CHAPTER 1
Introduction

1.1 Using the law in the fight for social justice

Legislative action is indispensable in the fight to combat the discrimination, abuse and social injustice experienced across the world by people with mental health problems.

This book is intended to assist and speed up legislative and policy reform. It presents a range of conceptual and empirical material which documents the role that legislative actions – whether applying internationally, regionally, at country level, or to devolved regions within countries – can play in combating the discrimination and abuse experienced by people with mental health problems. At the same time, we emphasise that such reform will effect changes ‘on the ground’ only if it is buttressed by enforcement mechanisms as well as societal and discursive shifts in how people with mental health problems are perceived and treated by other members of society.

The relationship between legislative action on the one hand and experiences of discrimination, abuse and social injustice on the other, is undoubtedly complex. It has been argued that ‘legislation has a limited capacity to achieve social transformation’ – but legislation does have significant ‘symbolic and authoritative power, particularly when enforced and publicised through litigation’ (Watchirs, 2005). The book therefore seeks to maximise the ‘symbolic and authoritative power’ of legislation, by further disseminating knowledge of how it can be used to effect change in the lives of people with mental health problems.

There have already been important strides taken in many countries, both in terms of overturning legislation that explicitly discriminates against people with mental health problems and in developing new legislation that better protects and promotes their rights.

There is also a powerful new impetus in the form of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). This Convention, which was adopted on 13 December 2006 and entered into
force on 3 May 2008, is a human rights instrument with an explicit social development dimension. The CRPD lays out a robust framework for promoting, protecting and ensuring the human rights and fundamental freedoms of people ‘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’. By October 2011, there were 153 signatories to the CRPD and it had 105 ratifications. The Convention is legally binding on every State Party that ratifies it, and commits States Parties: ‘to take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities.’

The CRPD has been heralded as a step-change in conceptualising disability and addressing discrimination on the grounds of disability (Lawson, 2008; Arnardóttir and Quinn, 2009; Bartlett, 2009). It has been seen as a document that ‘might indeed mark the dawning of a new era’ (Lawson, 2007). It was written with, and by, people with physical and mental disabilities and its development was characterised by the most significant involvement of civil society of any of the United Nations conventions. Fundamentally, it recognises the capacity of people with disabilities – that is people with mental health problems, people with intellectual disabilities and people with physical disabilities – and places the onus on society in terms of facilitating their full participation. In other words, the CRPD shifts away from a model of disability that is framed around individual dysfunction and culpability to a model in which disability is an issue of human rights and non-discrimination. The CRPD opens up the possibility of real transformation in legislation and policy relating to mental health, and offers new ways in which we might all think about disability and about the ways in which our societies are organised.

The coming into force of the Convention on the Rights of Persons with Disabilities indicates how much there is still to be done at a country level: to transform or abolish existing laws; to draft new laws that adhere to the CRPD; and to implement legislation in ways that have visible and enduring ameliorative impacts on the lives of people with mental health problems.

This book’s focus then, is on how legislation can be used to advance the rights and entitlements that people with mental health problems have as citizens. We hope it will contribute to the significant shift that the CRPD heralds in relation to how we conceptualise and address disability.

Many people still frequently assume that the intersection of mental health and law indicates the specific terrain of mental health legislation. This has exacerbated the tendency to regard those with mental health problems simply as patients, rather than as citizens entitled to the full
complement of rights (Sayce, 2000; Yamin, 2005). Many people who work in mental health services are accustomed to seeing those for whom they care primarily as (and, in fact, sometimes only as) patients. This book refocuses their attention – indeed, the attention of all of us – in order to address how legislation can be used to advance the rights and entitlements of people with mental health problems in their roles as citizens and members of communities and families (Sayce, 2000; Dhanda and Narayan, 2007). There is much talk about legislation intended to ‘protect’ society from people with mental health problems, but little debate about law that is designed to protect people with experience of mental illness from the wrongs that can be inflicted by society.

In approaching such legislation, it is helpful to consider what law can and cannot do. Overarching statements of principle – for example, those favouring non-discrimination – are to be found in many of the statutes and conventions we include and refer to throughout the book. Such overarching statements may be beneficial, as they may re-enforce social norms: law has, as we have already stated, a symbolic value, and that should not be underrated. It is much too simplistic to suggest that changing laws changes attitudes, however, and the overarching principles are likely to be difficult or impossible to enforce without much more specific, implementing legislation. Indeed, professions of ‘formal equality’ within statutes can act as a smokescreen if statutes are not backed up by significant efforts to ensure that laws are translated into real experiences of equality. ‘Formal equality alone,’ it has been argued, can end up simply ‘giv[ing] an illusion that all are equal and that fairness exists, without addressing underlying inequalities in power, access, and socioeconomic and political circumstances’ (Burns, 2010; see also Sayce, 2003). There is much still to be done conceptually – as well as in practice – to determine and to demonstrate how legislation can contribute to the diminution of social inequalities.

In the realm of enforcement, law is better at governing actions than ideas. It is difficult, for example, for the law to make people believe that people with mental health problems are fully-fledged citizens, but it is possible for the law to prohibit those people from harassing and abusing people with mental health problems, or from denying jobs to people with those problems when they are otherwise qualified to be hired. Law can similarly establish complaints mechanisms so that people with mental health problems who feel their rights have been violated can take concrete action for redress. And law can impose duties upon sectors and organisations to have due regard to the need to promote equality of opportunity and eliminate discrimination and harassment: this has the virtue of shifting emphasis away from the individual who has been wronged and placing the onus and responsibility on the body in terms of its facilitation of equality of opportunity.
But creating societies in which people with mental health problems can live their lives free from discrimination and abuse is not simply a matter for law: a non-discriminatory environment must become part of the lived experience of everyone in society – and that is a much bigger task than passing a statute. That is acutely clear in countries in which legislative frameworks are without significant power or authority. There is also a growing body of research from both low- and high-income countries that demonstrates the pernicious effects that can result from the close ties between poverty, disability and social exclusion. This research makes it clear that any use of legislation will need to dovetail with sustained social, structural and political action to address social and health inequalities, as well as social, political and economic marginalisation. To that end, we have included, where appropriate, sources detailing programmes for enhancing non-discriminatory environments that are not essentially legal in structure. Political and legal advocacy both by and on behalf of people with mental health problems is also an essential part of the required social change, and sources that provide advice on these matters are similarly referenced where appropriate. That said, we believe that legal change is one crucial part of this broader process and it is with the specifically legal aspects of reform that the book is concerned.

The book is titled *Mental illness, discrimination and the law: fighting for social justice*. We regard the nexus of discrimination, the law and mental illness as critical both in understanding why social injustice persists, and in mobilising for social justice. Social justice is, of course, based on the premise of the upholding of human rights and on equality of opportunity, but it also demands that individuals and groups within society have equal access to – and equal means of being able to enjoy – both the material and the psychosocial ‘goods’ that circulate within society (Harvey, 1975). Amartya Sen has argued in his recent work on justice that in judging the advantages and disadvantages that different people have in relation to one another, ‘we have to look at the overall capabilities they manage to enjoy’ (Sen, 2009). (Sen means by ‘capabilities’ the substantive freedoms that people have reason to value [e.g. to participate in community life, to appear in public without shame] – rather than income or financial assets.) For many social, economic, and cultural – as well as legal – reasons, people with mental health problems are often restricted in the capabilities they are able to enjoy. There is, additionally, increasing evidence of the unequal distribution of mental health problems within societies – and of its complex relationship with a range of indicators of material and psychosocial deprivation (Kelly, 2005, 2006; Melzer et al., 2004; Sheppard, 2002; WHO, 2010; Wilkinson, 2005; Wilkinson and Pickett, 2010). Improving the lives of people with mental health problems fundamentally demands pursuing social and structural – rather than individualised – solutions. A recent
publication from the World Health Organization (European Region) has argued that: ‘A focus on social justice may provide an important corrective to what has been seen as a growing overemphasis on individual pathology. Mental health is produced socially: the presence or absence of mental health is above all a social indicator and therefore requires social, as well as individual solutions. A focus on collective efficacy, as well as personal efficacy is required’ (Friedli, 2009).

We regard legislation as part of a diverse palette of ‘social solutions’ that can and should be used to combat the unequal distribution of poor mental health within and across societies. Legislation has contributed substantially to the undermining of people’s mental health – by removing people’s rights, denying their capacity, and preventing them from participating in society. But the flourishing of disability rights legislation in a number of countries across the globe over the last quarter century indicates the impact that legislation can have in improving people’s lives, as well as in enhancing community as well as individual self-efficacy (Lawson and Gooding, 2005; Quinn and Waddington, 2009; Waddington and Quinn, 2010). Indeed, the adoption of new legislation has often come after long and hard-fought advocacy by disabled people’s organisations (DPOs) (as well as by the organisations that work alongside and in partnership with them). We draw attention to the fact that the quotation above from the World Health Organization speaks of the need for a focus on collective, as well as personal efficacy. While in lay parlance, engagement with the law is frequently imagined as a realm in which it is individuals who are centre stage – as plaintiffs, defendants, and attorneys – we want to draw attention to how engagement with the law can build and enhance collective knowledge and solidarity. In other words, the more that people with mental health problems – as well as those organisations and stakeholders who work with and alongside them – become aware of their rights and understand the potential within legislation for positive change, the greater the possibility that they will be able collectively to use the law in advocating more broadly for social justice in relation to mental health.

1.2 Whom are we addressing?

Challenging the discrimination and abuse experienced by people with mental health problems ought not be seen as the responsibility of those who are most directly affected by such discrimination and abuse. It is, rather, the responsibility of us all. The potential readership for this book is therefore diverse and wide-ranging. We have endeavoured to minimise the amount of specialised language and terms (whether from the fields of law, disability studies or mental health) to ensure that readers with little
previous knowledge of the topics under consideration are able to map a clear path through the book. However, to assist clarity, a glossary of terms we use most regularly has been included in the Preliminary section of the book. We hope that the content of the book will be of interest to those with previous knowledge of and expertise in these issues as well as those new to them. We consider some of the key audiences to include:

- advocacy organisations and civil society organisations;
- clinicians dealing with mental disorders, allied health professionals and other health care staff;
- people with mental health problems – including people who use or have used mental health services, as well as people who have experienced mental health problems in the past;
- the families and friends of people with mental health problems;
- mental health service user organisations and disabled people’s organisations (DPOs);
- legislators, parliamentarians and people working within government;
- people working in sectors (such as employment, housing, education and public health) that have a significant influence on the everyday lives of people with mental health problems;
- representatives of the media.

It is our intention that readers of this book will:

- become better acquainted with the range of issues and domains over which legislation has influence in relation to the lives of people with mental health problems;
- understand the shift from viewing mental illness and disability only through an individualised, medical lens, to addressing them as matters of human rights and social justice;
- become better acquainted with the international and regional instruments (conventions, recommendations, guidelines etc.) of use in protecting and promoting the human rights of people with mental health problems;
- achieve greater familiarity with legislative frameworks and conceptual innovations that have been pursued in other countries to address the discrimination, abuse and social injustice experienced by people with mental health problems;
- find inspiration from some of the approaches taken in other countries and sectors in order to consider how they might be used in readers’ own countries and sectors.

We hope, indeed, that the book can be used in a number of contexts. These include:

- advocacy in a policy and/or legal context;
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- the development of programmes to address discrimination against people with mental health problems at a variety of levels of action;
- the development of legislative and administrative frameworks to address the discrimination, abuse and social injustice experienced by people with disabilities;
- dissemination of the power that legislation can and does have in shaping the lives of those affected by mental health problems.

### 1.3 The history of this book

The Association for the Improvement of Mental Health Programmes (AIMHP) works to improve and promote mental health programmes worldwide. Its activities include support of academic studies and other theoretical and practical work that can contribute to improving treatment and quality of life of people with mental illness and of their families and raise the value given to mental health by individuals and societies (http://aim-mental-health.org).

In 2006, the AIMHP commissioned a review of legislative actions of use – or potential use – in protecting people with mental health problems from abuse and discrimination. This book is the culmination of that review.

The developmental phase of this book traced a sinuous course. This is indicative of the challenges that are posed by working within this field. These include:

- the relative rapidity with which the legislative environment can sometimes shift (at the moment of this project’s conception, for example, the UN Convention on the Rights of Persons with Disabilities had not yet been adopted);
- the difficulties of ascertaining – given limited resources and personnel – the specifics of legislative environments in particular countries;
- the complexities of bringing together different kinds of expertise and conceptual frameworks when interpreting and ordering the material.

The phases of the project are briefly summarised below, so as to allow readers to have a clearer sense of how and why the book came to fruition in its present form.

#### 1.3.1 Initial review of legislation

The review that was commissioned by the AIMHP aimed to:

- identify and analyse international and country-specific legislative actions that might be held up as successful examples of legislation that combats discrimination and/or abuse on the grounds of actual or perceived mental health problems;
- identify the key principles and characteristics that underlie these successful legislative actions.
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The scope and objectives of the review were refined in light of other recently completed and ongoing projects on the use of legislation and policy to improve the lives of people with mental health problems (e.g. the mental health and legislation projects of the World Health Organization (Chapter 16.2).

The review sought to identify a linguistically and geographically diverse selection of current country-based legislation that could act as exemplars or possible models for the combating of discrimination experienced by people with mental health problems. Specifically, the review:

- endeavoured to represent all regions of the world;
- focused on legislative actions that advanced the rights and entitlements of people with mental health problems within civil society (i.e. focused neither on legislation addressing mental health settings, whether in the community or closed, nor on coercive measures);
- acknowledged that the complex categories of ‘mental health problems’ and/or ‘mental disorders’ are interpreted differently in different parts of the world and by different audiences. Nonetheless, the AIMHP specified that the review should, in determining the scope of relevant legislation, use the category of mental disorders as defined by the International Classification of Diseases (10th edition) (WHO, 1993) to define its area of interest;
- contextualised country-based legislation in light of existing international law, covenants, guidelines and recommendations that pertain to the protection of those with mental health problems and of those with disabilities from discrimination and abuse.

1.3.2 Contributions from key informants

In order to refine the scope and focus of the review, the lead author interviewed a select number of experts to discuss some of the current pressing issues associated with the use of legislative and administrative actions to combat the abuse and discrimination experienced by people with mental health problems. These experts were interviewed in person or by telephone. Key themes and lines of inquiry were distilled from those interviews to help structure the next phase of research, namely contact with a larger number of experts and country informants.

The lead author approached this larger group of key informants via email and/or telephone and asked them to respond to several short questions about legislative actions within their country or region of expertise. The material gathered from these responses did not necessarily represent the full range of relevant legislative/administrative actions available in any particular country. Informants often chose to focus on one or two
legislative actions or mechanisms when identifying relevant or interesting material.

Experts and informants included:

- non-governmental organisations (NGOs) with a focus on legislative and/or policy reform and advocacy to protect and promote the rights of people with mental health problems; these included service-user led, family/carer-led and clinician-led organisations;
- researchers and academics with expertise in legislative approaches to combating discrimination and abuse experienced by people with mental health problems (and by people with disabilities more broadly);
- governmental and intergovernmental organisations concerned with protecting and promoting the rights of people with mental health problems (and of people with disabilities more broadly);
- independent regulators and monitors of health and social care services;
- psychiatrists and other mental health professionals with a strong interest and/or involvement in legislative and/or policy reform in their country.

The sampling of countries on which to focus initially was purposive to ensure that material was acquired from countries with a range of legal traditions and social, political and economic environments. Contacts were initially made via experts known to the AIMHP. Subsequent to this, snowball sampling was also used: the lead author followed up references, organisations and names of additional experts mentioned by existing contacts and generated additional material. She concurrently identified, acquired and analysed relevant legal and policy material, as well as literature from the field of mental health and disability studies, to complement and add depth to country-based submissions. This material comprised both published and grey literature (i.e. materials such as working papers and reports from government agencies that cannot be found easily through conventional channels such as publications).

The lead author also collated international and regional instruments (conventions, recommendations, guidelines etc.) of use in protecting and promoting the rights and entitlements of people with mental health problems (Chapter 14). She critically assessed and assembled the various material gathered in the course of the review into a composite document that contained conceptual arguments as well as a wealth of country-based material. This document was submitted to the AIMHP in July 2008.

1.3.3 Transformation into a book

A small group of experts (several of whom had been interviewed at the start of the review) gathered to assess the review and consider how it might best be transformed into a book. This group – the co-authors of the book – convened in person twice, once in the summer of 2009 and again in 2010,
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to discuss the scope, content and structure of the book and to draft some additional material.

What became clear at this stage was: (a) the difficulty of identifying examples of ‘good practice’ from the material that had been submitted (many of the informants had lamented the inadequacies and weaknesses of the legal frameworks they had described); and (b) the overemphasis on mental health law in many of the submissions.

At that point, it was decided to reaffirm the commitment made in the initial AIMHP review to focus on legislation that pertains to people with mental health problems in their role as citizens and not to focus on mental health laws. This decision was also made in light of the extensive guidance that the World Health Organization has been developing in relation to the reform of mental health law.

It was also decided that it would be invidious for the book to pick out examples of ‘poor’ legislation that had been submitted by our informants. We determined, instead, to contextualise the case examples that we did wish to use through setting them within chapters that addressed some of the domains (e.g. housing, civil and political participation) that are front and foremost when one considers the impact that legislation can have on people’s everyday lives.

The adoption – and subsequent coming into force – of the UN Convention on the Rights of Persons with Disabilities (CRPD) during the course of the book’s development gave added authority to its central purpose. The CRPD also provided a strong framework with which to address one of the aims of the initial review – namely, to identify the key principles of legislation that protects people with mental health problems from discrimination.

The CRPD can be regarded as a distillation of much of the progressive thinking that has been taking place internationally over a number of years vis-à-vis how we might best promote, protect and ensure the rights and fundamental freedoms of people with disabilities. The CRPD, therefore, should be regarded as the font of many of the key principles and concepts that are used within the book in the context of combating the discrimination experienced by many people with mental health problems in diverse legislative contexts – recognising however that mental health problems are not always linked to disability.

The book that has emerged out of the initial review for the AIMHP is characterised by a number of features. The initial review did not survey comprehensively and systematically existing legislation on an international scale, but rather sought to identify a linguistically and geographically diverse selection of current country-based legislative and administrative actions that might act as possible models or ‘tools for thinking’. The book therefore provides a snapshot of some of the models and
frameworks in use in the early part of the twenty-first century to address discrimination and rights violations against those with mental health problems. The examples that are mentioned draw on a variety of mechanisms and are embedded within diverse legal frameworks. We do not advocate a particular legal framework, and we of course acknowledge that specific legislative or administrative actions will need to bear in mind the political, economic, cultural – as well as, of course, legal – contexts into which they will be inserted. While sustained attempts were made to include examples from all regions of the world in the review, there are regions that are not represented in the book. This was both because of difficulty in acquiring material from certain regions and because informants in some countries provided material about which it was impossible – either for them, or for us – to feel optimistic.

Many of the examples that were submitted offered weak protection and promotion of the human rights of people with mental health problems, which meant that we were unable to use them. We are sorry, therefore, that we have not been able to represent all of the countries from which we received submissions. We would also stress that if a country is not represented in the book, this does not mean that it does not have examples of legislative and administrative action that would be worthy of inclusion. Our selection of case studies is intended to be indicative of what is taking place internationally, rather than the result of a strict sampling frame. We were necessarily constricted by the limited number of countries that we could tap in the time and with the resources that we had. The book over-represents high-income countries (and, in particular, English-speaking countries within the Global North). This is for a number of reasons – one of which is the indisputable fact that certain countries that fall within this category (e.g. New Zealand and Scotland) have been at the forefront of developing robust legislative and administrative frameworks to address the discrimination, inequalities and abuse experienced by people with mental health problems. We have endeavoured as much as we can to include examples from middle- and low-income countries, and from countries outside of western Europe and north America.

The book does not provide readers with details about how to draft law. Nor does it provide substantive discussion of the complexities of legal judgments and of current disability law and of the philosophical debates within the field of disability studies. (Readers should turn for those to a growing number of excellent resources by disability law scholars and practitioners [e.g. see Quinn and Waddington, 2009; Waddington and Quinn, 2010 in relation to Europe].) Rather, it is intended to build the constituency of people and organisations for whom legislative reform and transformation is central in any attempt to address the discrimination, abuse and injustice experienced by people with mental health problems. The route it takes to
build that constituency is one of demonstrating what is possible – through
the use of brief country-based vignettes and case studies – in contexts that
range significantly in their financial resources, their legal traditions and
their social, cultural and economic specificities.

Material for the initial review was gathered over two years (June
2006–June 2008). Significant efforts have been made to check and, where
necessary, update all material that was chosen from the initial review for
inclusion within the book; we cannot guarantee that that has been possible
in all cases. In addition, because the book has relied on submissions (many
of which comprised translated material) from country-based informants
and has made use of a range of literature (published and grey literature,
as well as material available on and via the internet), we cannot directly
vouch for the accuracy of all the material that is presented here.

The review largely focused on the specifics of legislation itself, rather
than on how legislation has or has not been implemented. Country in-
formants were asked to indicate what they considered to be the strengths
and weaknesses of the legislation that they had identified. The majority of
them specifically raised, unprompted, problems of implementation when
addressing this question. This is cause for concern: legislation without im-
plementation makes no change to people on the ground, and it would be
naive to think that this is not the fate of a number of the examples pro-
vided in this book. Nonetheless, implementation requires good legislative
frameworks – and that is what we have focused on here.

1.4  How the book has been organised

In Chapter 2 (Principles and Concepts), we address key themes that clarify
the context, constraints and opportunities characterising attempts to use
legislation to improve the lives of people with mental health problems.

We present a brief history of the legislative frameworks that have shaped
the lives of people who have been judged to be mentally ill; explain the
distance between most mental health legislation and rights-based disability
legislation; discuss the various ways in which discrimination has been con-
ceptualised; comment on the use of general versus specific law; emphasise
the indispensability of enforcement mechanisms; introduce the concepts
of capacity and competence; provide a brief introduction to human rights;
reflect on the relationship between the stigma, discrimination and ‘struc-
tural violence’ experienced by people with mental health problems; and
clarify our central focus on social justice.

Chapters 3 to 11 cover a wide terrain. They consider some of the most
important spheres in which legislation ought to be and is being used to
combat discrimination and social injustice. Chapters focus on civil and
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political participation; private law and legal capacity; work and the workplace; education; housing; social security and social protection; and health, health care and the right to health. In addition, we consider protections against abuse in research that involves people with mental health problems. In Chapter 11 (Promotion of Mental Health and Prevention of Mental Illness), we discuss legislative and administrative efforts that are devoted to improving the mental health of all citizens, as well as to improving the lives of people with mental health problems specifically.

Chapter 12 (Implementation and Enforcement) discusses the range of tools and mechanisms to be considered when implementing and enforcing legislative transformations.

Chapter 13 (Summary and Conclusions) distils from the conceptual and empirical material presented elsewhere and summarises the journey that the book has taken. We hope that the arguments in this chapter will be in readers’ minds when they turn to the question of how best to develop, transform and use legislation to address the discrimination, abuse and social injustice experienced by many people with mental health problems in their own country or region.

Chapter 14 comprises summaries – and, in certain cases, the full texts – of important instruments, standards and guidelines of relevance in combating the discrimination, abuse and social injustices experienced by people with mental health problems. We include binding United Nations treaties; non-binding international instruments; regional human rights systems, treaties, conventions, charters and standards; and non-binding standards, guidelines and declarations.

Chapter 15 lists examples of disability legislation from across the world and Chapter 16 (Organisations and Resources) points readers to relevant legislation libraries and databases and to literature and resources produced by the World Health Organization. It also includes a list (including addresses and relevant resources) of relevant and prominent intergovernmental organisations and non-governmental organisations (NGOs) that are working to protect and promote the rights of persons with mental health problems.

Readers can choose to make their way through the book from start to finish, or can pick out particular chapters and read them in the order they themselves decide. We do recommend, however, that readers unfamiliar with this literature gain a thorough grounding in the overarching principles and concepts by starting with Chapter 2, Principles and Concepts. All readers will find it useful to move to and fro between Chapters 2 to 13 and the material in Chapters 14, 15 and 16, since we refer episodically in the earlier chapters to instruments, standards and guidelines about which we provide more detailed information in these later chapters.
We have included relevant website addresses and these were checked for accuracy as the book was going to press.

1.5 Terms used to describe mental health problems

Existing international and country-based legislation and policy use a wide variety of terms when outlining procedures and frameworks that relate to people with mental health problems. People with long-term mental health problems are one of the groups comprising ‘persons with disabilities’ within the UN Convention on the Rights of Persons with Disabilities (CRPD) and the phrase ‘persons with disabilities’ is undoubtedly gaining political and discursive traction in a number of spheres and contexts to describe people with mental health problems.

Nonetheless, the international terrain is still characterised by heterogeneous terminologies and categories influenced by history, culture, legislative frameworks, social norms, organisational decisions, domains of expertise and so on. You will therefore find that the material that appears in this book uses an array of terms to describe mental ill health. In much of our main text, we have tended to use the phrase ‘mental health problems’, since this phrase is commonly accepted by many people who have received a psychiatric diagnosis and/or who have experienced mental distress. The term ‘mental disability’ includes people with intellectual disabilities (what used to be called ‘mental retardation’) as well as those with mental health problems and this term features substantially in legal literature. Many people within the disability rights movement prefer the term ‘psychosocial disability’ (rather than ‘mental health problems’) because it moves away from the medical model of disability and instead emphasises the interaction between psychological and social components of disability. The term adheres to the social model of disability (Chapter 2.6), through emphasising that a medical diagnosis becomes a disability when the individual experiences discrimination on account of that diagnosis. The term ‘mental illness’ is used in the title of the book and in some of its sections. ‘Mental illness’ – as well as the term ‘mental disorder’ – is commonly used by mental health clinicians, in health contexts and in many countries’ policy documents.

The wide array of terms – many now considered stigmatising – that are used in case material and resources that were surveyed for inclusion within the book include:

- criminally insane (individuals)
- disabled person/disability/persons with disabilities
- handicap(ped) (person/people)
- intellectual(ly) disabled/disability
- learning disabled/disability
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- mental(ly) disabled/disability
- mental disease
- mental(ly) disorder(ed)
- mental health consumer
- mental health issue/problem
- mental health service user/consumer/survivor
- mental ill health
- mental illness
- mental impairment/mentally impaired
- mental incapacity/mentally incapacitated
- mental patient
- mentally disordered offender
- mentally retarded
- mentally ill (person)/the mentally ill
- person(s) with disabilities
- psychiatric disability/psychiatrically disabled
- psychiatric disorder
- psychiatric illness
- psychiatric patient
- psychosocial disability

People who have received psychiatric diagnoses, and/or people have been categorised as disabled, have powerfully argued and demonstrated that both the specific terms used, as well as the concepts underlying those terms, have a profound effect on society’s attitudes towards people with mental health problems and disabilities (Sweeney et al., 2009; Beresford, 2005; Oliver, 1996). Indeed there is a long history of people who have been described and categorised through the use of disparaging, paternalistic and/or stigmatising language working to transform the terms of political and societal debate. We emphasise that we do not – for the reasons just described – list the terms above in order to recommend any of them for use. We do so to alert readers to how they might, when doing further research of their own, need to expand the terms they use when searching for potentially relevant material.

It is also important to point out that the manner in which legislation defines both mental health problems and disability can have significant consequences for those who then fall under, or are categorised through, that legislation. For example, legislation can compound discrimination if, when establishing the criteria for involuntary psychiatric admission, the thresholds are set too low. In this respect, the World Health Organization has emphasised that: ‘[L]egislation that is primarily concerned with involuntary admission and treatment may restrict the category to only severe mental disorders. On the other hand, legislation concerned with positive
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rights may define mental disorder as broadly as possible to extend the benefits of legislation to all persons with mental disorders (WHO, 2005).

It should also be remembered that many mental health problems are intermittent and episodic. This implies that care should be taken when defining disability as ‘long term’, since this might unwittingly exclude some people with mental health problems from the protections one is wishing to provide through legislation (Lawson, 2008). Legislative efforts to counter discrimination on grounds of disability have thus far – and for a number of complex reasons – arguably been more effective in addressing the discrimination and exclusion of persons with physical impairments than those with mental health problems and intellectual disabilities. One contributing factor to this disparity may well be the way in which physical and mental impairments and resulting disabilities are defined and described.

We wish to point out that the primary focus within the book is on people with mental health problems. Legislation that is relevant will often encompass ‘people with mental disabilities’ – that is will include people with intellectual disabilities as well as people with mental health problems. The term intellectual disability is used increasingly often to avoid the term ‘mental retardation’ which has been found unacceptable by NGOs and individuals concerned and those working in this field. At particular moments in the book, therefore, you will find material that specifically refers to people with intellectual disabilities (e.g. Chapter 5.2: Intellectual disabilities and labour force participation). Please note, however, that our book does not claim to cover all legislative issues that are relevant to people with intellectual disabilities; these are covered elsewhere (Dimopoulos, 2010; Herr et al., 2003).

1.6 Our authorial voice(s)

The book has been written by a number of authors who are differently located within the complex terrain of mental health and human rights. The authors’ expertise includes mental health law, psychiatry, sociology, stigma and discrimination, service user research, epidemiology and socio-legal studies. There were, unsurprisingly, differences in terms of how authors approached the conceptual, legal, practical and political issues addressed by the book, and lively discussions and differences of opinion in the course of drafting some of the content. (Any of you who have participated in forums that bring together lawyers, psychiatrists, mental health service users, disability rights experts and sociologists, for example, will be familiar with the inevitable terminological tussles that characterise them!) The domain of mental health is undoubtedly a political and politicised one, not least because there is substantive and ongoing debate over the

Different authors took overall responsibility for the development of and content within different parts of the manuscript, with the help of informants from a number of countries around the world (given in the Acknowledgements in the Preliminary section of the book). We have tried to ensure that the book that has emerged coheres in terms of its substance, register and rhetoric. Nonetheless, the book bears the imprint of the many discussions and viewpoints that contributed to its development, and careful readers will be able to find traces of more than one discourse concerning mental health and mental illness as the book progresses.

References


Chapter 1


