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.