

Book proposal to Hart Publishing

János Fiala-Butora, 2023

I. Proposed title

Implementing the Right to Decide: A Framework for Supporting the Legal Capacity of Persons with Severe Disabilities

II. Synopsis

This book addresses one of the most controversial questions of current human rights law: how can people with severe disabilities make their own decisions?

For two millennia, the law has denied persons with disabilities the possibility to make decisions. Courts have appointed guardians to make decisions on their behalf, which has led to violations of autonomy and severe human rights abuses. The Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006, aims to overcome guardianship by replacing it with supported decision-making, a system in which persons with disabilities make their own decisions with the help of supporters.

Despite the best intentions, no state has been able to implement this international requirement to date. Governments have repeatedly claimed that it requires the impossible: some persons' disability is so severe that they will never be able to make their own decisions, even with the highest degree of support. Some academic commentators agree with this position and argue that guardianship should be retained, albeit in a limited form. Others argue that guardianship should be abolished, but have so far failed to explain how supported decision-making can be applied to persons with severe disabilities.

This book fills this gap. It accepts that some persons cannot make their own decisions, but argues that this does not mean that they need guardianship. Rather, the book presents a unique Modified Support Framework, which can incorporate all persons with disabilities. While not all persons with disabilities will be able to make their own decisions, the model ensures that anybody able to use support will not be restricted by the law. The proposed solution thus performs better than guardianship or existing models of supported decision-making.

The book tackles the issue of decision-making by persons with disabilities from both a legal and theoretical perspective. It compares how guardianship and currently existing models of supported decision-making affect the rights of various sub-groups. It engages with an issue never before addressed in the literature: if supported decision-making is supposedly so much better than guardianship, why has it been unable to replace it? It posits that this is because guardianship performs several functions better than supported decision-making. Existing proposals of supported decision-making are instead ideal models which cannot be enforced in practice. The book's central thesis is that we need a set of rules which produce the best overall outcomes. Supported decision-making has to fulfil all of guardianship's functions to become a valid legal alternative to it.

The book analyses the functions of guardianship and supported decision-making, and their positive and negative effects on various sub-groups of persons with disabilities. It develops a comprehensive framework, formally based on support, which pursues the goals of both systems,

and is devoid of their deficiencies. It then tests how decisions are made by various sub-groups of persons with disabilities in the proposed model, and the two existing ones: guardianship and ideal models of supported decision-making. It concludes that with respect to current alternatives, the Modified Support Framework performs better for some sub-groups and similarly for others. It concludes that it is the superior solution overall, and should be adopted by governments intending to reform their legal capacity laws.

III. Outline of contents

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Short summary of the chapters

1. Introduction (3000 words)
 - 1.1 What does it mean to be a person before the law?
 - 1.2 Recent challenges to guardianship

This part explains the relevance of decision-making to equality and the enjoyment of human rights by persons with disabilities. An assumption of contemporary legal systems

is that all subjects entering legal transactions are capable of rational decision-making to pursue their interests. For two millennia, persons with disabilities have been considered to fail to meet this criterion. They have been denied the right to make their own decisions, and the law has authorized other persons, their guardians, to make decisions on their behalf. From subjects, they have been reduced to objects of the law, unable to enter into legal transactions on their own. This legally recognized incapacity stigmatizes persons with disabilities and results in violations of their autonomy in many areas of their lives, also leading to their exclusion from conceptions of equal citizenship.

Guardianship has recently come under challenge with the adoption of the Convention on the Rights of Persons with Disabilities (CRPD). Article 12 of the CRPD arguably requires the abolishment of guardianship and its replacement with supported decision-making. However, no country has been able to implement this provision yet. Governments and most commentators consider it impossible, because they do not think persons with severe disabilities could make decisions with support. The section explains the book's objective, which is to present a proposal on how persons with severe disabilities could nevertheless be incorporated in a supported decision-making framework.

2. Legal capacity (6000 words)

- 2.1 What is legal capacity?
- 2.2 A historical overview
- 2.3 Legal capacity as a human right

This chapter explains the legal basis of guardianship. Guardianship has many forms and names, which are all variations of the concept of substitute decision-making: they transfer the power to make decisions over one's body and property from the person with disability to another person, their guardian.

Guardianship exists in all countries of the world. It has historical roots in Roman law and medieval English law. It changed significantly in the 20th century, when less restrictive forms of guardianship appeared. The situation of persons with disabilities is in many ways historically analogous to that of other oppressed groups: serfs, women, and racial minorities were all subject to similar limitations of autonomy in the past, which were also justified by their supposed lack of rational capacities. These groups have gradually made progress to overcome these restrictions. Persons with disabilities (and the other currently restricted group: children) are still waiting for liberation.

Legal capacity was recognized as a human rights issue relatively late, at the end of the 20th century. Some aspects of it were criticized by international bodies such as the European Court of Human Rights, the Council of Europe, and the UN Human Rights Committee. This chapter analyses the three typical ways in which guardianship falls short of human rights requirements. Two of the three, procedural flaws and violation of fundamental rights, can be potentially remedied. However, the third, the denial of autonomy, is an inherent feature of guardianship, and cannot be overcome by improving the guardianship system.

3. Article 12 of the CRPD (10 000 words)

- 3.1 Conflicting views on how to interpret Article 12
- 3.2 The text of Article 12 and its implications

3.3 A social model of legal capacity restrictions

Article 12 of the CRPD requires that persons with disabilities enjoy legal capacity on an equal basis with others. There is no agreement on the correct interpretation of this provision. One group of commentators argues that it requires the abolishment of guardianship, but these scholars have no solution for how this would apply to persons with severe disabilities. Others argue that guardianship must be retained for persons with severe disabilities; this, however, deviates from both the text and the spirit of the CRPD, and reinforces the current problems with guardianship, which the CRPD aims to overcome rather than preserve.

This chapter argues for a contextual interpretation of Article 12. The meaning of the provision will depend on whether a reasonable solution can be found for incorporating persons with severe disabilities into a support framework. Declaring that they should be incorporated is not helpful: the open question is *how* this can be done.

4. Guardianship and the dark side of protecting the vulnerable (7000 words)

4.1 The inherent features of guardianship

4.2 Different legal approaches to guardianship

4.3 How to evaluate the different approaches?

This chapter analyses in detail how the law currently approaches the decision-making of persons with disabilities. Guardianship is often criticized for the abuses it leads to. However, it has not been abolished in any country of the world, which means it must have some positive features as well. It is necessary to understand these if one wishes to offer a better alternative.

The chapter separates the essential, irreplaceable features of guardianship from those problems that could be overcome by improving it. It identifies the core functions guardianship fulfils (allowing decisions to take place, protection from abuse, promoting legal certainty). These functions are served differently by various forms of guardianship: the status, outcome, and functional approaches. The fulfilment of these functions serves as a metric in the book for evaluating the different forms of guardianship and any alternatives to it, such as supported decision-making.

5. The alternative: supported decision-making (10 000 words)

5.1 What is supported decision-making?

5.2 The psychological assumptions behind supported decision-making

5.3 Forms of supported decision-making

This chapter clarifies the various forms of supported decision-making and the use of this term in practice. While supported decision-making can be understood as a principle and a form of decision-making, the book's goal is to define it as a legal institution fully capable of replacing guardianship.

The chapter explains the concept of interdependent decision-making, which is the basis of supported decision-making. By drawing on relevant work in psychology, it argues that important insights about decision-making are indeed not captured by legal capacity laws: guardianship and the expert assessments leading to it ignore important sources of support crucial for persons with disabilities.

6. Supported decision-making as a legal institution (13 000 words)
 - 6.1 A theoretical framework for the legal regulation of support
 - 6.2 The functions of the legal regulation of supported decision-making
 - 6.3 Comparing guardianship and supported decision-making
 - 6.4 Equal autonomy, or equal basis for autonomy?

This chapter argues that existing proposals on supported decision-making are ideal models which cannot serve as a basis for legal regulation because they cannot be enforced in practice. Supported decision-making as a legal institution must be based on general rules, which produce the highest number of positive outcomes overall. The chapter applies the metric used to evaluate guardianship: supported decision-making must fulfil the same functions. It has to allow decisions to be made, it has to protect individuals from abuse, and it has to protect legal certainty. Contrary to other scholars, I do not think that supported decision-making excludes the possibility of overruling decisions of persons with disabilities. The law sometimes allows even for fully capable persons' decisions to be overruled to protect them from abuse. The question is whether a mechanism can be found such that the overruling of decisions occurs only in circumstances in which it is indeed necessary.

The chapter argues that supported decision-making is a very flexible institution: depending on design choices (e.g. who has power to overrule decisions, through what procedures, on what legal basis) it can balance between the various functions of legal capacity laws in different ways. Depending on the needs of a given jurisdiction to prevent specific harms, it can emphasize autonomy over protection from abuse, or vice versa, in various combinations. Guardianship is an extreme way of resolving such dilemmas. The chapter shows that supported decision-making is clearly better for most persons with disabilities. While guardianship has advantages for state bodies (cost and ease of administration) which cannot not be overlooked, these are not a legitimate reason for retaining guardianship.

7. The case of persons with high support needs (14 000 words)
 - 7.1 Existing solutions – and their flaws
 - 7.2 The Modified Support Framework – a proposal for a third option
 - 7.3 Safeguards
 - 7.4 Equality of persons with high support needs

Building on the arguments and analyses presented in the preceding chapters, this chapter deals with the question of how persons with severe disabilities can be incorporated into a support framework. The book recognizes that some persons are unable to make decisions with support. However, this is not a reason to retain guardianship for them. Decisions on their behalf can also be made in a Modified Support Framework. I argue that supported decisions can be enforced up to the point at which outside observers (e.g. courts) can be satisfied that the decision was indeed made by the person with disability, and not by their supporters. Therefore the legal cut-off point for enforcing decisions is the ability of the disabled person to communicate their decisions. Beyond this point, the legal system cannot differentiate between supported and other types of decisions. The book relies on the concept of facilitated decisions, but it is argued that these are subject to a different legal regime than supported decisions.

The chapter evaluates the Modified Support Framework by comparing it to guardianship and the currently existing proposals on supported decision-making. It divides persons with disabilities for analytical purposes into four distinct groups, and evaluates how the different systems would treat them: persons able to make decisions alone, persons able to make decisions with support and able to communicate them, persons able to make decisions with support but unable to communicate their choice, persons unable to make decisions. The chapter argues that the Modified Support Framework is better for some groups, and not worse for others, than its alternatives. Therefore it is the best solution overall: it allows the most persons to benefit from supported decisions without giving up on protection from abuse.

8. Shortcomings of other alternatives without supported decision-making (8 000 words)

Improving guardianship with (or even without) introducing supported decision-making at the same time is a popular alternative for governments. Therefore this chapter analyses a proposal for improving guardianship by introducing into it some of the features of supported decision-making. It has been argued that by placing restrictions on how and on what basis decisions of the person with disability can be overruled, guardianship can become a form of co-decision-making, very similar to supported decision-making. Nevertheless, even this form of improved guardianship suffers from an important weakness: it is based on ex-ante categorization of persons with disabilities. This locks these persons into false categories and therefore does not benefit from supported decision-making's flexibility. Guardianship can certainly be improved, but this chapter argues that there is a limit beyond which supported decision-making becomes the superior alternative.

9. Conclusion (2 000 words)

This chapter explains the relevance of this book's proposal to the lives of persons with disabilities. Most reform proposals suffer from aiming for the impossible: allowing all persons with disabilities to always make autonomous choices. This book argues that this is a false standard: autonomy is not absolute even for persons without disabilities. It is influenced by factors such as education, income, the existence of social networks, and others. Legal capacity laws cannot eliminate such social barriers. At best, it can aim at strengthening rather than weakening decision-making abilities, but it cannot compensate for all social disadvantages.

The book concludes by highlighting how the supported decision-making model proposed would empower persons with disabilities to the fullest extent possible while protecting them from abuse at the same time. It underlines that the goal should be for them is to be as autonomous as other persons who are similar to them in their social characteristics. Law cannot compensate for all disadvantages, but it must aim at strengthening rather than weakening individuals' decision-making abilities.

IV. Goals and intended audience

This book has two main goals and hence intended audiences. First, it aims to resolve one of the most controversial issues of international human rights law, the question of the equality of persons with severe disabilities in decision-making, which is of great interest to academics.

Second, the book provides guidance on how to reform legal capacity laws, a highly relevant topic for practitioners in the field.

The question of how persons with severe disabilities can be equal with regard to exercising their legal capacity is a hotly debated topic in academia. Scholars, researchers, and students of human rights and disability studies are well aware of the controversy, and will all appreciate a proposal that can move the field forward. They are the first main audience of this book. The book will be very relevant for all courses related to the Convention on the Rights of Persons with Disabilities (CRPD). Nowadays most European law schools offer such a course – I have myself taught one at both Harvard Law School and Central European University (Budapest), and several at the National University of Ireland Galway. Legal capacity is a central theme of such courses and the book has the potential to become the number one point of reference.

The second main target audience of this book are practitioners involved in administering legal capacity laws, and more generally, those interested in promoting human rights of persons with disabilities. While legal capacity is an issue that is relatively little known to the general public, it is considered one of most important human rights issues in the 21st century (as stated by the Council of Europe’s Commissioner for Human Rights). It affects close to 1% of the population of developed countries, and as populations continue to age, its importance will only increase. Most elderly persons will need some form of supported decision-making in their lives, and this book proposes how to create a universal framework for this. Guardianship reform is the top priority for most countries’ disability rights activists, and is also the biggest obstacle, the most contested issue, for governments intending to implement the CRPD.

184 countries have ratified the CRPD so far, and others will soon follow. The book provides guidance on how to implement the CRPD through guardianship reform to create inclusive societies which protect the fundamental rights of persons with disabilities. This will make it of crucial importance to all practitioners in the field of legal capacity. Among practitioners, the first interested group includes policy-makers and civil servants in ministries of justice and disability affairs, and in legislative bodies. The second large group includes actors administering the guardianship system: courts deciding guardianship cases (judges, clerks), expert witnesses (psychiatrists, psychologists, social workers), attorneys practicing in this area, and public administration bureaus such as guardianship authorities and social protection offices. The third large group includes advocates pushing for reform, such as NGOs, persons with disabilities and their family members. I will use the book, and so will other advisors to governments, to provide advice on how to reform guardianship systems in line with the requirements of the CRPD.

The book draws on examples mostly from the European context, but the proposal is not specific to any jurisdiction; it is applicable to all countries of the world.

V. Author’s profile and relevant expertise

My interest in the issue is not merely theoretical. I have been a human rights attorney for 18 years, representing persons with disabilities before the highest domestic courts and international bodies such as the European Court of Human Rights in Strasbourg, the European Committee on Social Rights, and the UN Committee on the Rights of Persons with Disabilities. I have litigated legal capacity issues in high profile cases, such as *Kiss v. Hungary*, *Stanev v. Bulgaria*, and *Sykora v. the Czech Republic* in Strasbourg, and *Bujdosó v. Hungary* before the UN CRPD Committee. My advocacy predates the CRPD – I was one of the first lawyers in the world to

work on this issue internationally. I contributed to drafting the key relevant article of the CRPD during its negotiations in 2005. When Hungary became the first country to implement the CRPD through guardianship reform in 2007, I was involved in the Ministry of Justice's working group drafting the relevant parts of the Civil Code. The bill was later withdrawn by a new government, but was adopted successfully by other countries in the region.

My experience in this field led me to pursue an SJD degree at Harvard Law School and write my dissertation on this topic. As a member of the Harvard Law School Project on Disability (HPOD), and later as an Executive Director of Validity Foundation (formerly the Mental Disability Advocacy Center – MDAC), I received numerous requests and advised advocates and governments all around the world about how to implement a CRPD-compliant guardianship reform, in places as varied as Bangladesh, Croatia, Peru, Mexico, the USA, Canada, Ireland, Finland, Norway, Uganda, Kenya, Somalia, South Africa, India, Slovakia, the Czech Republic, and Germany. I am convinced that this is the book that they need. It is a culmination of my research and my career as an attorney and a person involved in legislative reform.

My practical experience makes me uniquely positioned to address this topic. Other books have addressed the issue, but none to date have been able to come up with a proposal which incorporates persons with severe disabilities in a support framework.

I am currently continuing my research in this area. I am a Lecturer at the National University of Ireland Galway's Centre for Disability Law and Policy (CDLP), where I am Director of the LLM in International and Comparative Disability Law Programme. I am teaching Legal Capacity Law, and publishing articles in this field. CDLP is one of the few research institutions in Europe focusing solely on disability rights and offering this type of degree. We are well connected with academics and international organisations interested in disability rights worldwide. I am also a long-time Affiliate of the Harvard Law School Project on Disability, which allows me to reach audiences interested in disability rights worldwide.

VI. Length

The book will be approximately 75 000 words long.

VII.

I attach my full CV at the end of this proposal.

VIII. Competing titles

Several other books have addressed the issue of legal capacity of persons with disabilities, but have been unable to formulate a universal framework for laws based on support able to convincingly incorporate persons with severe disabilities. Most commentators of supported decision-making, including in peer reviewed journals, refrain from commenting on the status of such persons. The few who do note that the issue is difficult and controversial, and do not have a solution at the moment. Those who have tried to incorporate persons with severe disabilities into a support framework have been criticized for denying the inability of these persons to make decisions (Tina Minkowitz, Amita Dhanda), or for simply recreating guardianship for them under a different name (Michael Bach and Lara Kerzner, Eilionóir Flynn, Anna Arstein-Kerslake).

Two large commentaries on the CRPD have been published so far: Valentina Della Fina, Rachele Cera, Giuseppe Palmisano (eds.), *The United Nations Convention on the Rights of Persons with Disabilities – A Commentary* (Springer, 2017); and Ilias Bantekas, Michael Ashley Stein, and Dimitris Anastasiou (eds.), *The UN Convention on the Rights of Persons with Disabilities – A Commentary* (Oxford University Press, 2018) (I contributed two chapters to the latter volume.) These two books contain an analysis of the international legal standards relating to the legal capacity of persons with disabilities, and note the controversy related to persons with high support needs. While important contributions to the field, the two books focus primarily on international legal sources, notably the jurisprudence of the UN Committee on the Rights of Persons with Disabilities, which contains a strong mandate to prohibit guardianship and to involve persons with disabilities in a support framework, but is insufficient to explain how that could be done.

Another edited collection, Charles O'Mahony and Gerard Quinn (eds.), *Disability Law and Policy: An Analysis of the UN Convention* (Clarus Press, 2017) contains several chapters on legal capacity (one is written by myself). These chapters analyse the experience of countries in reforming their guardianship systems, which were unable to extend supported decision-making to persons with severe disabilities. The chapter by Tina Minkowitz offers a radical proposal to abolish all guardianship measures, without addressing how to safeguard the interests of persons who are unable to make decisions with support. Minkowitz's implicit position is that no such persons exist, which is widely rejected in academia.

A book by Eilionóir Flynn, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011) identifies guardianship reform as crucial to implement the CRPD, and notes the difficulties involved, notably the situation of persons with high support needs. It explores the factors critical for success of national disability strategies, such as leadership on the part of government and civil society, participation of disabled people in implementation and monitoring, transparency and accountability in reporting on progress. However, the volume does not apply these general suggestions to how specifically guardianship reform can incorporate persons with high support needs.

Another book by Eilionóir Flynn, *Disabled Justice?: Access to Justice and the UN Convention on the Rights of Persons with Disabilities* (Ashgate, 2015) addresses legal capacity as a key issue in access to justice for persons with disabilities. It analyses the experience of people with disabilities in the justice system, from making a complaint, to investigation, and through the court process, from the perspective of various roles people with disabilities participate in through the justice system. The book calls for a reform in line with the CRPD's requirements, but does not contain a proposal on how to achieve it.

The book by Camillia Kong, *Mental Capacity in Relationship: Decision-Making, Dialogue, and Autonomy* (Cambridge University Press, 2017), argues persuasively for a relational understanding of capacity from a philosophical perspective. It convincingly explains the shortcomings of individualistic conceptions of autonomy for persons with disabilities, and offers a plausible alternative based on relational autonomy. While the proposed solution is elegant, the book does not explain how to operationalize the theoretical approach in legal practice. Importantly, it also fails to explicitly incorporate persons with severe disabilities in its scope.

Lastly, Anna Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities: Realizing the Right to Equal Recognition before the Law* (Cambridge University Press, 2017), analyses in detail human rights abuses related to guardianship. It discusses the importance of decision-making and identifies the international standards designed to ensure the equal right to make decisions for persons with disabilities. It also explores the need to reform legal capacity laws and notes the controversy about incorporating persons with severe disabilities into a support framework. It does not have a solution on how to achieve it.

IX. Concluding comment

The proposed book will radically change the state of the field of international human rights law related to disability rights. It addresses the most difficult, most controversial question in this area, the decision-making of persons with severe disabilities, and proposes a solution which overcomes the deadlock in current academic debate. It does so by developing a Modified Support Framework, which is based on support and eliminates guardianship and its inherent restrictive features, but at the same time allows substituted decisions to be made on behalf of persons with severe disabilities who cannot make their own decisions. I anticipate that it will have a major impact on scholarship, by becoming a reference point for all academic work in this area. It will be an important textbook for human rights courses on disability rights. I expect it also to be the most important reference point for governments, practitioners and international organizations interested in reforming and administering legal capacity laws all over the world. It is important that such a book receive the publishing and distributional support it deserves; therefore I look forward to working with Hart Publishing in its publication.