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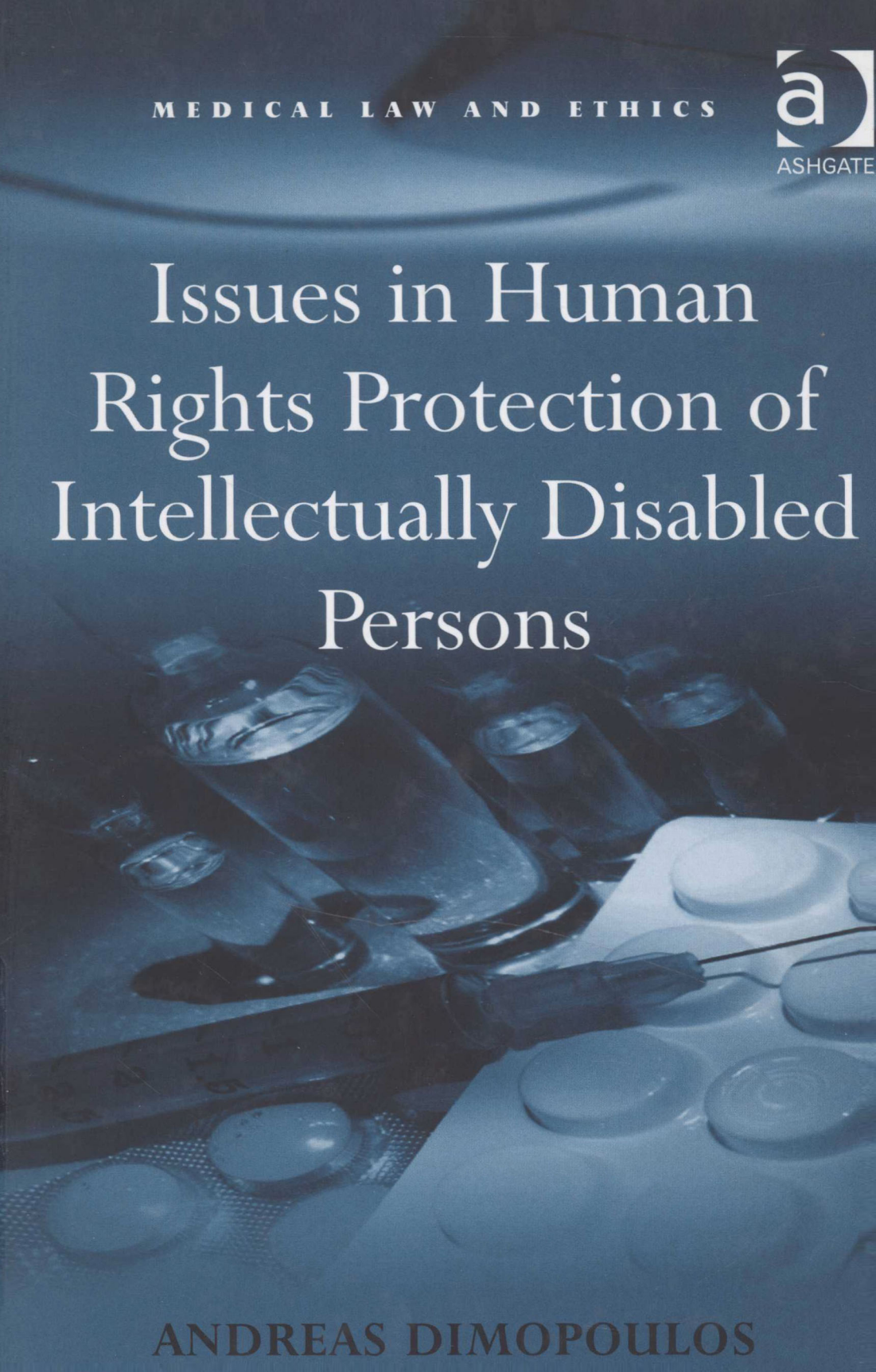

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ISSUES IN HUMAN RIGHTS PROTECTION OF INTELLECTUALLY DISABLED PERSONS

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Preface

This book aims to examine several conceptual difficulties in liberal human rights theory which are linked to intellectual disability. The first issue is the theoretical problem of accommodating non-autonomy within liberalism. The second issue relates to English law, and concerns the critique of common law best interests. The final issue touches upon the European Convention on Human Rights and the necessity of updating the Convention through the means of a disability protocol. These issues are treated as themes running through the argumentation of the book rather than being dealt with in separate chapters.

The term 'intellectual disability' has been used throughout the book to draw attention to the cognitive impairment of the person. We felt that this term is more in line with the distinction that the social model of disability draws between the impairment of the person (the biological factor) and her disability, which is brought about by exclusionary social practices. The more appealing term 'learning disabilities' has therefore not been used.

Even though much of the argumentation of the book is based on or inspired by disability rights theory, the analysis remains very much a legal argument as to how human rights theory may include persons with intellectual disability as equals in liberal legal systems. Intellectual disability poses a rather different set of legal issues when compared to other forms of disability. This book tries to reflect these differences and present a convincing argument as to how these differences may cohere with current human rights practices.

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To my parents, Christos and Paraskevi

Contents

Introduction

Theories of liberalism are based on the assumption that the individual is an autonomous agent. Contested questions of public morality have been answered in liberal theory by recourse to concepts such as autonomy and consent. What is more, human rights within liberalism have also been inextricably linked to autonomous choice. Negative rights especially, as the inalienable rights of man, were primordially conceived of as areas of freedom where the state could not interfere and where the citizen was empowered to act independently.

On the contrary, the present volume shifts the focus of attention in liberal theory from autonomous agency to cases where the individual is not autonomous, or has contested autonomy. The analysis examines the legal position of persons with intellectual disability within liberalism and human rights theory, as the paradigm case of contested autonomy in the context of liberal theory. The question here is whether and how the human rights of persons with intellectual disability are being exercised by the bearers of the rights themselves and/or protected by third parties.

The analysis shows convincingly that persons with intellectual disability are currently enjoying a low protection of their human rights. In several instances, such as involuntary sterilisations or donations of regenerative organs and tissue, legal safeguards against abuse are in practice unacceptably low.

The adoption by the General Assembly of the United Nations of the Convention on the Rights of Persons with Disabilities (CRPD) in late 2006 is hoped to provide the much-needed benchmark against which current practices in relation to persons with disabilities will be measured and will eventually change for the better.

Even though the rights protected by the CRPD do not make any formal distinction between intellectual disability and other forms of disability, this volume attempts to gauge the potential impact of the CRPD on issues of intellectual disability and human rights protection.

In further contrast to the CRPD, we will focus on intellectual disability as a rather distinct (but not separate) issue within the greater disability rights debate. An important argument in this volume is that intellectual disability poses a distinct set of human rights challenges when compared with other types of disability. This difference lies in the character of intellectual disability. Intellectual disability is stereotypically considered to diminish the autonomy of the person and thereby undermine the position of the person with intellectual disability as an *active* bearer of human rights. In other words, intellectual disability means contested autonomy, which is the prerequisite of liberalism, and as such, intellectual disability requires a reworking of our understanding of liberalism.

Even though the CRPD does address many of the specific issues that intellectual disability raises in respect of human rights protection, further thinking is required in order to buttress the position of persons with intellectual disability as equal bearers of human rights within liberalism.

With this analysis of the current state of things as a theoretical backdrop, the aim of this volume is to present a theory as to how persons with intellectual disability can be allowed to flourish in a liberal setting through the exercise of their human rights, even though they may be perceived as non-autonomous. Here, we borrow elements from the disability rights movement as well as human rights theory, in order to develop a legal argument as to how persons with intellectual disability may fit within liberalism and human rights.

In order to better understand the parameters of this question, we take a close look at the position of persons with intellectual disability in the English legal system, and comparatively, at German law. Immediately, the initial question behind this analysis becomes apparent. When everything in liberal legal systems is structured on autonomy and consent, and one is presented with an individual whose autonomy is contested, how can a liberal political community respond in a way which, firstly, grasps the issues at stake and secondly, respects that difference?

Historically, an early liberal response to this question has been paternalism. Persons without autonomy, or contested autonomy, were denied rights as they were considered unfit to control their exercise. Subsequent changes in social attitudes, and the renewed emphasis placed on autonomy and consent in relation to ethical questions posed by the rapid expanse of medical science, have now eroded the acceptability of paternalistic attitudes, even for persons with contested or no autonomy. Through the relentless efforts of the disability rights movement, paternalism has become increasingly harder to justify, whereas more freedom of choice has been granted to persons with disabilities.

The driving force behind the disability rights movement has been a new way of engaging with disability. Persons with disabilities have been stereotypically portrayed as sick and deviant, whereas their lives have been described as a personal tragedy. In contrast to this medical model of disability, the social model advanced by the disability rights movement describes disability as social oppression. Disability is the product of social exclusionary practices. People *become* disabled when faced with economic, environmental or cultural barriers which society places in their way.

This novel way of conceptualising disability has indeed had a liberating effect on disabled persons. The blame is rightly put on an exclusionary and indifferent society, whose practices must change. The person with disability is a blameless victim, who must stand up and fight for her rights.

Naturally, the social model of disability applies with equal force to persons with intellectual disability. However, the general description of disability as social oppression fails to focus on the distinguishing feature of intellectual disability. Here, the disabling feature, the exclusionary practice is a legally important criterion, the prerequisite for valid legal actions: whether the person has autonomy

or not. It follows, at least for this volume, that a different way of conceptualising liberalism and human rights is required, so that the exclusionary criterion of autonomy is suitably modified or even removed from liberal theory, at least in respect of persons with intellectual disability.

To make matters worse, the issue of contested autonomy in the case of intellectual disability has been phrased in a dichotomy between claims for freedom and the need for protection. Persons with intellectual disability may sometimes lack the intellectual capacity or social skills and experience to prevent serious harm to their person, and their freedom must be curtailed accordingly. However, framing the question according to these terms does not help to advance the claims of persons with intellectual disability for more freedom, but rather inadvertently serves to justify paternalistic attitudes. In many instances, a so-called objective answer as to whether a person with intellectual disability is in need of protection may be hard to find.

However, the argument of this volume is that a principled approach to issues of intellectual disability is indeed possible. Since the disabling feature of intellectual disability is legal – the prerequisite of autonomy – a different legal analysis of autonomy is required. The argumentation adopted transposes the dichotomy between claims for freedom and the need for protection in a more rigorous legal vocabulary. The claim of the disability rights movement for more freedom is replaced by human rights, and the need for protection of vulnerable persons, such as persons with intellectual disability, is regarded as interference with these rights.

In other words, the theoretical issue shifts from a clash between freedom and protection to an analysis of what it means for persons with intellectual disability to hold human rights. The question changes in order to ascertain to what extent the intellectual disability of a person may justify an interference with her rights. This is a question which is designed to protect areas of freedom held by persons with intellectual disability from unnecessary intrusions. Moreover, conceptualising the issue of intellectual disability in human rights terms introduces a more nuanced analysis, since concepts such as proportionality immediately come into play. In the context of the English legal order, this analysis is particularly relevant after the incorporation of the European Convention on Human Rights (ECHR) in the Human Rights Act (HRA) 1998.

Parallel to this line of argumentation runs a broader enquiry, as to whether a legal framework of liberal theory can be found to support this human rights reasoning. Can a legal theory of liberal equality be found for persons with intellectual disability? Liberal theory bases equality on equal moral worth. Women, or black people, whose rights were being suppressed for centuries, gained their status as equal participants in liberal society as they convincingly put the argument forward that they are autonomous moral agents. Persons with intellectual disability however may have limited understanding of morality, or limited autonomy, or both. Their inclusion as equals in theories of liberalism underpinned by the importance of autonomous moral agency is therefore doubtful.

We will overcome this problem by engaging with the theory of liberal equality proposed by Ronald Dworkin.[1] This volume argues that Dworkin's ethical individualism can be modified to accommodate persons with intellectual disability as equals in liberal theory. The theoretical issue develops into an analysis as to how a liberal political community can set down a legal framework which is inclusive enough to ensure equality for persons with intellectual disability on the same footing as autonomous persons.

The principles which support these two lines of enquiry differ from the usual language of autonomous agency that liberal theory uses. Since there is contested autonomy, or no autonomy in the case of persons with intellectual disability, a different way of conceptualising liberalism and human rights is required. The argument has to be structured differently, but also in a way which coheres with liberalism.

As a solution to this issue, we will present an interpretive argument based on human rights theory. Human rights form an inextricable part of contemporary liberal theory, where, in the case of negative rights, the autonomous exercise of a human right is protected against state interference. In human rights declarations and related human rights documents, it is stressed that all persons are equal in dignity and rights. Human dignity is regarded as the normative fountainhead of human rights. It follows that in cases where there is no autonomous exercise of human rights, the residual principle of human dignity has to be applied in order to answer how these rights are to be protected and exercised.

Article 3 of the CRPD reinforces this argument, since human dignity features at the top of the list of principles underlying the CRPD, together with autonomy. Moreover, we will argue that this human dignity argument applies with equal force in the case of the ECHR. Human dignity may be used as a general principle in the interpretation of the ECHR in order to provide a higher standard of human rights protection to persons with intellectual disability. Finally, however, the argument of this volume is that an additional disability protocol to the ECHR is needed in order to bring the ECHR more in line with the developments in international human rights law which were brought about by the CRPD.

Part I develops these ideas and presents the arguments in relation to intellectual disability, liberalism and human rights. Chapter 1 defines intellectual disability. It provides a brief presentation of social policy relating to persons with intellectual disability. The social model of disability is also analysed in relation to intellectual disability. Chapter 2 moves on to present the challenges intellectual disability poses to liberalism. It presents the normative content of human dignity for this volume. It develops the human dignity argument we will advance, as well as a theory of liberal equality for persons with intellectual disability, based on human dignity.

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1 R. Dworkin, *Sovereign Virtue: The Theory and Practice of Equality* (Cambridge, MA: Harvard University Press, 2000).

We will claim that, even though human dignity is philosophically complex, the principle has been used rather simplistically in human rights law: what does it mean, after all, that all human beings are equal in dignity and rights? Subsequently, we will analyse how liberal theory can ensure equality for persons with intellectual disability, by engaging with the theory of liberal equality advanced by Ronald Dworkin.

Part II turns to the current legal practice, which relates to the protection of human rights of persons with intellectual disability. In respect of international law, Chapter 3 examines the CRPD and attempts to gauge its potential impact on the rights of persons with intellectual disability. Chapter 4, on the other hand, scrutinises the existing case law of the European Court of Human Rights (ECtHR) in relation to intellectually disabled applicants. The argument of the volume is that the ECtHR has not been able to develop a coherent and fully fledged interpretation of human dignity in its case law, and for this reason, problems of human rights protection arise when the ECtHR is faced with disabled applicants.

Chapters 5 and 6 are devoted to a comparative analysis of national law. Chapter 5 furnishes an analysis of English law relating to persons with intellectual disability. We will argue that the challenges of intellectual disability are not adequately addressed by English law. The incorporation of the ECHR by means of the Human Rights Act 1998 has radically changed the legal position of persons with intellectual disability. This has not filtered into the provisions of the Mental Capacity Act 2005.

Chapter 6 compares the position of English law in respect of persons with intellectual disability to that of the German legal system, which is squarely based on the principle of human dignity and the protection of constitutional rights. We will claim that German law has developed a coherent legal framework in order to protect the rights of persons with intellectual disability, even though there are several German court judgments which offer hardly any protection to persons with intellectual disability.

The final part of this volume brings the analysis to a close by providing illustrations as to how the human dignity argument we have advanced makes a difference in the law. In Chapter 7, we revisit the sterilisation case law from the human dignity perspective to argue that important safeguards are still missing from the approach of English law. The application of German law in relation to authorised sterilisations is also criticised. The importance of human dignity is further examined in the context of the CRPD.

The volume concludes in Chapter 8 by arguing that a disability protocol should be added to the ECHR. This protocol should clearly flag disability as a sensitive issue within the rights protected by the ECHR. Furthermore, the protocol could prohibit non-consensual sterilisations for non-medical reasons, and set down restrictions to non-consensual transplantations. Most importantly however, adopting a new protocol on disability would also provide a unique opportunity for the Council of Europe to set down a minimum standard for positive rights for persons with disability and intellectual disability, which would be enforceable through the ECtHR.