capacity were acknowledged by the court, but the court was unwilling to find a violation of Article 8 of the ECHR. Using the language of the UN Convention on the Rights of Persons with Disabilities (CRPD), deprivation of legal capacity directly causes loss of a number of rights. As the *Stanev* case illustrated in chapter 6, a central right is living independently in the community, set out in Article 19 of the CRPD, whose provisions are set out in chapter 4.

The other part of the answer is contained in chapters 7 and 8 which examine how deprivations of legal capacity impact upon two connected legal domains: medical law and ethics, and the international system of torture prevention.

The rights of people with mental disabilities have frequently been disregarded or devalued within the healthcare system, found chapter 7, which suggested that one of the reasons is the existence of discriminatory laws – including guardianship laws – which result in poor clinical practices and exclusion of people with disabilities in public health and other development programmes. The conclusion was that the CRPD is an opportunity for healthcare professionals to critically assess engagement with their patients who have disabilities and to shift from a best interests approach (suited for children rather than adults) to one that respects and enhances autonomy and consent-based treatments. The chapter recommends that professionals alter care practices in the name of justice, beneficence and non-maleficence. It points out that this will raise a multitude of dilemmas: How to move from a model of proxy consent to one which truly respects the will and preferences of the person with disabilities when accessing healthcare? How to move from best interests to best interpretation of will and preferences? How to ensure that support in decision-making is not usurped by substitution? How to prevent supporters exercising undue influence? And how to ensure a person with disabilities does not lose out on their right to health because of the (in)actions of their support network? It is too early in the bedding down of the CRPD for there to be any set-piece answers to these questions (see ‘Future research agenda’ section, below).

Chapter 8 analyses the interface between legal capacity and the international torture framework as set out in the UN Convention against Torture and its innovative Optional Protocol. It found that the world's apex monitoring body – the UN Subcommittee for the Prevention of Torture – had visited mostly 'traditional' places of detention: prisons and police lock-ups, and only a very low proportion of 'non-traditional' places of detention such as mental health and social care institutions. This, the chapter concludes, requires urgent rectification, so as to prevent domestic monitoring bodies copying this bad practice. The chapter finds that inspectorates should stop dancing around abuses by colluding with the medical community (in a way it would not countenance with regard to police officers or prison officials) and actually name the range of human rights violations taking place behind closed doors and with impunity. Referencing two successive UN Special Rapporteurs on Torture, the chapter sets out the various ways in which people with disabilities detained in psychiatric and social care institutions are at increased risk of torture and ill-treatment due to conditions, treatment, violence and discrimination.

The chapter identifies the need to integrate CRPD into the mechanics of preventive monitoring. That is to say, Article 33(3) of the CRPD establishes the principle that people with disabilities (including users and survivors of psychiatry, as well as people with intellectual disabilities) should as a matter of international law be invited to participate in monitoring processes. Beneficiary participation enhances the effectiveness of torture prevention: people who have experienced violations bring to the monitoring enterprise an awareness that others lack and identify violations others may not notice. Beneficiaries can be role models when they go to institutions, empowering those still inside that recovery and life on the outside are possible. Their input into creating reports means that advocacy emanating from monitoring missions will have enhanced relevance to people's actual needs and rights. Establishing links with civil society organisations representing people with disabilities enhances the likelihood that these groups carry out their own advocacy to ensure that the authorities act upon recommendations made in the reports. In this way, both the power imbalances and legal invisibility of people formerly stripped of their legal capacity can be reversed in practical ways.

Lastly, the chapter suggests a growing need post-2006 to harmonise disability across the array of UN human rights standards, since many of the pre-CRPD standards accept that people can be legally incapacitated, and regular rights can be suspended. Both the universal nature of human rights and the desire by the UN apparatus to have a streamlined approach are both at risk if this does not happen. The worst-case scenario is that no treaty bodies other than the CRPD Committee will champion the right to legal capacity, the need for States to provide access to supports, and the right to live independently and be included in the community.

Turning now to the second research question, namely the extent to which international human rights law recognises the right to legal capacity of people with mental disabilities. The introduction chapter explained how contemporary legal systems of guardianship for adults with mental disabilities have their roots in Roman law, systems that to contemporary legal scholars look unnecessarily blunt and alarmingly discriminatory.

Chapter 2 sought to directly answer this research question by using a standard legal analysis to establish what international law has had to say about this, and then analyse the emergence of the right to legal capacity through the development of international standards. It examined the extent to which mechanisms established by the United Nations, the Council of Europe and the European Union have begun to grapple with what the right to legal capacity should mean. The chapter noted how the CRPD has clustered together obligations and rights: notably the right for everyone to have legal recognition, to have legal capacity at all times throughout their life and in all areas of their life. It explained how the CRPD has established safeguards and how it has articulated a range of operational tasks for States to carry out in order to prevent, identify and remedy all forms of exploitation, violence and abuse.

It took at least three years for the international human rights mechanisms to comment on how these CRPD provisions were profoundly important. In 2009 the Parliamentary Assembly of the Council of Europe focused on legal capacity in a Resolution and Recommendation on the rights of people with disabilities. The same year, the Office of the United Nations High Commissioner for Human Rights declared the ‘centrality of [Article 12] in the structure of the [CRPD] and its instrumental value in the achievement of numerous other rights’, recommending to world governments that this area be a ‘priority area for legislative review and reform.’ In October that year, the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) decided to hold its first ‘day of general discussion’ about a CRPD topic, and it chose the right to legal capacity. In the same year, the European Court of Human Rights decided the case of *Glor v. Switzerland*, and notwithstanding the case was about something other than legal capacity, it was the first judgment in which the European Court of Human Rights cited the CRPD.

In 2014 the CRPD Committee issued its general comment number 1, on legal capacity. It has been consistent in its recommendations to States that they must abolish regimes where decisions are made on behalf of people with mental disabilities to systems wherein laws enable people to access the supports which they may need to exercise their legal capacity which respect their will and preferences.

Yet despite the universal agreement at the inter-governmental level both about how legal capacity sits at the core of the so-called paradigm shift which the CRPD seeks to usher in, and about the need for legislative, policy and service delivery level action, the content of Article 12 of the CRPD remains a matter of significant contention. Several governments are on record (in the numerous reservations and interpretive declarations and in their submissions responding to the draft general comment in early 2014) in opposing what they view as an absolutist, unfeasible and unhelpful abandonment of substituted decision-making. The views of these governments, shared by many national human rights institutions, are that some people’s will and preferences are impossible to interpret, and decisions about their healthcare, daily care and finances need to be made lawfully by someone else – otherwise the person will end up neglected and harmed. Chapter 2 suggested that the CRPD Committee could usefully move beyond its statements of high principle to garner policy traction with, and the trust of, States.

Chapter 3 and 5 were published in 2007 and 2011 respectively. The former is a chapter in the first examination of legal capacity under the European Convention on Human Rights, written at a time when there were very few cases and the ink of the CRPD text was not yet dry. The chapter attempts to construct a jurisprudential architecture, laying down markers on how the case-law might – and in the authors' views should – play out. European Court of Human Rights judge Sir Nicholas Bratza wrote the foreword to the book of which chapter 3 (of this book) is part (in 2012 he presided over the seventeen-judge Grand Chamber that adjudicated the *Stanev* case). He observed that since the first major mental health case of *Winterwerp v. the Netherlands* in 1979, 'the jurisprudence of the Court in the succeeding twenty years is notable for the almost complete dearth of judicial decisions in this vitally important area.' He went on to observe that the gap, 'is a reflection not of adequate safeguarding by member States of the Convention rights of those with mental disabilities but rather of the acute practical and legal difficulties faced by an especially vulnerable group of persons in asserting those rights and in bringing claims before both the domestic courts and the European Court.'

By the time chapter 5 was written in 2010 there was a handful of legal capacity judgments to analyse. These included *Shtukaturov v. Russia*, a case that provided an opportunity to the ECtHR to adjudicate on the common scenario whereby a guardian of a person deprived of legal capacity could order that person's detention and forced treatment in psychiatric hospitals on a 'voluntary' basis, thereby bypassing many legal safeguards. Mr Shtukaturov's legal capacity was restored in subsequent domestic proceedings, and unlike the proceedings by which he was divested of legal capacity, he took part in the fresh ones and presented evidence. The Russian Constitutional Court in the same case quashed three areas of law that the ECtHR had criticised. Given the barriers to accessing justice, the number of people seeking remedies for a violation of their rights flowing from a restriction of legal capacity is relatively few, and focusing on a singular case like Pavel Shtukaturov's can have significant impact. Chapter 5 predicted that as the CRPD beds down in international interpretation and domestic legal awareness, lawyers are likely to litigate more legal capacity test cases.

The much anticipated and above-mentioned judgment *Stanev v. Bulgaria* was issued in 2012 and Chapter 6 of this book is an extended case-note. *Stanev* is one of the most significant disability milestones in European legal jurisprudence. In his 2007 foreword, Judge Bratza had referred to the difficulty for clients to bring cases to the Court. Presiding over the *Stanev* bench he was likely aware that Mr Stanev got his case to Strasbourg thanks to the free legal advice and representation provided to him by a Bulgarian nongovernmental organisation working in conjunction with an international one.

The *Stanev* case exposed the intimate link between legal capacity and long-term deprivation of liberty in one of the many thousands of unseen social care institutions in Europe, illustrating a central theme of this book. Rusi Stanev – to whom this PhD thesis is dedicated – was placed under guardianship in proceedings about which he was not notified. His guardian contracted with a social care institution where he spent the next eight years in deplorable conditions. This factual matrix enabled the Court to critically analyse the guardianship regime that allowed these string of violations to take place, a point noted in the judgment. That the Court did not offer a robust analysis about guardianship and societal exclusion was to many commentators frustrating, as Chapter 6 points out. This commentator has said that these are still early days in the European disability rights movement. The chapter concluded by explaining how the Court has a different role from the UN Committee on the Rights of Persons with Disabilities: it generally neither comments on governmental progress nor does it make general recommendations to States.

An underlying realpolitik in Strasbourg is that some European governments have over the last few years asserted considerable pressure onto the Court to prevent it from overstepping the boundary between national sovereignty and universal human rights. A curiosity or disappointment about the *Stanev* case which Chapter 6 attempts to unravel, is how that the Court did not interpret the ECHR in the light of the CRPD, whereas it has referred with authority to other UN treaties when given the opportunity in non-disability cases. Chapter 6 warns against early pessimism, however, as CRPD provisions do not map neatly onto the ECHR (the latter contains no explicit right to live in the community or right to legal capacity, for example), and the job of Strasbourg judges is to interpret the ECHR, not the CRPD.

The critique notwithstanding, *Stanev* is the first judgment of an international or regional human rights tribunal to find that a person who was detained in a disability institution without his consent and without proper procedural guarantees was deprived of liberty, and unlawfully so (finding, in this case, a violation of Article 5 of the ECHR). Equally it is the first case that the ECtHR has found that the regime and conditions of a disability institution violated the absolute right to be free from degrading treatment, declaring a violation of Article 3 of the ECHR. At risk of labouring the point, these violations occurred only because of the deprivation of Mr Stanev's legal capacity.

Stanev is an example of strategic litigation, an advocacy tool which Chapter 5 suggests can play a pivotal role in advancing legal capacity jurisprudence, and can have a ripple-out effect into other areas: capacity-building of key professionals, public awareness-raising, empowering 'victims' and opening the door to policy advocacy. As chapter 5 concludes, strategic litigation on its own may not erode the devaluation of particular differences, but it does provide a basis from which to challenge the power that operates to define some differences as less worthy and deserving of respect and rights than others.

Over the last nearly decade strategic litigation as a tool of legal advocacy has forced a fundamental re-evaluation of positions and has advanced the expressive value of human rights, a framework that is applied to mental disability rights in chapter 4 of the book. That chapter points out how the CRPD is the longest and most programmatic of the UN human rights treaties, and suggests that as well as its normative force, its utility is to transform the political process to the point that the norm is justice rather than continuous aspiration. A textual analysis of the CRPD reveals several obligations on the State to establish structures to reverse the power imbalance between it and individuals. Public participation is the Convention's life-blood. Processes are likely to be transformed if people with disabilities, their family members and carers, providers of services, governmental authorities, and a range of civil society actors are open to participating by critically thinking about ideas, even those that may initially be uncomfortable. Creative policy-making includes, the chapter suggests, establishing pilot project that test out supported decision-making in an attempt to learn how micro programmes can comply with Article 12 of the CRPD. This would answer the call of the UN Commission for Social Development, that, '[n]ew and innovative thinking and collaboration are required to utilize the CRPD so as to bring the maximum benefit to persons with disabilities and society'.

In summary, the second research question asks whether international human rights law recognises the right to legal capacity of people with mental disabilities. The answer had two strands. The first strand pointed out how UN and European political mechanisms are now agreed at the principle level. However, governments are pushing back against high principles they consider not to be feasible to transpose into domestic norms because a small cohort of people with disabilities would be left vulnerable to abuse and neglect. Shifting everyone under the supported decision-making umbrella would not, they argue, eliminate harm, but merely shift it. The CRPD Committee has suggested that every scenario can be dealt with under supported decision-making and there is never any need for substituted decision-making. This approach has resulted in significant confusion and angst among those charged with developing domestic policies to meet what is now seems to be an established international legal standard. The second strand to the second research question was that the European Court of Human Rights is beginning to adjudicate legal capacity cases, but very much in its own time, on its own terms and without yet weaving the CRPD into its jurisprudence. It is early days, however, and international human rights mechanisms do not exist in a vacuum. In countries where they are not persecuted, civil society organisations and human rights lawyers are instrumental in agitating and cajoling the executive, the legislature and the judiciary to take appropriate action, whether through monitoring, policy advocacy or strategic litigation.

Writing chapters for this book began in 2006. Since then the results of civil society strategies in empowering disability groups, developing jurisprudence and reforming laws is quite considerable.

3. Limitations

The various chapters of the book have been written over a time span of nine years, and as a PhD by published work, each chapter has been written with a certain publication in mind. Some have been commissioned pieces, and others have been pitched to journals. Each journal or book in which the chapters have been published have their own contexts, audiences, word limits, styles and deadlines. These inevitably mean that the flow from one chapter to the next is not as smooth as a thesis not based on publications would be. A sense of cohesion has been attempted in the introduction and conclusion chapters.

Another limitation of the study is that the scholars, policy-makers and judges working on legal capacity globally are but taking the first baby steps along the journey of interpretation and implementation of the right to legal capacity in international human rights law. This field has a tiny written literature to draw on. Conceptual heavy-lifting continues apace, and there are far few people engaged in this process that makes writing about it more challenging. Dispassion has also been challenging, not only because the author’s day job is to run an advocacy organisation active in the international legal capacity sphere, but many of the key authors – Michael Bach, Gerard Quinn, Anna Lawson – are friends.

A final limitation is that people working in governments, national human rights institutions and civil society organisations often do not say publicly what they say in private. Many are acutely aware of the problematics raised in this book. Human rights enthusiasts publish a lot: in blogs, in policy papers, conference speeches, sometimes in journals and on Twitter. Legal capacity reform sceptics are willing to talk about their views in private, but remain silent in public. This book is not an empirical study, and has resisted citing many insightful yet informal conversations. Cherry-picking and publicising private conversations would have been methodologically unsound, unethical, cheapened the analysis, and would have risked the author's ability to have confidential discussions in the future.

4. Future research agenda

Like all research endeavours, more questions have been raised than answered. All of the questions deserve further study but are outside the scope of the specific research questions this book set out to answer. As a result of the study, further research might well be conducted into the following topics.

How are domestic legal capacity laws being changed to bring States into compliance with their obligations under Article 12 of the CRPD? And how effective are those laws in advancing societies towards the utopic vision set out by the CRPD Committee in its general comment? What are the elements in various countries that help or hinder the implementation of such laws? What lessons can be learned from pilot projects that may be relevant for other settings? At the micro level, can law ever shine a bright light between substituted and supported decision-making? The answer to this question may well require a collaboration of philosophers, sociologists, psychologists and neuroscientists. Lawyers may have the least interesting things to say.

Turning to human rights mechanisms. How does the hesitancy of the European Court of Human Rights with regard to mental disability rights compare to other fields, such as LGBT rights or women's rights? At the UN, a similar question would be to look through the history of the treaty body system to ascertain whether other treaty bodies in their early years encountered similar teething troubles as the CRPD Committee has. Chapter 8 revealed how the UN Subcommittee for the Prevention of Torture had been reluctant to visit mental health or social care institutions where people labelled with mental disabilities are subject to being detained. This begs the questions: why, and has this situation changed?

5. Policy implications

The findings of this book imply a set of policy and practices at the operational level. Each relevant chapter has tried to tease these out. Clustering them per stakeholder group, the lines of possible activities include the following.

Governments should clarify exactly why they have entered reservations and ministers and civil servants should do everything possible in their capitals to enable them to withdraw the reservations in New York. The risk is that maintaining reservations unravels the tapestry of international law. Governments should engage with civil society organisations in their own country, and experts from abroad, to sketch out what an Article 12 compliant system looks like, seek out those who may hold opposite views, interrogate their differences and use the principles of the CRPD to guide discussions. Above all, ministers and civil servants should be bold and take action: people locked in the manacles of legal incapacity want to get out and people working for governments hold the keys.

Human rights litigators should bring test cases to courts. Justice systems have installed many barriers for people they have labelled ‘incompetent’ and smart litigators can dismantle these disabling barriers. Putting unjust systems into the dock can rebalance power and directly cause (or at least contribute to the momentum for) whole-scale law reform. The difficulty remains of mapping CRPD principles onto other legal systems such as the ECHR and into domestic civil law (let along criminal law – which this book has steered clear of) structures, but that difficulty is no reason for inaction. Flowing from this, domestic judges should at the minimum hear cases, and be creative when it comes to certain practical or procedural barriers in dealing with cases (see e.g. the way the ECtHR dealt with the case of *Centre for Legal Resources (on behalf of Valentin Câmpeanu) v. Romania* in 2014) instead of throwing applicants out of court for lacking legal standing (the *Shtukaturov* and *Stanev* scenario). Courts should give due consideration to CRPD arguments, even if they are not experts in human rights or mental disability. Inspectorates should integrate the legal capacity conundrums into their work: if people are detained because a guardian has placed them in an institution and they want to leave, it is well within an inspectorate's mandate to comment on this type of unlawful detention, because torture and other forms of ill-treatment can take place with impunity when liberty is restricted and the public averts its gaze.

International human rights mechanisms such as the CRPD Committee should evaluate how effectively they are nudging States from rhetoric to action. The book has suggested that it is unhelpful to ignore concerns that States and service providers have made in good faith, because this potentially undercuts the traction that international treaty bodies can have between human rights policy and programming.

6. Critical conversations

The central theme of this book has been to frame substituted decision-making as a human rights concern and suggest that these concerns be addressed by the exchange of ideas in critical conversations: in the courtroom, in policy papers to government, and in the corridors of power. The CRPD Committee has begun to thrash out a path that no State seems willing to follow. This is unfortunate, as human rights are not simply normative instructions in which the United Nations speaks and subservient States act. If the post-war human rights project has signalled anything, it is to prefer persuasion over violence. This entails listening to the concerns of others, facilitating differing opinions, interrogating that which has worked as well as that which has not, and finding out the reasons why.

Conducting critical conversations about the way we enable and support people to author their own lives is an urgent task precisely because of the gravity of what happens when someone's legal capacity is restricted. Conversations between diplomats, between lawyers and judges, between parliamentarians, between civil society and governments: these dialogues can help flesh out how principles can be implemented in laws, policies, systems and budgets taking into account the wildly differing contests, cultures, traditions, resources and practices across the world. A such, it is a good thing that the human rights framework does not provide the operational detail policy-makers and service providers crave. What international human rights law does do is set out a vision of respect for diversity, the obligation to recognise autonomy, to provide access to support and, to a certain extent, to let go and allow people take some risks in their lives. It tells States to treat people as humans.

Rusi Stanev put it in a less convoluted way: ‘I’m not an object, I’m a person, I need my freedom,’ he said as he climbed the steps of the European Court of Human Rights in Strasbourg to hear arguments before the Chamber in his case in 2010. The deprivation of his legal capacity made him feel that his destiny had been reduced to his diagnosis and that he was at the mercy of the whims of others. Without his legal capacity, he his personhood had been violated and his freedom stripped from him. Reversing the dogma which has been embedded in our legal systems over several centuries will require a multitude of constructive conversations about power, about what it means to author our own lives, and about the activism needed to establish a more just society. Those are big conversations to which this book is a small contribution.

Summary in English

The book is divided into three blocks. After Chapter 1 that serves as an introduction, comes Block 1 (chapters 2, 3 and 4). These chapters examine the substantive content of the right to legal capacity and how it is situated within the architecture of international human rights law. Block two (chapters 5 and 6) examines the role of the judiciary and analyses the key jurisprudence on the right to legal capacity. Finally, block three (chapters 7 and 8) examines two areas that are impacted by legal capacity: medical law (and ethics) and the international framework on torture prevention.

Block one

Chapter 2 sets out the history of legal capacity under international human rights law. It establishes the approach to legal capacity articulated in Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD) and summarises theoretical approaches to legal capacity. The CRPD is the standard by which legislation and practice must be assessed so the relevant provisions are examined in detail. The chapter explains how substituted decision-making systems of guardianship are incompatible with the CRPD. It analyses how the text calls for law reform to create systems based on autonomous decision-making plus supports that a person may need in order to forge their way through life. The chapter analyses a significant threat to the roll-out of CRPD-compliant laws, namely the interpretative declarations and reservations which nine States have entered on Article 12 of the CRPD. The chapter suggests how many of these reservations are unlawful under established public international law.

Chapter 3 analyses how traditional guardianship regimes fare against Article 6 (fair trial) and Article 8 (privacy) of the European Convention on Human Rights. It argues that courts and legislators should take guardianship issues more seriously.

Chapter 4 steps outwards and takes a macro view of disability rights. It explains why the CRPD exists, how it serves its beneficiaries and how it progresses the human rights project as a whole. The chapter sets out the provisions of the CRPD which are relevant to mental health law. It suggests that the CRPD embodies the expressive role of human rights by encouraging actors to rethink assumptions, evaluate positions and shift existing concepts or paradigms. It reviews the independent mechanisms at international and domestic levels, something which can only be done if beneficiaries – people with disabilities – are entitled to legal capacity and enabled to act.

Block two

Chapters 5 and 6 examine how courts have grappled with the right to legal capacity. Chapter 5 analyses how courts have dealt with the challenge of implementing the right to legal capacity in the CRPD era. It lays out some of the benefits of strategic litigation as an advocacy technique to highlight the otherwise largely invisible plight of people with mental disabilities and suggests ways to conceptualise a strategic approach to bringing test cases in this field.

Chapter 6 is an extended case-summary of the European Court of Human Rights' judgment of *Stanev v. Bulgaria* in 2012, which is arguably one of the most important disability cases decided by the Strasbourg court so far. Its importance lies in the fact that it is the first case where the Court has found a violation of the right to liberty of someone who had been placed in a social care institution against his will, and the first disability case in which the Court has found a violation of Article 3 of the European Convention on Human Rights. The chapter explains how these violations only took place because Mr Stanev was deprived of his legal capacity.

Block three

Chapters 7 and 8 each examine a domain in which people deemed incompetent. Chapter 7 is a book chapter co-authored with Aart Hendriks which layers medical law and ethics onto disability. It sets out the relevant legal and ethical theory, and explores the rights, principles and issues most prominent for the interrelationship between disability on the one hand and medical law and ethics on the other. The chapter discusses the various meanings of the term 'disability', and the way this concept was finally defined in the CRPD. It outlines the implications flowing from human rights standards for the right to health in theory, and for healthcare professionals in practice.

Chapter 8 is a paper co-authored with Dorottya Karsay and returns to a central theme of the thesis explored particularly in chapters 2, 5 and 6, namely the nexus between legal capacity and institutionalisation, and the human rights and other legal implications. Focusing on abuse and neglect, the chapter sets out how torture prevention mechanisms established by international law have tended to focus on prisons and police stations to the detriment of assessing the situation of people in psychiatric and social care institutions, leaving people with mental disabilities in these institutions prone to being exposed to torture and ill-treatment carried out with impunity.

The book finishes with Chapter 9, which sets out the conclusions and attempts to answer the two research questions: namely the consequences of deprivation of legal capacity, and the extent to which international law has recognised the right to legal capacity. Despite the universal agreement at the inter-governmental level both about how legal capacity sits at the core of the so-called paradigm shift which the CRPD seeks to usher in, and also about the need for action at legislative, policy and service delivery levels, the content of Article 12 of the CRPD is a matter of significant contention. International human rights law is nearly consistent in recognising the right to legal capacity of people with mental disabilities. The UN and European political mechanisms are now agreed at the principle level but governments are pushing back against high principles they consider unfeasible to transpose into domestic norms. The risk is that the sorts of legal reforms suggested by the CRPD Committee would arguably leave a small cohort of people with disabilities vulnerable neglect – even if unintended – such as being denied healthcare where the person is not able to clearly consent to treatment, or being left without any mechanism to help with financial planning. This approach would not eliminate harm, some governments argue, but merely shift it. The CRPD Committee has suggested that every scenario can be dealt with under supported decision-making and there is never any need for substituted decision-making. This approach has resulted in significant confusion and angst among those charged with developing domestic policies to meet this international standard. Further work is required to launch and evaluate pilot projects on supported decision-making so as to allay the legitimate fears of policy makers. The chapter ends by suggesting that a way to narrow the gap between human rights rhetoric and lived reality is to encourage critical conversations: between diplomats, between lawyers and judges, between parliamentarians, and between civil society and governments. Open discussions can help put flesh on high-level principles. Ultimately, the conclusion chapter suggests notwithstanding the fact that the human rights framework does not set out operational detail, its value is in establishing a global vision of respect for diversity, the obligation to recognise autonomy and to provide access to support. Crucially, the human rights framework gives people a way to raise their concerns when things go wrong.

Summary in Dutch

‘Handelingsbekwaamheid en internationale mensenrechten’

Dit boek bestaat uit drie delen. Na het inleidende hoofdstuk 1 volgt deel één (hoofdstukken 2, 3 en 4). Dit hoofdstuk onderzoekt de materiële inhoud van het recht op handelingsbekwaamheid en hoe het is gesitueerd binnen het bouwwerk van het internationale mensenrechtenrecht. In deel twee (hoofdstukken 5 en 6) onderzoek ik de rol van de rechterlijke macht en analyseer ik de belangrijkste jurisprudentie met betrekking tot het recht op handelingsbekwaamheid. Tenslotte richt deel drie (hoofdstukken 7 en 8) zich op drie gebieden die worden beïnvloed door handelingsbekwaamheid: het gezondheidsrecht, het internationale kader van de preventie van foltering, en wereldwijde geestelijke gezondheid.

Deel een

Handelingsbekwaamheid heeft een gestage evolutie in het internationale mensenrechtenrecht ondergaan - enkele karakteriseren dit als een revolutie.

Hoofdstukken 2, 3 en 4 geven aan hoe door de geschiedenis heen internationale juridische normen ‘handelingsbekwaamheid’ hebben benaderd en de hoofdstukken verklaren de radicaal andere visie op de handelingsbekwaamheid in het VN-Verdrag inzake de rechten van personen met een handicap (CRPD).

Hoofdstuk 2 bevat het volledige arsenaal aan uitspraken van internationale organisaties over handelingsbekwaamheid. Het bekrachtigt de aanpak van de handelingsbekwaamheid verwoord in artikel 12 van het VN-Verdrag inzake de rechten van personen met een handicap en geeft een samenvatting van de geschiedenis van de handelingsbekwaamheid en bijbehorende concepten.

Het CRPD is nu het wereldwijde normatieve kader met betrekking tot handelingsbekwaamheid en de daarin vervatte relevante bepalingen zijn in detail onderzocht. Het hoofdstuk legt uit hoe plaatsvervangende besluitvormingssystemen van voogdij niet zullen kunnen voortbestaan, bekeken door de lens van de CRPD.

Dit hoofdstuk analyseert hoe de CRPD pleit voor hervorming van wetgeving om systemen op basis van autonome besluitvorming te creëren plus de ondersteuning die een persoon nodig kan hebben om zijn weg door het leven te vinden.

Het hoofdstuk analyseert de grootste internationale bedreigingen die de CRPD kunnen ondermijnen, namelijk de interpretatieve verklaringen en voorbehouden die negen verdragsstaten op artikel 12 van het VN-Verdrag hebben gemaakt. Het hoofdstuk stelt dat veel van deze voorbehouden misschien onrechtmatig zijn volgens het gevestigde internationaal publieke recht.

Hoofdstuk 3 analyseert met name artikel 6 (recht op een eerlijk proces) en artikel 8 (privacy) van het Europees Verdrag voor de rechten van de mens en stelt dat voogdijkwesties veel serieuzer genomen moeten worden door rechtbanken. Het hoofdstuk citeert de toenmalige VN-secretaris-generaal in 2003 die heeft gezegd dat het doel van voogdij is om mensen te beschermen, en dat we 'oneigenlijk gebruik van, en het gebruik van voogdij regelingen moeten voorkomen.'

Hoofdstuk 4 belicht de reden waarom het VN-Verdrag bestaat, zich verhoudt tot mensenrechten, en de relevantie voor de geestelijke gezondheid. Het suggereert dat het VN-Verdrag "de expressieve rol belichaamt van de mensenrechten door actoren aan te moedigen om aannames te heroverwegen, posities te evalueren en bestaande concepten of paradigmas te herzien". Het geeft een overzicht van de onafhankelijke mechanismen op internationaal en nationaal niveau en hoe begunstigde deelname is gegarandeerd.

Deel twee

Hoofdstukken 5 en 6 onderzoeken hoe rechtbanken hebben geworsteld met het recht op handelingsbekwaamheid. Hoofdstuk 5 is de eerste analyse uit het post-VN-Verdrag tijdperk van de wijze waarop rechters omgaan met de uitdagingen van de uitvoering van het recht op handelingsbekwaamheid. Het legt uit wat de voordelen zijn van strategische rechtszaken als belangenbehartigingstechniek om de anders grotendeels onzichtbaar benarde situatie van mensen met een verstandelijke handicap te markeren.

Hoofdstuk 6 bevat een uitgebreide annotatie op de uitspraak van het Europees Hof voor de Rechten van de Mens in de zaak *Stanev t. Bulgarije*, een zaak waarin MDAC mede-verzoeker was. *Stanev* is waarschijnlijk een van de belangrijkste zaken die het Straatsburgse Hof heeft behandeld: het is de eerste zaak waarin het Hof een schending vond van het recht op vrijheid van iemand die tegen zijn wil onder curatele werd geplaatst en overgebracht naar een residentiële instelling, en de eerste ‘handicapzaak’ waarin het Hof een schending van artikel 3 van het Europees Verdrag voor de Rechten van de Mens heeft gevonden.

Deel drie

Hoofdstukken 7-8 onderzoeken elk drie domeinen waarin mensen als handelingsonbekwaam of incompetent worden bestempeld. Hoofdstuk 7 is een hoofdstuk uit een boek dat ik met Aart Hendriks schreef, waarin we proberen het concept handicap vanuit het gezondheidsrecht en ethiek te problematiseren. Het bevat de relevante juridische en ethische theorieën, en verkent de meest prominente rechten, beginselen en vraagstukken voor de onderlinge relatie tussen handicap aan de ene kant en het medisch recht en ethiek aan de andere kant. Het hoofdstuk bespreekt de verschillende betekenissen van de term ‘handicap’, en de manier waarop dit concept uiteindelijk werd gedefinieerd in het VN-Verdrag inzake de rechten van personen met een handicap. Het schetst de gevolgen die voortvloeien uit mensenrechtennormen voor het recht op gezondheid in theorie, en voor professionals in de gezondheidszorg in de praktijk.

Hoofdstuk 8 is met Dorottya Karsay geschreven. Het is de eerste in een speciale uitgave over foltering en arbeidsongeschiktheid dat we gezamenlijk bewerkt hebben. Terugkerend naar een centraal thema van het proefschrift (met name in hoofdstukken 2, 5 en 6), namelijk de relatie tussen handelingsbevoegdheid en institutionalisering, en sommige slechte praktijken die in instellingen gebeuren: misbruik en verwaarlozing. Het zet uiteen hoe in het internationaal recht mechanismen ter voorkoming van foltering de neiging hebben om zich te concentreren op de gevangenissen en politiebureaus ten koste van de mensen in psychiatrische en andere zorginstellingen, waardoor mensen met een verstandelijke handicap blootgesteld worden aan marteling en mishandeling en die ongestraft uitgevoerd worden.

Het boek eindigt met Hoofdstuk 9, waarin conclusies worden gegeven als antwoorden op de twee onderzoeksvragen. Ondanks de universele overeenkomst op het intergouvernementeel niveau, zowel over hoe handelingsbevoegdheid zit in de kern van de zogenaamde paradigmaverschuiving die het VN-Verdrag tracht in te luiden, en ook over de noodzaak van maatregelen op wetgevend, beleids en dienstverlening niveaus, bestaat er over de precieze inhoud van artikel 12 van het VN-Verdrag nog geen consensus.

In het hoofdstuk worden de beperkingen van het onderzoek, en een aantal aanbevelingen voor toekomstig onderzoek beschreven. Het extrapoleert ook een aantal beleidsimplicaties voor overheden, verdedigers van mensenrechten, internationale mechanismen van de mensenrechten en de geestelijke gezondheidszorg.

Het hoofdstuk eindigt met suggesties dat om de kloof te dichten tussen de ‘smalle’ mensenrechten retoriek en de geleefde realiteit kritische gesprekken aangemoedigd moeten worden: tussen diplomaten, tussen advocaten en rechters, tussen parlementariërs, en tussen het maatschappelijk middenveld en overheden.

Uiteindelijk is de conclusie die het hoofdstuk suggereert dat, hoewel het kader van mensenrechten niet voorziet in operationele details, een globale visie nodig is op respect op voor diversiteit, de verplichting om de autonomie te erkennen en om de toegang tot ondersteuning te bieden.

En het geeft mensen een middel om hun zorgen te verhogen als er iets misgaat.

Dedication

I dedicate this book to Rusi Stanev.

'I'm not an object, I'm a person. I need my freedom.'

- Rusi Stanev, before his hearing at the European Court of Human Rights, 10 November 2009

The Bulgarian law 'failed to meet contemporary standards for ensuring the necessary respect for the wishes and preferences he was capable of expressing.'

- Partly dissenting opinion of Judge Kalaydjieva to the Grand Chamber judgment in the case of *Stanev v. Bulgaria*, 17 January 2012

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Thanks to my former students at the Central European University, the MDAC summer school and at the Indian Law Society, because teaching is learning. Many are now talented advocates, litigators and colleagues: I am embarrassingly proud of them. Lastly, to the people deprived of legal capacity who have battled through the court system: they have risked personal retribution so that others may be treated better.

Curriculum Vitae

Oliver Lewis was born in 1975 in Bristol, UK. He serves as Executive Director of the Mental Disability Advocacy Centre, an international non-governmental organisation that uses law to secure equality, inclusion and justice for people with mental disabilities worldwide. He was MDAC's Legal Director from the organisation's inception in 2002 until 2006. He was called to the Bar of England and Wales in 2000, and is an associate barrister at Doughty Street Chambers, London. Before training as a barrister, Oliver worked a research assistant to an expert committee and subsequently for the Department of Health, on mental health law reform in the UK.

Oliver is recurrent Visiting Professor in Law at the Central European University in Budapest where since 2003 he has taught a course called 'mental disability law and advocacy' to MA and LLM students. He is also Visiting Lecturer in Law at the University of Leeds, UK. Since 2009 he has been a faculty member of the International Diploma on Mental Health Law and Human Rights, run by the Indian Law Society in Pune, India.

Oliver has overseen litigation and advocacy strategies that have held both international bodies and national governments to account for the commitments they have made under international human rights law. He has worked with a variety of stakeholders, including UN treaty bodies, UN Special Rapporteurs, the European Commission and Parliament, the European Court of Human Rights, the Venice Commission, the European Committee for the Prevention of Torture. He is an experienced public speaker, trainer and facilitator and has worked on all continents of the world with disabled people's organisations, human rights activists, inspectorates, lawyers and judges.

Oliver holds an LL.B. (Hons.) from the London School of Economics and Political Science (1998), a Master of Arts in Medical Ethics and Law from King's College, London (1999) and a Master of Public Administration from the Open University Business School (2009). He is a Fellow of the Royal Society of Arts and a Fellow of the Institute of Leadership and Management.