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

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

[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

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

[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

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).

[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

[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

[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.

[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.