DISCRIMINATION AGAINST PERSONS WITH MENTAL DISORDERS: THE IMPORTANCE OF LEGAL CAPACITY

Studies from India

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Discrimination against Persons with Mental Disorders: The Importance of Legal Capacity

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“We are all mad here, I’m mad, you are mad” said the Cat

- Alice in Wonderland

Dedicated to
My Father
For teaching me the difference between Law and Justice
&
Seema
For Everything
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Chapter 1 through 3 comprise the introduction to the overall thesis. Chapter 4 to 10 are based on 7 co-authored articles that have been published or submitted to peer-review articles. Chapter 11 consists of an Epilogue and the discussion and conclusions follow in Chapter 12.

Part 1
Chapter 4


Part 2
Chapter 5


Part 3
Chapter 6

Pathare, S, Nardodkar, R, Shields, L, Bunders, J & Sagade J. (Accepted for publication) Gender & mental illness and the Hindu Marriage Act, 1955. *Indian Journal of Medical Ethics*

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Epilogue
Chapter 1
Introduction

Violations of the human rights of persons with mental disorders is common occurrence around the world. These include violation of civil, political, economic, social and cultural rights. Violations of rights happen not only in institutions but also in the community. These violations are largely due to absence of legal protections against improper and abusive treatment as well as due to discrimination (WHO, 2005).

1. Discrimination against persons with mental disorders

Discrimination suffered by persons with mental disorders is universal. It continues to happen with distressing regularity to this day as is illustrated by the following three brief case descriptions.

Romania:

“Valentin Câmpeanu was born in 1985 in Romania and was abandoned at birth. He was of Roma origin and grew up in orphanages and like so many other children, was infected with HIV through blood transfusion. He developed learning disabilities at a young age. On reaching the age of 18 he was transferred to an adult institution which denied him antiretroviral medication. When his physical health deteriorated, he was – bizarrely – transferred to a psychiatric hospital.

On 20 November 2004, staff of the NGO Centre for Legal Resources (CLR) visited the hospital and met Mr Câmpeanu, half-clothed, kept in a side room in sub-zero temperatures and severely malnourished. They saw how nurses refused to touch him for fear of contracting HIV. A few hours later, he died.

Following his death there was no investigation and no-one was held to account.”

- Mental Disability Advocacy Center, 2014
Brazil:

“Damião Ximenes Lopes, Brazilian, was 30 years old in October, 1999 when he was admitted by his mother to the only psychiatric clinic in the municipality of Sobral, in the state of Ceará. Damião was suffering from a severe mental condition, which is why his mother, Albertina Viana Lopes, took him to the aforementioned institute to receive medical attention. The clinic, called Casa de Repouso Guararapes (Guararapes Rest Home), was accredited by Brazil’s public health care service, known as the Unified Health System (SUS). Four days later, his mother returned to visit her son at the clinic. (Cássia Maria Rosato & Ludmila Cerqueira Correia, 2011, p. 96)

He [Damião] came to her [his mother] staggering, with his hands tied behind his back, bleeding from his nose, his head swollen and his eyes practically shut, collapsing at her feet, filthy, hurt and smelling of feces and urine. He fell at her feet crying out for her to call the police. She did not know what to do and asked that he be untied. His body was covered in bruises and his face was so swollen that he was barely recognizable.”


Damiao later died.

India:

“Twentyfive mentally ill persons, including 11 women, were killed and five suffered burns in a devastating fire which swept across a private home for mentally ill at Erwadi, a tiny pilgrim centre 27 km. from Ramanathapuram in Tamil Nadu, early on Monday.

The fire began around 5.10 a.m. and, as the home was thatched with coconut palm fronds, the entire shed was gutted in 10 minutes, before fire tenders reached the spot.

Eyewitnesses said the fire broke out in the northern part of the shed and spread like wildfire in a short span of time. All that remained at the site were charred bodies fettered in chains and pieces of flesh, making it impossible to identify those killed.
On seeing the flames, villagers as well as pilgrims rushed to the spot and saw smoke billowing out of the shed. The entire area was steeped in darkness and they could not hear anything but the inmates' groans.

As all the inmates of the asylum were kept in fetters (the so-called "divine chains" put round the feet of the mentally-ill), they could not come out of the shed.”

Suresh Kumar, 2001

We are aware of the above stories as they are in the public domain. There are many more such incidents which go unreported and undocumented. These are extreme cases which resulted in death and relate only to mental health care, but they are by no means uncommon around the world.

Discrimination is an everyday occurrence for many people with mental disorders in all spheres of life. Discrimination leads to denial of opportunities to live a normal social life (for example the lack of job opportunities), exclusion from the community (forced to live in segregated mental institutions) and abuse (physical, mental and sexual) (Amnesty International Ireland, 2009; Funk, Drew, Freeman, Faydi, & WHO, 2010; Harnois & Gabriel, 2000; Mental Disability Advocacy Center, 2007; Mental Disability Rights International & Asociación Pro Derechos Humanos, 2004; Open Society Mental Health Initiative, 2006; Read, Adiibokah, & Nyame, 2009; Santegoeds, 2007).

Stigma and discrimination affects people’s income generation potential and negatively impacts their ability to lift themselves out of poverty. There is evidence that persons with mental health conditions are also discriminated against in development programmes and this leads to deeper economic and social marginalization (Funk et al., 2010).

Stigma and discrimination are inter-related and represent two facets of the same underlying phenomena. Stigma represents the negative attitudinal aspects associated with mental disorders, while discrimination represents its behaviour component. We have had little success in changing attitudes (and therefore reducing stigma) towards mental disorders (Kapungwe et al., 2010; Sartorius, 2010; Thornicroft, Rose, Kassam, & Sartorius, 2007). There are many difficulties, not least of all, measuring attitudes and attitude change. It may be argued that we are better off directing our energies to reducing discrimination.
Since discrimination is behavioural, it is directly observable and potentially can be prevented.

Discrimination can be addressed directly by legislative efforts (e.g. laws to prevent discrimination) and policy efforts (e.g. affirmative action). Addressing discriminatory laws and discriminatory policies also send out a strong anti-stigma message to the community.

This thesis hopes to shed light on this important issue and suggest possible solutions for addressing discrimination faced by persons with mental disorders.

1.2. International Efforts to stop Discrimination against persons with mental disorders

This section does not intend to do a review of all international conventions per se, but to highlight specific conventions and articles in these conventions which are directly related to the concept of non-discrimination. So for example, while non-discrimination forms the bedrock of the International Covenant on Civil and Political Rights (ICCPR) (UNGA, 1976a), it does not specifically include an article on non-discrimination for persons with disabilities and hence it is not reviewed here.

1.2.1 Universal Declaration of Human Rights

“All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood”

- Article 1, Universal Declaration of Human Rights, 1948, p. 2

The Universal Declaration of Human Rights (UDHR) in 1948 was one of the first international attempts at ending discrimination and protecting human rights of ALL the people of the world without any distinction (UNGA, 1948). Article 1 reiterates that all persons (including persons with mental disorders) are equal in dignity and rights. Article 1 also categorically states that all [emphasis added] persons are endowed with reason – which has importance when one talks about decision making abilities of persons with mental disorders.

Article 2 of the UDHR further clarifies that all persons are entitled to all rights and freedoms without distinction of any kind [emphasis added] and Article 6 reiterates that everyone has a right to recognition everywhere [emphasis added] as a person before the law.
Unfortunately, persons with mental disorders have been denied these very basic rights which the international community guaranteed to citizens of countries which signed the UDHR, more than 60 years ago (WHO, 2005). In many of these same countries which have signed the UDHR, including India, laws and policies discriminate against persons with mental disorders; for example they are presumed to be unable to make reasoned decisions and this is used to justify the denial of decisional capacity as well as legal capacity. (European Union Agency for Fundamental Rights, 2010; Mental Disability Advocacy Center, 2007)

1.2.2 International Covenant of Economic Social and Cultural Rights (ICESCR)

“The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”

Article 2.2 ICESCR, p. 7

The International Covenant of Economic Social and Cultural Rights (ICESCR, (UNGA, 1976b) along with the UDHR and the International Covenant on Civil and Political Rights (ICCPR) together make up what is known as the International Bill of Rights. The division of rights between the ICESCR and the ICCPR is now accepted as an artificial division, a relic of Cold War history and it is now generally accepted that rights are indivisible.

The Committee on Economic, Social and Cultural Rights (CESCR), the treaty monitoring body for the ICESCR has adopted two General Comments of specific interest to persons with mental disorders: General Comment 5 on persons with disabilities and General Comment 20 on Non Discrimination in Economic, Social & Cultural Rights (Committee on Economic, Social and Cultural Rights, 1994, 2000)

General Comment 5 adopts the definition of disability as included in the Standard Rules, 1993. “People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature.” (Committee on Economic, Social and Cultural Rights, 1994, p. 2)

This General Comment states that the ICESCR prohibits discrimination on the grounds of disability with disability being included in ‘other status’ in Article 2.2 above. It also refers to both ‘de jure’ and ‘de facto’ discrimination and the need to eliminate both. The General Comment (paragraph 15) states clearly “For the
purposes of the Covenant, “disability-based discrimination” may be defined as including any distinction, exclusion, restriction or preference, or denial of reasonable accommodation based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights.”(p. 5)

General Comment 5 also clarifies that Article 10 of the ICESCR implies the rights of persons with disability to marry and have their own family.

General Comment 20 (Committee on Social Determinants of Health, 2009) states that non-discrimination is “an immediate and cross-cutting obligation in the Covenant” (p. 3) and is not subject to ‘progressive realization’ as the rest of the Covenant. Hence a lack of financial and other resources cannot be a sufficient excuse for countries to fail to take action to eliminate discrimination. Countries that have ratified the Convention (and India has) are expected to take steps to remove all forms of discrimination including formal discrimination, substantive discrimination, direct as well as indirect discrimination and address systemic discrimination faced by certain groups.

General Comment 20 prohibits discrimination on the grounds of disability, including disability due to mental disorders. It includes health status, including mental health status under the category of ‘other status’ as grounds resulting in discrimination. Countries are also expected to “adopt measures to address widespread stigmatization of persons on the basis of their health status, such as mental illness...” (p. 10). These measures include (a) Legislation to address both formal and substantive discrimination and impose obligations on private and public actors to prevent discrimination; (b) Policies, plans and strategies to address both formal and substantive discrimination by public and private actors and (c) Steps to eliminate systemic discrimination by taking an active approach with a range of laws policies and programmes including temporary special measures.

1.2.3 UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (MI Principles)

In 1991, the MI Principles were adopted by a UN General Assembly Resolution (UNGA, 1991). The MI Principles tried to establish minimum human rights standards of practice in the mental health field by establishing standards for treatment and living conditions in mental health facilities, and created protections against arbitrary detention in such facilities. The MI Principles also recognized that persons with mental disorders have a right to live, as far as
possible, in the community. The MI Principles have been criticized for their uncritical acceptance of the medical model of mental disorder and treatment and the Principles’ endorsement of involuntary detention and treatment (Rosenthal & Rubenstein, 1993). Although the MI Principles support the principle of free and informed consent, this is however limited when the person is considered to lack capacity. This limitation of capacity along with the MI Principles’ endorsement of the medical model of mental disorders, provides clinicians with a broad discretion to impose medical treatment on the basis of ‘the best interests’ principle (Weller, 2010).

1.2.4 Convention on the Rights of Persons with Disabilities (CRPD)

“States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.”

- Article 5.2 CRPD, p. 7

The CRPD is the first comprehensive treaty of the 21st century and one of the fastest negotiated human rights treaties. It was the first human rights convention to be opened for signature by regional integration organizations such as the European Union (UN Enable, n.d.; UNGA, 2007)

Although the UDHR, the ICCPR and the ICESCR promote and protect rights of all persons, it was felt that persons with disabilities were left out of the international human rights framework. The CRPD brings together in one instrument, civil, political, social, economic and cultural rights supplemented by a participatory framework (Wilderman, 2013). The CRPD adopts a social model of disability so that disability is viewed as arising from an interaction between the individual, with physical and mental impairments, and barriers in the environment. This contrasts with a medical model where disability is perceived as solely due to impairments in the individual. The adoption of a social model of disability opens possibilities for social action to facilitate the full enjoyment of all human rights by persons with disabilities.

The CRPD states that persons with disabilities “include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” (p. 4)

Thus persons with mental disorders are clearly identified as beneficiaries of this Convention.
Article 2 of the Convention defines discrimination as “any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms.” (p. 4)

CRPD further reaffirms the principle of Equality and Non-Discrimination in Article 5 by stating that all persons with disabilities “are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.” (p. 7)

This principle of Non-discrimination before and under the law is further reinforced by Article 12 of the Convention which pertains to legal capacity. Article 12 is said to represent a ‘paradigm shift’ in the way we perceive persons with disabilities. Article 12.2 states “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” (p. 10)

Article 12.3 requires countries to put in place a system of supports to assist persons with disabilities to exercise their legal capacity. Thus the CRPD through Article 12 encourages countries to replace systems of substituted decision making with systems for supported decision making.

The Committee on the Rights of Persons with Disabilities has recently adopted a General Comment on Article 12. The General Comment states the following:

“Legal capacity is indispensable for the exercise of civil, political, economic, social and cultural rights. It acquires a special significance for persons with disabilities when they have to make fundamental decisions regarding their health, education and work. (The denial of legal capacity to persons with disabilities has, in many cases, led to the deprivation of many fundamental rights, including the right to vote, the right to marry and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty.)” (Committee on the Rights of Persons with Disabilities, 2014, p. 2)

The General Comment further says “The CRPD (Article 12) now makes it clear that ‘unsoundedness of mind’ and other discriminatory labels are not legitimate reasons for the denial of legal capacity (legal standing and legal agency).” (p. 3)

There is a close relationship between the two concepts of Non-Discrimination and Legal Capacity which is recognized in this General Comment on Article 12.
Denial of legal capacity is inherently discriminatory and on the other hand, discriminatory labels such as ‘unsound mind’ are used to deny legal capacity to persons with mental disorders.

The General Comment very eloquently outlines the impact that such discriminatory denial of legal capacity has on the lives of persons with mental disorders:

“In most of the State party reports that the Committee has examined so far, the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed. This is decided simply on the basis of the diagnosis of an impairment (status approach), or where a person makes a decision that is considered to have negative consequences (outcome approach), or where a person’s decision-making skills are considered to be deficient (functional approach). The functional approach attempts to assess mental capacity and deny legal capacity accordingly. (Often based on whether an individual can understand the nature and consequences of a decision and/or whether she/he can use or weigh the relevant information.) This functional approach is flawed for two key reasons. The first is that it is discriminatorily applied to people with disabilities. The second is that it presumes to be able to accurately assess the inner-workings of the human mind and to then deny a core human right – the right to equal recognition before the law – when an individual does not pass the assessment. In all these approaches, a person’s disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but rather requires that support be provided in the exercise of legal capacity.” (p. 4)

The General Comment also reminds countries that the CRPD (through Article 12 (3)) proposes a solution by exhorting countries to move to a system of supported decision making (see paras 14, 15, 16 of the General Comment).

1.3 The importance of Legal Capacity

Self-determination or the right to choose and act based on personal choice is fundamental to enable people to achieve their full potential (Ryan & Deci, 2000). Laws recognize this capacity of persons to act independently to promote self-determination and enable persons to achieve their full potential as human beings. However as Dhanda & Narayan say, this capacity to act has been
regarded as questionable for persons with mental disorders (Dhanda & Narayan, 2007). Legal systems across the world presume that persons with mental disorders (and with intellectual disabilities too) are unable to act and manage their lives independently. This presumption of incapacity has been given legal recognition through laws that deny legal capacity to persons with mental disorders (Dhanda, 2008).

Denial of legal capacity affects many spheres of a person’s life. In the health sector, for example, denial of legal capacity and the consequent appointment of a guardian means the person has no role in choosing the type of treatment they will receive or the setting (hospital, community etc) where the treatment will be delivered. The guardian can also decide where and with whom they should live, how their money, property, and personal affairs should be managed, and other aspects of their daily lives (European Union Agency for Fundamental Rights, 2010; Mental Disability Advocacy Center, 2007). Denial of legal capacity also means that a person is excluded from participation in political life and social life, such as for example the right to vote, the right to marry and to have children (European Union Agency for Fundamental Rights, 2010; Funk et al., 2010).

The presumption of lack of capacity for self-determination and the consequent denial of legal capacity to persons with mental disorders is the fundamental discrimination which then leads to discrimination in other spheres of life.

Weller (2010) argues that mental health laws must conceptualize capacity along a continuum of capability and recognize the decision making capacity of persons with mental disorders. Some radical user activists (Minkowitz, 2010) argue that mental health laws violate the CRPD, facilitate torture and ill-treatment and “cannot be reformed and should be abolished...” (p. 177). There is tension between this radical position of user activists with the professional position (Widerman, 2013) which has proposed a ‘fusion law’. This covers all persons, regardless of whether they have a ‘mental’ or a ‘physical’ illness, and only allows involuntary treatment when a person's decision-making capability for a specific treatment decision is impaired — whatever the health setting or cause of the impairment — and where supported decision making has failed (Szmukler, G., Daw, R., & Callard, F., 2014). These authors argue that a fusion law is consistent with the CRPD and eliminates discrimination against persons with mental disorders.
1.4. Challenges to Mental Health Care in India

International Conventions such as ICESCR and the CRPD are ‘hard’ international law and are binding on countries that ratify these conventions. Although all international conventions have well defined monitoring mechanisms, it needs to be acknowledged that the international community has very few tools to enforce compliance by countries that ratify these international conventions. Monitoring largely depends on ‘name and shame’ and is essentially voluntary. That is, countries voluntarily agree to subject themselves to convention based monitoring mechanisms.

Thus international conventions are essentially a promise made by countries to its own citizens as well as to the international community that they will follow these conventions. Real people benefit only if these international conventions and covenants are implemented in countries. This requires efforts within countries at different levels. In some countries (especially India) legislative efforts are needed to domesticate the convention based rights into national legislation. There is also a need to address resource issues such as financial resources and human resources for implementing these conventions. Implementing conventions may require additional human resources or additional training of existing human resources or both. Efforts are also required to raise awareness about these convention rights and sensitize the broader community and society. Stakeholders and the broader community may have their own concerns about how these convention based rights will work in their own culture and society. These concerns will need to be addressed if these conventions are to be implemented and are to improve the lives of the intended beneficiaries.

Moreover, in the area of mental health care, the CRPD has brought a ‘paradigm shift’ in the way society perceives persons with mental disorders. This paradigm shift from ‘objects of charity’ to ‘subjects with rights’ challenges the established way of doing things and providing mental health care. The move from a ‘medical model’ of disability to a ‘social model’ of disability represents another paradigm shift which is especially challenging to mental health professionals who are largely trained in a medical model of disability.

India has ratified all the above international Conventions including the CRPD. Mental health care, as delivered in India (as in most parts of the world), faces challenges in addressing the issue of discrimination and the denial of legal capacity. Mental health laws in many countries, including India, adopt a ‘status
approach’ to deny legal capacity to persons with mental disorders. India’s Mental Health Act, 1987 (MHA) provides for full and plenary guardianship for persons with mental disorders based on a status approach (The Mental Health Act, 1987a)(see Dhanda, 2010). There are also many procedural deficiencies in the MHA with respect to guardianship. There is no provision for appeal against this guardianship provision and the law does not require the presence of the person who is alleged to have mental disorder to be present or to be legally represented when guardianship decision is made.

There are challenges to implementing a supported decision making regime for persons with mental disorders in India. There are no models for supported decision making which take into account the cultural context of Indian society and the financial and human resource constraints faced by a low-middle income country like India (see Dhanda, 2010). A further challenge is the predominance of a medical model of health and social care for persons with mental disorders in India. India’s health and social care laws are based on a medical model (as opposed to a social model) of disability. (See The Mental Health Act, 1987b; The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1996).

There is a direct link between the above issues. Laws and policies need to move to from a medical model of disability to a social model of disability as this will lead to recognition of legal capacity of persons with mental disorders. In turn, the recognition of legal capacity of persons with mental disorders will force the health system and other systems such as the justice system to look for, and implement models of supported decision making for persons with mental disorders.

Based on the above, it is hypothesized that, Indian laws and their judicial interpretation systematically discriminate against persons with mental disorders through the denial of legal capacity and thus prevent their full and effective participation in society. The legal regime therefore acts as a significant barrier to implementing CRPD in India for the benefit of persons with mental disorders. These legal barriers go hand in hand with attitudinal barriers of mental health professionals towards persons with mental disorders.

Based on this hypothesis the overall research question guiding this thesis is as follows:

*What are the legal barriers to implementing full citizenship rights for persons with mental disorders in India and what strategies and opportunities can be
identified to move towards a more rights based system for persons with mental disorders in India?

1.5 Outline of the Thesis

This thesis consists of five parts. The first part includes a global review of discrimination experienced by persons with mental disorders (Chapter 4) and it sets the stage for the subsequent chapters. Part 2 of this thesis focuses on the content of mental health legislation at the international level (Chapter 5). Part 3 of the thesis focuses on the content of one particular legislation in India (The Hindu Marriage Act) exploring how the content and practice of this law impacts persons with mental disorders (Chapter 6). Part 4 of the thesis is focused on strategies for changes needed at the legislative and professional level and consists of 4 papers (Chapter 7-10). Part 5 of the thesis (Epilogue Chapter 11) focuses on applying lessons learnt into practice, whilst drafting India’s new Mental Health Care Bill.
Chapter 2
Theoretical Concepts

This chapter will elaborate on a number of theoretical definitions and concepts relevant to the themes presented in this thesis. The chapter starts with a brief discussion of the difference between the medical model of disability versus a social model of disability and why a social model is preferred. The concept of personhood and capacity, how conventional definitions of capacity deny personhood to people with mental disorders, the need for an expanded and broader definition of capacity and the essential features of such a broad capacity definition are then discussed. The essential features of a supported decision making paradigm and how it is different from substitute decision making are also discussed. The discussion also emphasizes the reasons for moving from a categorical classification of capacity (present/absent) to understanding capacity as a continuum ranging from fully autonomous decision making at one end to substitute decision making at the other end with different types of decision making (including supported decision making in the middle). Finally, this chapter will conclude with how such a conceptualization of capacity helps persons with mental disorder retain legal capacity while not jeopardizing their need for care and treatment.

2.1 Social Model of Disability versus a Medical Model of Disability

The medical model of disability essentially focuses on individual bodily impairments and disability is seen as a deficit of functioning due to this physical or mental impairment. In stark contrast, the social model of disability rejects this conceptualization of disability outright. Social model theorists conceptualize ‘impairment’ as a loss of functioning of some physical or mental organ or the loss of a body part. However they conceptualize ‘disability’ as a society that discriminates, disadvantages and excludes people with impairments, as it does not make appropriate accommodations and gives preference to those without impairments (Oliver (1990, 1996a) and Barnes (1991, 1999) as cited in Anastasiou & James Kauffman, 2013). As Barnes (1991, 2) (as cited in Anastasiou & James Kauffman, 2013) defines it: “Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers” (p. 442). Social model theorists see disability as purely a social construct and hence emphasize the need to
change social structures which lead to discrimination and exclusion of persons with disabilities.

The Convention on Rights of Persons with Disabilities (CRPD) (UNGA, 2007) also uses a social model to understand disability. It too conceptualizes disability as a social construct and says “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others’ (preamble e, p. 1)

This conceptualization of disability in the CRPD is not without its critics. The social model of disability does include the notion of ‘impairment’ but the CRPD focuses almost entirely on the social barriers (Bartlett, 2012; Kayess & French, 2008). Bartlett (2012) also notes that the literature from within the UN and academic community has focussed almost entirely on the social barriers.

2.2 Personhood and Capacity

The concepts of ‘personhood’ and ‘capacity’ are intertwined and closely related. Conventionally, laws recognize ‘persons’ as those who can make autonomous or independent decisions (Bach, 2007; Dhanda & Narayan, 2007). This notion of having the capacity to make independent decisions is an important point which requires a more in-depth conceptual exploration. As outlined in Chapter 1, many legal jurisdictions have moved to a functional approach to capacity. The functional approach (WHO, 2005) determines capacity on the basis of a person’s ability (or inability) to:

a) Understand the information relevant to the decision and;

b) Retain that information and;

c) Use or weigh that information as part of the process of making the decision and;

d) Communicate his or her decision by any means (by talking, using sign language or any other means)

Bach (2007) argues “this notion of personhood has roots that go back at least a few thousand years. It has served to diminish, and in many cases abolish, the moral and legal status of persons with intellectual disabilities who are considered unable to ‘measure up’ to these criteria.” (p. 8). Quinn (2010) states
the debates around legal capacity are basically about competing conceptions of personhood.

While Bach (2007) speaks of intellectual disabilities, as shown by the General Comment from the Committee of Rights of Persons with Disabilities (2014), this is equally true of persons with mental disorders.

The capacity definition above is a cognitive (rational) definition of capacity (Wilderman, 2013) which means that many persons with mental disorders will automatically be excluded from it. However many authors including Quinn (2011) question this depiction of capacity and decision making as a purely cognitive process. Quinn criticises this definition by calling it the ‘myth of the masterless man’ – that is, individuals making rational decisions on their own with no reference to emotion, experience or social factors. He argues that we make decisions in a relational sense – that is, taking into account the wishes of important others, that we do not always make ‘rational’ (cognitive) decisions and past experience plays an important role in decision making (Quinn, 2011).

Another important issue is that many legal jurisdictions (that use a status approach or an outcomes approach to capacity), require persons with mental disorders to prove their capacity and thus be recognized as persons before the law. This presumption of lack of capacity (Dhanda, 2008) creates an unfair burden on persons with mental disorders. It is important to highlight here that for people without mental disorders (that is, the rest of society) the presumption is one of capacity, that is the law presumes that a person has capacity and legal personhood, while incapacity has to be proved. The situation is reversed in the case of persons with mental disorder. This reverse presumption is particularly discriminatory to persons with mental disorders, as the legal system is effectively ‘raising the bar’ for persons who because of their disability are likely to have difficulties in decision making.

To summarize, there is a need to address two specific issues: (a) a new definition of capacity is needed, which is broader and encompasses persons with mental disorders and (b) a presumption of capacity is needed for persons with mental disorders. The Convention on Rights of Persons with Disabilities tries to bring about this ‘paradigm shift’ in our understanding of personhood and capacity.

The current definition of capacity is dichotomous: so a person either has capacity or lacks capacity. In reality, capacity is more fluid. Bach (2007) has proposed a broader definition of capacity, as follows:
Persons who have capacity are individuals of legal age:

(i) who can *make decisions*, with or without the assistance of others; and/or

(ii) who can *make their will and intent* known to others (with assistance of others); and/or

(iii) whose *narrative coherence* (in the terms of moral philosophy) can be presented; or whose personal identity and life story (past, present, and hopes for the future) can be narrated or told in a way that makes sense to others (p. 8).

If we accept the above definition of capacity, it leads us to perceive decision making capacity as a continuum ranging from fully autonomous decision making on one end to substituted decision making at the other end with supported decision making in the middle. It also means we see capacity as a fluid process, where people can move along the spectrum at various times and depending on the decision to be made.

Bartlett (2012) raises three specific questions based on CRPD’s conceptualization of capacity:

To what extent can incapacity as a concept still be used at all?

Can decisions ever be made by an individual on behalf of a person with disabilities, and if so on what criteria?

Insofar as the exercise of legal capacity may be limited, what safeguards are required?

[See Bartlett (2012) for a full discussion of these questions]

It is important to note here that Canada and Australia entered reservations on Article 12 to ensure that their systems of substitute decision-making could remain for people lacking capacity, implying that they saw incapacity as a relevant concept.

On the other hand, user-survivor activists refuse to accept any limitations on capacity and claim that all determinations of incapacity are inherently discriminatory under the CRPD and such legislative arrangements should be dismantled (Minkowitz, 2007).

The United Nations High Commissioner for Human Rights veers towards the user-survivor interpretation of CRPD’s view on capacity (UNGA Human Rights
Council, 2009). The UN High Commissioner says ‘[where] the existence of a disability is a direct or indirect ground for a declaration of legal incapacity, legislation of this kind conflicts with the recognition of legal capacity of persons with disabilities enshrined in article 12, paragraph 2’ (p. 14)

Szmukler et al (2014) propose a fusion law (as discussed in Chapter 1) to try and reconcile these conflicts around compliance of mental health laws with the CRPD. The fusion law proposal, while recognizing the legal capacity of persons with mental disorders, also addresses the specific situation when irrespective of the disorder (physical or mental illness) a person’s decision making capacity may be impaired and where supported decision making has failed. The fusion law proposal is based on the Bach and Kerzner (2010) model of decision making discussed below:

Source: (Bach & Kerzner, 2010, p. 96)

This model allows for extreme situations when capacity may be limited and a facilitated decision maker has to make decisions on behalf of the person with disability. Bach and Kerzner implicitly through their model interpret the CRPD as recognizing some limitations on capacity and refer to Articles 12 (3) and (4) for ensuring that such limitations are done with due process and with adequate protection.
This also leads us to consider the meaning of accommodation and supported decision making and how this can be facilitated for persons with mental disorders.

2.3 Accommodation and Supported Decision Making

Two inter-related concepts need to be considered when discussing supported decision making: Accommodation and Support. Both these concepts are enshrined in the CRPD. Article 12 (3) requires State Parties (countries) to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” (p. 10) and Article 5 (3) requires that State Parties “In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided” (p. 7).

Accommodation and Support are essential enabling ingredients to eliminate discrimination and promote the exercise of legal capacity by persons with mental disorders. The CRPD defines Accommodation in Article 2 as “Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.” (p. 4)

Accommodation is integral to the exercise of many rights enshrined in the CRPD and is therefore specifically mentioned in articles dealing with access to justice (Article 13), liberty and security of person (Article 14), education (Article 24), work and employment (Article 27). Accommodation is thus a broad anti-discriminatory provision as highlighted by CRPD in Article 2 (Definitions) where, under the definition of discrimination the CRPD says “It includes all forms of discrimination, including denial of reasonable accommodation.” (p. 4)

Ability to make decisions is not dichotomous and it can be enhanced by accommodation to facilitate the exercise the right to decision making by persons with mental disorders (Bach & Kerzner, 2010).

The purpose of Accommodation is to remove discrimination. The CRPD talks about “reasonable accommodation”. This means that the duty to accommodate is not unlimited and accommodations are only required to the point of undue hardship (Bach & Kerzner, 2010).
The Supreme Court of Canada in *Council of Canadians with Disabilities v. VIA Rail Canada Inc.* (2007) in relation to people with disabilities, elaborated on the duty to accommodate to the point of undue hardship, as follows:

“The concept of reasonable accommodation recognizes the right of persons with disabilities to the same access as those without disabilities, and imposes a duty on others to do whatever is reasonably possible to accommodate this right. The discriminatory barrier must be removed unless there is a bona fide justification for its retention, which is proven by establishing that accommodation imposes undue hardship on the service provider” [emphasis added].  

*Council of Canadians with Disabilities v. VIA Rail Canada Inc.*, 2007, p. 698

Bach and Kerzner (2010) also highlight another important aspect of accommodation: that it must be individualized to the needs of the person needing accommodation. Bach and Kerzner further argue that accommodation must always be a legal requirement for persons whose decision making capability may be in question.

Bach and Kerzner (2010) outline a broad range of accommodations that may be required including informal assistance from family and friends, plain language assistance, assisted/adaptive communication, visual aids, etc., supported decision-making representatives/networks and interpreters (sign and spoken language) and interveners (for people who are deaf-blind).

Thus supported decision making is a type of accommodation to enable persons with mental disorders to exercise their legal capacity to make decisions. The person providing support (supporter) is someone who has personal knowledge and relationship with the person who is receiving the support and can (i) ascribe to the person actions, personal intent and will consistent with the person's identity and (ii) take consequential actions to give effect to that will and/or intentions of the individual. (Bach & Kerzner, 2010). The supporter may be an related individual (e.g. family member, friend) or by a related group (a group of friends) or unrelated individuals appointed by the State (Sweden’s Personal Ombudsman - “Kort information om PO-Skåne,” 2004).

The key difference from substituted decision making is that the supporter in a supported decision making arrangement is bound to comply with the person’s wishes (Bach & Kerzner, 2010; Brayley, 2009). Thus supported decision making does not rely on the ‘best interest principle’ which underlies substituted decision making.
General Comment on Article 12 by the Committee on Rights of Persons with Disabilities also clarifies the meaning of “support” (UN Committee on the Rights of Persons with Disabilities, 2014).

‘Support is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication. Support to persons with disabilities in the exercise of their legal capacity might include measures relating to universal design and accessibility, —such as requiring private and public actors such as banks and financial institutions to provide understandable information or the provision of professional sign language interpretation —, in order to enable persons with disabilities to perform the legal acts required to open a bank account, conclude contracts or conduct other social transactions. Support can also constitute the development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences. For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others. All persons with disabilities have the right to engage in advance planning and should be given the opportunity to do so on an equal basis with others.’ (p. 4)

2.4 Decision Making Capability

Following from the arguments outlined above, it is important to move away from questioning the capacity of the person making the decision to enhancing the capacity of the decision making process (Quinn, 2011). In addition, a focus is needed on the person’s ability and strengths rather than on their disability (Bach & Kerzner, 2010; Stein, 2007). Bach and Kerzner (2010) have proposed a model of decision making which applies not only to persons with disabilities but is an integrative model which applies to all persons with or without disabilities. This model can be summarized as follows:

Decision making Capability = Decision making ability (Mental Capacity) + Support + Accommodation

Thus someone who has no impairment in decision making ability will require little or no support and little or no accommodation. Persons with mental
disorders who may have varying levels of decision making ability may require varying levels of support and accommodation. The purpose of the support and accommodation is to ensure that there is adequate decision making capability to make what are considered as *competent decisions*. This model also takes into account that decision making abilities fluctuate over time (and so support and accommodations will fluctuate over time) and decision making ability varies depending on the decision being made. For example, a person may have sufficient ability to decide whether he wants to take a particular medication or not, but may have less or more ability to make financial decisions. In this model, the level of support and accommodation in the first instance (to decide which medicine to take or not) will be very low, but the person may require a high level of support and/or accommodation to make the second decision (about finances).

### 2.5 Substituted decision making

General Comment on Article 12 by the Committee on Rights of Persons with Disabilities (para 23) gives a clear interpretation of the term ‘substituted decision making’. It says that substituted decision making includes plenary as well as partial guardianship. It further goes on to identify certain common characteristics of supported decision making systems - “(i) *legal capacity is removed from a person, even if this is just in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will or (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences.*”(UN Committee on the Rights of Persons with Disabilities, 2014, p. 6)
Chapter 3
Research Design

This Chapter presents the aims and objectives of this thesis and the research questions and the sub-questions on which it is based. The Chapter also discusses the research approach, validity of the data and ethical considerations for the research conducted for this thesis.

3.1 Aims & Objectives

The aim of this thesis is to explore how persons with mental disorders face discrimination and to explore the relevance of law and its practice in reducing such discrimination.

The objectives of the thesis are:

(a) To contribute to a better understanding of how laws and their implementation contribute to discrimination and denial of legal capacity to persons with mental disorders.

(b) To provide insights into how laws and practices can be changed to recognize the legal capacity and thus reduce discrimination against persons with mental disorders.

(c) To analyse how supported decision making tools can be used to promote legal capacity for persons with mental disorders.

3.2 Research Questions

As mentioned in Chapter 1, the main research question of this thesis has been formulated as:

What are the legal barriers to implementing full citizenship rights for persons with mental disorders in India and what strategies and opportunities can be identified to move towards a more rights based system for persons with mental disorders in India?

The literature reviewed in Chapter 1 showed that the Convention on the Rights of Persons with Disabilities (CRPD) has brought a ‘paradigm shift’ in the way
society perceives persons with mental disorders. This paradigm shift from ‘objects of charity’ to ‘subjects with rights’ challenges the established way of providing mental health care. The move from a ‘medical model’ of disability to a ‘social model’ of disability represents another paradigm shift which is especially challenging to mental health professionals who are largely trained in a medical model of disability.

In Chapter 1 it was hypothesised that Indian laws and their judicial interpretation systematically discriminate against persons with mental disorders and prevent their full and effective participation in society by not recognizing the legal capacity of persons with mental disorders. The legal regime in India thus acts as a significant barrier to implementing CRPD for the benefit of persons with mental disorders. These legal barriers go hand in hand with attitudinal barriers of mental health professionals towards persons with mental disorders.

Based on this hypothesis, the main research question is further broken down into following sub-questions:

1. **To what extent are persons with mental disorders treated as persons with rights in low and middle income countries?**

   In order to answer this question, we brought together different sources of evidence from reports and publications in addition to experiences of 51 people with mental disorders from across low and middle income countries to provide a comprehensive picture of the human rights violations experienced by persons with mental disorders. The key findings from this study were that discrimination led to pervasive human rights violations. One of the issues central to human rights violations was the denial of legal capacity. This led to the development of the following sub-questions:

2. **Does the content of mental health laws discriminate against people with mental disorders and if so, how?**

   To answer this sub-question we conducted a review of mental health legislation in Commonwealth countries. Laws in these countries follow a common law principle based on their colonial legacy. We were particularly interested in exploring how the mental health laws dealt with the issue of legal capacity and supported decision making.
3. Does the practice of law in India discriminate against people with mental disorders and if so, how?

To answer this particular sub-question, the Hindu Marriage Act, 1955 (HMA) was analysed to explore how it deals with the issue of legal capacity of persons with mental disorders in the context of marriage and divorce. We also analysed cases of divorce on the grounds of mental disorder filed at one Family Court to see how HMA worked in practice in cases involving persons with mental disorder.

4. What strategies can be employed at the legislative level and at the professional (judicial professionals and mental health professionals) level to prevent discrimination by recognizing legal capacity of persons with mental disorders?

To address this sub-question, a review of laws in different countries was performed to understand how the concept of supported decision making had been operationalized and the lessons for low and middle income countries such as India in implementing a supported decision making regime. Psychiatric Advance Directives (PAD) are one form of supported decision making which allows the person with mental disorder to retain control over her treatment even during periods of illness when there may be severe impairment of decisional capacity. PAD have been introduced in the draft mental health law in India (Mental Health Care (MHC) Bill) which is currently in Parliament. Although PAD are hailed as promoting legal capacity, the experience world-wide has been mixed with poor implementation across many countries. A literature review was done to identify barriers to implementing PAD in different countries and how this may have lessons for implementation in India. And finally, a field-based study was conducted to understand how persons with mental disorders in India may use PAD (as provided for in the MHC Bill) when receiving mental health care.

5. How can lessons learnt from the above inquiries be applied in practice?

The author was a technical consultant to the Ministry of Health and Family Welfare for drafting the new mental health law (MHC Bill) for India. For the past 3 years, the author was also a member of the Policy Group appointed by the Ministry of Health and Family Welfare to draft a National Mental Health Policy and Plan. This epilogue represents a reflection of the author’s application of research findings in mental health and human rights to the MHC Bill as well as work as a member of the Policy Group.
Research Approach

Methodological approach

A mixed methods design was used in this thesis. Different research and methodological approaches were used to answer the different sub-questions of the thesis. Reviews of published literature and reviews of domestic legislation in different countries were appropriate to obtain a global understanding of discrimination faced by persons with mental disorders, best practice examples of countries trying to implement the CRPD in their domestic laws, and the barriers to such implementation. To assess the magnitude of a particular problem or to assess choices expressed by persons with mental disorders, a quantitative approach was considered appropriate. Qualitative methods were used to get a more in-depth understanding of why persons with mental disorders choose particular treatment options.

The methodology used for individual studies is briefly described sequentially below. For more details methods for data collection and analysis refer to the chapters that describe these studies (see Table 1).

Study 1: Human Rights violations of people with mental and psychosocial disabilities: an unresolved global crisis.

This study first reviewed the English language academic literature and publications from WHO & UN agencies, non-governmental agencies and press reports (grey literature) from 1994 to 2011 to summarize the evidence for types of human rights violations experienced by persons with mental disorders in low and middle income countries as well as strategies to prevent these violations and promote human rights in line with the CRPD. The second part of this study is a broad consultation with a convenience sample of 51 persons with mental disorders from low and middle income countries to draw from their expertise and perspective.

Study 2: Mental Health: A legislative framework to empower, protect and care. A review of mental health legislation in Commonwealth member states

The study was commissioned and published by the Commonwealth Health Partners Alliance and was presented at the Commonwealth Partners Forum in May 2013. The Forum is held as part of the Commonwealth Health Ministers’ Meeting during the World Health Assembly in Geneva. For the study we used the provisions of the CRPD to enable systematic comparison of legislation from
different countries. We restricted analysis to dedicated mental health legislation. Most countries do not have ‘consolidated’ legislation covering all areas relevant to persons with mental disorders, but used a ‘dispersed’ style of legislation. Thus provisions related to issues such as employment, housing, social security for example are usually not covered in mental health legislation but may be covered in other relevant legislation on these topics. These ‘dispersed’ provisions are not analysed in this study, as the focus of this research was an analysis of dedicated mental health legislation.

We searched for mental health legislation in 53 of the 54 countries of the Commonwealth, leaving out Fiji which is currently suspended from the Commonwealth. We were unable to obtain mental health legislation from 4 countries and there is no mental health legislation in 4 other countries. Thus we obtained mental health legislation from 45 countries which are included in the analysis.

**Study 3: Gender & mental illness and the Hindu Marriage Act 1955**

For the study exploring the role of mental disorders in divorce petitions under the Hindu Marriage Act, data was collected at the Family Court in Pune, Maharashtra. It is difficult to get permission from Courts in India to do an analysis of cases filed in Courts and the only access to legal judgements is for those where such judgements are released for publication. In most instances, it is cases from the High Courts and Supreme Court that are published and there are usually no publications from lower courts such as Family Courts. An opportunity was afforded by the willingness of the Hon. Principal Judge of the Family Court, Pune to allow access to study and analyse cases at their Court. We believe this is the first instance of this kind of access and analysis of divorce cases involving mental disorders from Indian judicial system.

We first searched through the yearly registers of cases filed for divorce at the Family Court Pune, and found details of the cases where annulment under Section 12 (1) (b) or Section 12 (1) (c) or divorce under Section 13(1) (iii) of HMA were pleaded (these sections allow annulment/divorce respectively on grounds that the spouse has a mental disorder). We then systematically examined the case records and read through these records manually. We had initially planned to find relevant cases for a period of 20 years, backwards from 2012 to 1993. However, it was progressively difficult for the staff of the Family Court to find cases for the earlier years and we were only able to find cases for decisions given by the Family Court throughout a 17-year period (1996 to 2012).
Data extraction from the cases included information on: date of marriage, date of separation, date of filing the petition, date of judgment, who had filed the petition (husband or wife), what type of relief was sought, what type of medical evidence was presented in the petition, and the final judgment of the court. No personal identifying information such as name, address, contact details were recorded from the case records.

To obtain similar cases at the High Court level, an electronic database search was conducted using the Supreme Court Cases Database (SCC Online) as well as Indiankanoon.org for a period from 1976 (when HMA was amended) to 2013. The first relevant judgement extracted from the search was from the year 1981. Cases were included if they were filed under the current HMA and the grounds pleaded for nullity or divorce were mental disorder (Section 12 (1) b or 12 (1) (c) or Section 13 (1) (iii)).

**Study 4: Supported decision making for persons with mental illness**

The aim of this study was to analyse supported decision-making processes in the light of Article 12 of the CRPD, examine best practices in supported decision-making internationally and point towards how components of supported decision-making can be implemented. In particular we were interested in exploring models of supported decision making of relevance for low and middle income countries where resource constraints may act as a barrier to shifting legal and social sectors to a model of supported decision making. To this end, we conducted a literature review.

Studies in decision-making are not always conducted as Randomized Controlled Trials (RCTs), and restricting inclusion to a particular study design could substantially limit relevant data included in the evidence base. We therefore included RCTs, quasi-experimental studies, and qualitative studies and grey literature (policy documents, legislation, unpublished presentations, reports) in this review. In total, we reviewed 25 research studies and 30 papers providing information on legislation in 16 countries.

**Study 5: Barriers to using psychiatric advance directives in clinical practice**

PAD are legal documents detailing a person’s preferences for future mental health treatment and care in advance of decisional incapacity. PAD are a form of supported decision making and meet the requirements of Article 12 of the CRPD (Committee on the Rights of Persons with Disabilities, 2014). PAD have been included in India’s MHC Bill but concern had been expressed regarding the
utility and operationalization of such PAD in Indian context (Kala, 2013; Sarin, Murthy, & Chatterjee, 2012).

Previous research on usage of PAD in the United States (US) has shown that between 4 and 7% of those surveyed have completed a psychiatric advance directive (Swanson et al., 2003) but there is high demand with 66 to 77% of service users expressing a desire to write a PAD (Swartz, Swanson, Van Dorn, Elbogen, & Shumway, 2006; Wilder et al., 2013).

The aim of this study was to obtain greater understanding as to why it has been difficult to implement PAD globally by reviewing the barriers highlighted in the existing evidence base. Another purpose of the review was to put forward potential research questions, which can be tested to inform how particular barriers could be alleviated and how PAD uptake could be scaled up.

We therefore reviewed the English language literature for papers focusing on PAD and included studies as long as at least 50% of the sample population reported mental illness. As studies in this area are often not conducted as randomized controlled trials, we broadened our inclusion criteria to include qualitative studies. We included 30 studies in the review and barriers were assessed at 3 levels: the system level, health professional level and at the user level.

**Study 6: Unpacking the psychiatric advance directive in under-served settings: An exploratory qualitative study in Tamil Nadu, India**

This study uses a qualitative approach to assessing the feasibility of PAD once implemented into practice in India. Data were collected at an NGO (Banyan) run mental health clinic at Chennai, Tamil Nadu. The Centre for Mental Health Law and Policy, Indian Law Society, has ongoing collaborative relationship with Banyan for teaching and research activities and this provided an opportunity for this research. The clients (service users) of Banyan are broadly representative of persons with mental disorders accessing services from public mental health services in the country. The study included a total of 51 semi-structured interviews with clients (n=39) and carers (n=12) and these were analysed thematically.
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Study 7: What do service users want? A content analysis of what users may write in psychiatric advance directives

The aim of this study was to collect additional evidence to facilitate the conceptualization, operationalization and use of PAD in India. We were interested in knowing what users of mental health services in India are likely to write in a PAD if the MHC Bill became law and to assess whether professionals’ fears that PAD will be used to refuse psychiatric treatment (Antony, 2014; Kala, 2013; Sarin et al., 2012) have any empirical basis.

Clients were enrolled in this study from various outpatient clinics run by Banyan in Tamil Nadu, India. Selected clients were asked if they would be interested in completing a PAD after being briefed by the health worker about the PAD. The sample was stratified by gender and location (rural and urban). This was done to ensure that clients living in rural areas and women were represented in the study. The final sample consisted of 75 clients.

Ethical Issues

For study 3, permission was obtained from the Hon. Principal Judge of the Family Court, Pune. No personal identifying information such as name, address or contact details were recorded from the case records in Court.

For studies 6 & 7, local ethical approval was obtained from the Ethical Review Committee of the The Banyan Academy for Leadership in Mental Health.
Informed consent was also obtained from all clients (persons with mental disorders) participating in both studies.

Participants were briefed about the purpose of the study, given an opportunity for terminating their participation in the study without any impact on their ongoing clinical care. Participants had answers to questions or queries raised. In terms of data storage, completed PAD and interview files were stored in locked cabinets with restricted access and available only to core research team members.

For studies 3, 6 & 7, all cases were assigned unique case IDs to replace any personal identification details to protect confidentiality.

**Research Validity**

*Validity of quantitative Data*

For study 3, we did a thorough manual search of the case records to find all cases related to persons with mental disorders for the period from 1996 to 2012. Each case was read, summarized and coded by one researcher and this was reviewed independently by another researcher in order to reduce bias in assessing cases.

For studies 6 and 7, in order to address external validity and generalizability *a priori*, we ensured adequate representation of people with different diagnoses, women (who are typically under-represented in many such studies) and persons from rural backgrounds (who are often sampled less than urban populations). To ensure content and criteria related validity we pilot tested the questionnaire and all researchers were trained in using the questionnaire and facilitating the completion of the PAD.

*Validity of qualitative data*

As Study 6 was a qualitative study, several techniques were used to ensure that the data was replicable and credible. For example, interviews continued until saturation was reached (that is, no new data or themes emerged from the interviewees) triangulation of the data was done at the investigator level and all interview data was reviewed by an independent researcher to check level of agreement on codes and qualitative analysis to enhance inter-rater reliability.

*Validity of data obtained from reviews*

The reviews (studies 1, 2, 4 and 5) were designed as literature reviews with systematic search elements. We included in the reviews, all available literature
(including grey literature) to answer specific questions which were relevant to the audience of this research. Inclusion and exclusion criteria as well as the sifting criteria were documented in all the review studies. All articles included were cross-checked for additional references that could be included in the review and may have been missed in our search strategy. For studies 4 & 5, multiple researchers extracted data and reviewed the papers for inclusion. We also included grey literature which is usually left out of systematic reviews. For study 2, the coding of laws for compliance with the CRPD were reviewed independently by another member of the research team to check that the laws were analysed appropriately.
Part 1

Chapter 4

Human rights violations of people with mental and psychosocial disabilities: an unresolved global crisis
Human rights violations of people with mental and psychosocial disabilities: an unresolved global crisis

Natalie Drew, Michelle Funk, Stephen Tang, Jagannath Lamichhane, Elena Chávez, Sylvester Katontoka, Soumitra Pathare, Oliver Lewis, Lawrence Gostin, Benedetto Saraceno

This report reviews the evidence for the types of human rights violations experienced by people with mental and psychosocial disabilities in low-income and middle-income countries as well as strategies to prevent these violations and promote human rights in line with the UN Convention on the Rights of Persons with Disabilities (CRPD). The article draws on the views, expertise, and experience of 51 people with mental and psychosocial disabilities from 18 low-income and middle-income countries as well as a review of English language literature including from UN publications, non-governmental organisation reports, press reports, and the academic literature.

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Introduction

All over the world, people with mental and psychosocial disabilities experience violations of many civil, cultural, economic, political, and social rights. We investigate the types of human rights violations experienced by people with mental and psychosocial disabilities (panel 1) in low-income and middle-income countries, and review a series of effective strategies to end violations and promote human rights.

Although human rights violations against people with mental and psychosocial disabilities occur in all countries irrespective of income level, the focus of this Series is low-income and middle-income countries, where this issue has been under-researched. Most evidence from these countries comes from reports by non-governmental organisations (NGOs), UN documents, government reports, and the media, rather than from scientific research. Furthermore, the knowledge and opinions of people with mental and psychosocial disabilities have rarely been sought. We therefore undertook a broad consultation of 51 people with mental and psychosocial disabilities from 18 low-income and middle-income countries to draw from their expertise and perspective. We consulted people from the following countries: Belize (n=3), Bosnia and Herzegovina (n=3), Egypt (n=4), Georgia (n=3), Ghana (n=1), Indonesia (n=3), Jordan (n=8), Kenya (n=1), Lithuania (n=1), Mexico (n=1), Nepal (n=9), occupied Palestinian territory (n=2), Paraguay (n=1), Peru (n=2), South Africa (n=2), Sri Lanka (n=4), Tajikistan (n=1), Zambia (n=1), unspecified (n=1). We attempted to contact respondents from low-income and middle-income countries across different parts of the world, but this was limited by time, resources, and the constraints of our convenience sample. As such, we bring together different sources of evidence from reports and publications in addition to the experiences of the consultation group, to provide a comprehensive picture of the situation.
We interpret our findings to offer guidance on how best to act on the UN Convention on the Rights of Persons with Disabilities (CRPD), which since its entry into force in 2008 provides the first comprehensive and legally binding international framework for promoting the rights of people with mental and psychosocial disabilities. The CRPD was drafted with the active participation of disability organisations, including organisations that represent people with mental and psychosocial disabilities, and has been embraced widely by the disability movement as the universal standard for the human rights of all people with disabilities.

Key messages

- Stigma and discrimination lead to pervasive human rights violations against people with mental and psychosocial disabilities in low-income and middle-income countries
- Human rights violations span basic civil, cultural, economic, political, and social rights
- In the health-care context, two major concerns are lack of access to mental health care, and ill treatment and abuse by health workers
- Issues central to human rights violations are the denial of people’s right to exercise legal capacity and discrimination in employment
- Adopting and applying the framework of the UN Convention on the Rights of Persons with Disabilities and using a range of evidence-based strategies can help put an end to these violations and to promote human rights
- These strategies include: changing negative and incorrect beliefs, providing services in the community and empowering people with mental and psychosocial disabilities, reforming law and policy, and establishing legal and oversight mechanisms

Consultation with people with mental and psychosocial disabilities

We undertook individual consultations with 51 people with mental and psychosocial disabilities from 18 low-income and middle-income countries. In each consultation we sought the respondent’s opinion on, and experiences of, mental health and human rights issues. All respondents were informed about the purpose of the consultation and the use of their views as part of this report. Informed consent was built into the questionnaire. The beginning of the
questionnaire contained a statement about voluntary participation, confidentiality, and how responses would be used, allowing respondents to indicate how they would or would not want their responses to be used. Their expertise was sought around three key areas: (1) what kinds of human rights violations are experienced by people with mental and psychosocial disabilities; (2) the context in which these violations occur; and (3) what changes are required to improve the human rights situation. In addition to a series of open-ended questions, this qualitative consultation was guided by a list of potential human rights violations derived from the WHO QualityRights Assessment Tool (panel 2) for assessing the quality and compatibility with human rights of mental health facilities, and their adherence to the CRPD.

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<th>Search strategy and selection criteria</th>
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<td>We have selectively summarised the English-language evidence, including from the WHO/UN publications, non-governmental organisation and press reports, and the academic literature (using the PubMed/Medline and Google Scholar databases) published from January, 1994, to January, 2011. A wide range of search terms were used. In summary, terms were used to limit the literature to evidence for mental health (e.g., “mental health problems”, “mental illness”, “mental disorder”, and “mental health services”) and restrict the focus to low-income and middle-income countries where possible (e.g., “low-income countries”, “middle-income countries”, and “low- and middle-income countries”). If no data for these countries were available, the broader literature (typically from high-income countries) was reviewed if we judged it reasonable to apply the findings to low-income and middle-income countries. Search terms were also used to return results relevant to general or specific human rights violations (e.g., “violations”, “abuse”, “discrimination”, “stigma”, “exclusion”, “financial”, and “employment”); and identify strategies (e.g., “mental health literacy”, “empowerment”, “service user organisations”, “complaints mechanisms”, “rehabilitation”, and “advocacy”).</td>
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Respondents were contacted by use of a convenience sampling method. The author’s identified organisations representing people with mental and psychosocial disabilities and other relevant entities (e.g., NGOs, disabled people’s organisations, and foundations working with people with mental and psychosocial disabilities) in low-income and middle-income countries as the initial contact point. Organisations that were willing to participate and that had direct contact with people with mental and psychosocial disabilities were
provided with a questionnaire (available in English and Spanish) for distribution to potential respondents. Respondents who wished to take part were able to submit their completed questionnaire directly and anonymously to us electronically. After a coding comparison process between ND, MF, and ST, to ensure consistency, responses were categorised into themes by use of an open coding method—i.e., the thematic codes were generated directly from the responses, as opposed to attempting to fit responses into pre-existing themes or codes.

All respondents were current or former users of mental health services, and identified themselves as having a mental or psychosocial disability. 17 respondents were female (33.3%), 32 were male (62.7%), and two were unspecified (3.9%), and the median age was 41.0 years with a range of 18–71 years. 31 respondents (60.8%), two unspecified (3.9%), were members of organisations of people with mental and psychosocial disabilities. All respondents were literate, and most were involved in advocacy around mental health issues. As such, one limitation of our consultation is that it captures the expertise and opinions of people already knowledgeable about issues of mental health and human rights.

Panel 1: People with mental and psychosocial disabilities

We use the phrase “mental and psychosocial disabilities” to refer to people who have received a mental health diagnosis, and who have experienced negative social factors including stigma and discrimination and exclusion. The concept of disability is set out in article 1 of the UN Convention on the Rights of Persons with Disabilities, which states that “[p]ersons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. Accordingly, we refer to people who have a longer-term impairment, as opposed to transient or predominantly situation-responsive distress (such as where a person experiences one episode of a mental health condition in her or his lifetime). Although the personal and social impacts of shorter-term mental health conditions should not be downplayed, it is a topic beyond the scope of this article.
Panel 2: WHO QualityRights Project

The WHO’s QualityRights Project aims to improve quality and human rights conditions in mental health facilities and social care homes, and promote a civil society movement for mental health. The project includes a number of different components:

• Visiting committees are established, consisting of people with mental and psychosocial disabilities and their family members, mental health professionals, and legal and human rights experts.

• The visiting committee receives training on the QualityRights Assessment Tool, used to assess the quality and human rights in outpatient and inpatient mental health and social care facilities.

• After the assessment of the facility, the visiting committee works collaboratively with residents of facilities, family, and staff to develop a plan to improve conditions in the facilities. This is also an opportunity to raise awareness and educate everyone involved on human rights issues.

• Technical and administrative support is provided to people with mental and psychosocial disabilities from the facilities and community on how to set up and strengthen organisations led by people with mental and psychosocial disabilities, to provide mutual support and information about mental health and human rights, to undertake advocacy and campaigning, and to participate in decision-making processes.

The QualityRights Assessment Tool uses the UN Convention on the Rights of Persons with Disabilities as a framework for providing countries with information and guidance on human rights standards that need to be respected in facilities, including living conditions, the treatment available for physical and mental health care, and how service users are treated by staff. The specific themes covered include:

• The right to an adequate standard of living

• The right to the enjoyment of the highest attainable standard of physical and Mental health

• The right to exercise legal capacity and to personal liberty and the security of person
• Freedom from torture or cruel, inhuman or degrading treatment or punishment and
From exploitation, violence, and abuse
• The enjoyment of civil, cultural, economic, political and social rights

Panel 3: Most common human rights violations as described by respondents, sorted by descending frequency
• Exclusion, marginalisation, and discrimination in the community
• Denial or restriction of employment rights and opportunities
• Physical abuse/violence
• Inability to access effective mental health services
• Sexual abuse/violence
• Arbitrary detention
• Denial of opportunities for marriage/right to found a family
• Lack of means to enable people to live independently in the community
• Denial of access to general health/medical services
• Financial exploitation

Panel 4: Environments in which human rights violations are most likely to take place, as described by respondents, sorted by descending frequency
• General community settings in everyday life
• Home and family settings
• The workplace or potential workplace
• Psychiatric institutions and mental health services
• Hospitals and health-care services
• Prisons, police, and the legal system
• Government and official services
• Schools and the education sector

Violations of human rights

To explore the lived-out reality of rights and their violation in countries with low and middle incomes, we first asked respondents to give their personal definition of human rights. Although there was some variability in the responses, several broad themes emerged. Human rights were seen by respondents to be “inherent entitlements” which “no one can take [away]”. In addition to meeting basic needs (e.g., health, food, education, and employment) and guaranteeing basic freedoms (e.g. freedom from discrimination, freedom of expression), respondents believed that human rights allow a person to “live a decent life in society”, and have a life that is “harmonious and happy”. Respondents further noted that human rights involves the freedom to participate in community life while being able to live independently. By contrast with alienation, marginalisation, and denied opportunities, human rights confer “full recognition of a sense of being human” with “mutual respect of our human dignity”.

In the context of disability, according to one respondent from Nepal, human rights are “that which says that all are equal despite their disabilities and that [everyone] should be treated the same without discrimination”. Another respondent from Jordan said that “the most important right is my right to have the knowledge of all of my rights and to be empowered to [confront] violations against my rights”. The most common types of human rights violations that respondents described from their own experience are shown in panel 3.

Restriction of civil, cultural, economic, political, and social rights

The stigma and misconceptions associated with mental and psychosocial disabilities often result in people being ostracised from their community. Pervasive stigma and discrimination affects a person’s ability to earn an income, lift themselves out of poverty, and gain access to treatment and support to integrate or reintegrate into their community and recover from their illness.\(^1\)

The denial of the right to work because of stigma and discrimination is a frequent rights violation with far-reaching consequences. Respondents reported that discrimination at all stages of the employment process was one of the main kinds of human rights violation that takes place, both in terms of pervasiveness and impact (panel 4). Difficulties begin at the stage of finding
work, even when the person is well qualified. A respondent from Ghana reported that “even though I’m trained as an auto mechanic, I find it difficult to get jobs because I’m deemed to be ‘insane’ and not in the right frame of mind to do any meaningful work”. Even when a person has a job, the discrimination continues. A respondent from Belize reported that “we [people with mental and psychosocial disabilities] tend to be underpaid and overworked. We are considered unprofessional, dangerous and incapable... Our years of experience and performance are totally disregarded because we always receive entry-level pay and do not get benefits that others do”.

According to a previous report, 2 unemployment rates of up to 90% are not uncommon among people with mental and psychosocial disabilities—a far higher rate compared with people with other types of disabilities and people without disabilities. Discrimination in employment contributes to poverty, with some studies showing that mental and psychosocial disabilities are twice as frequent among people in the lowest income groups compared with people in the highest income groups.1 31 respondents (60.8%) said that having a mental and psychosocial disability adversely affected their ability to find or maintain a job, and 28 respondents (54.9%) said that their disability contributed to their or their family’s poverty. A common theme was the need to hide mental and psychosocial disabilities from employers. One respondent from Kenya said that “one has to lie or deny having a mental illness in order to be considered for employment. When employed one has to hide the illness and blame it on any other more ‘appropriate illness’ that is socially acceptable or risk termination”.

Additionally, many people with mental and psychosocial disabilities do not have access to social security benefits or health insurance, which often leads to difficulties in reintegrating into society. When social security is available, which tends to be limited to middle-income, rather than low-income countries, it is often structured in a way that creates a disincentive for recovery, financial independence, and workplace participation.4 This tends to perpetuate patterns of unemployment and dependence.1,5–8

As reviewed in WHO’s Mental Health and Development report, children and adolescents with mental and psychosocial disabilities (including intellectual disabilities) face disproportionate barriers in accessing their right to inclusive education.1 Poverty-related constraints mean they are usually the first to be deprived of the possibility of going to school.1 In many low-income and middle-income countries, children and adolescents with mental or psychosocial disabilities are institutionalised in facilities that do not offer any kind of
If they are able to go to school, children in many countries are sent to segregated or so-called special schools that offer low-quality education, rather than being included in mainstream education with tailored support. Failure to provide appropriate support can result in poor academic performance, school failure, and high drop-out rates compared with other children and adolescents.

People with mental and psychosocial disabilities are also restricted from exercising many civil rights. In many low-income and middle-income countries, people with mental and psychosocial disabilities are denied the right to marry and have children. Marriage legislation in a number of these countries states that being of “unsound mind” or having a long-term mental health condition can be grounds for annulment or divorce.

Legislation in other countries with low and middle incomes prohibits people with mental or psychosocial disabilities from filing for divorce because these decisions are made for them by their guardian. Their parental rights are often also terminated.

**Lack of access to mental health services**

In many low-income and middle-income countries, people do not have access to basic mental health care. The problems associated with affordability and access to mental health services in these countries is one of the few issues to have received attention in the literature. At the heart of the issue is the dearth of funding and services provided by governments in many low-income and middle-income countries. Mental health services are non-existent in many places. One respondent from Belize said that his country “does not have enough trained [professionals] in [mental health] areas to serve the entire population. It took me 15 years to meet a psychiatrist”. Even when mental health services are available, they are often inaccessible. Consistent with previous studies, 12 respondents (23.5%) noted that services were disproportionately concentrated in major cities, which can be many hours away. One Jordanian respondent who lived 3 hours away from the nearest services said that “it is costly financially and physically to get to the services”. These accessibility problems inhibit a large part of the population from having proper access to mental health services because they cannot afford the journey, the transportation systems are too unreliable, or the opportunity costs involved are too high.
In most countries with low and middle incomes, the absence of community-based mental health care means there is a disproportionate reliance on psychiatric institutions as the main provider of mental health services.\textsuperscript{20} Not only does this discourage access to services and hinder a person’s ability to live and participate in their own community, but these institutions are often associated with gross human rights violations (panel 4).

**Abuses in residential facilities and places of detention**

Many previous reports have documented the poor physical conditions in many facilities accessed by people with mental and psychosocial disabilities.\textsuperscript{1,21–23} Although this usually refers to substandard living conditions in residential mental health facilities and psychiatric hospitals, it is important to recognise that poor conditions and infrastructure are also prevalent in prisons, nursing homes, halfway houses, and facilities for traditional or spiritual healing.\textsuperscript{24}

The absence, or denial, of the basic necessities of living (including adequate shelter, food, and sanitary facilities) is itself a violation of a person’s fundamental human rights. Several previous reports and responses from respondents have documented living conditions in residential facilities that are inhuman and degrading because of problems such as overcrowding, outbreaks of preventable diseases caused by unsanitary conditions, poor physical infrastructures, hypocaloric food, and pervasive tobacco smoke.\textsuperscript{23,25,26} Deficiencies in the built environment of mental health facilities can impede effective treatment and recovery,\textsuperscript{27} which can result in worsened mental and physical health of service users.\textsuperscript{1}

This is shown by the account of one respondent’s admission to a psychiatric institution in Zambia: “alas, the place of my treatment and care turned out to be a horrible place to live in. It was characterised [by] Unhygienic living conditions, physical abuse, nakedness, and lack of enough food. This experience taught me that mental hospitals are more of a torture chamber causing more mental anguish and torment than ameliorating the mental situation of patients...It led to feelings [of] worthlessness, helplessness and hopelessness”.

Beyond the human rights violations caused by the poor conditions in facilities, people with mental and psycho-social disabilities are often subjected to ill-treatment including physical, mental, and sexual abuse, and neglect. These are common occurrences in facilities throughout the world and are well documented in previous reports and in the responses of respondents.\textsuperscript{22,25,28}
Panel 5: Major strategies for improving the human rights of people with mental and psychosocial disabilities as identified by respondents, sorted by descending frequency

- Running public-awareness and anti-stigma campaigns, and providing education about the rights of people with mental and psychosocial disabilities, as well as about mental health in general
- Providing better training of mental health professionals, increased funding for mental health services, and provision of better mental health services, especially in the community
- Promoting the empowerment, rehabilitation, and participation of people with mental and psychosocial disabilities in their communities
- Implementing effective and humane laws and policies to protect and promote the human rights of people with mental and psychosocial disabilities
- Encouraging the formation of, and providing ongoing support to, organisations of people with mental and psychosocial disabilities
- Monitoring and assessment of human rights of people with mental and psychosocial disabilities, and of mental health services generally
- Integrating mental health into overall health and development policies

Arbitrary detention takes place in many low-income and middle-income countries, whereby psychiatric confinement is ordered without any basis by the justice system or others in a position of power.\textsuperscript{21,29} The result is that people are often locked in hospitals for years without their legal or medical status being assessed, and subjected to psychiatric interventions without informed consent.\textsuperscript{30–32} Seclusion, isolation, and restraint—used as punishment or coercion—are another feature of many institutions.\textsuperscript{5,19,33,34} In many low-income and middle-income countries, there is an absence of recovery-oriented treatment,\textsuperscript{35} with people with mental and psychosocial disabilities chained to beds or posts and made immobile for long periods of time.\textsuperscript{1,36}

A further problem is the use of harmful practices often described as mental health treatments. One such so-called treatment is unmodified electroconvulsive therapy (ECT), which is done without anaesthesia or muscle relaxants—a condemned practice that can constitute torture or ill-treatment, but one that continues in several countries with low and middle incomes.\textsuperscript{27,31,37}
In other contexts, harmful treatment practices can involve abuse by some traditional healers and religious practitioners, including beatings and the use of shackles and chains as purportedly curative measures.\textsuperscript{1,5,19,24}

**Restriction on the exercise of legal capacity**

Human rights violations often occur when individuals are denied their right to exercise their legal capacity. In many countries, including some with low and middle incomes, people with mental or psychosocial disabilities are deprived of their legal right to make decisions, and the authority is handed to a third person, a guardian. This guardian—often a family member, a government official, or a local service provider—can then make decisions on behalf of the person in areas such as where and with whom they should live, how their money, property, and personal affairs should be managed, and other aspects of their daily lives.\textsuperscript{16,38}

Decisions concerning health care are also made by guardians, which can result in people being detained in mental health facilities and treated against their will. Despite the far-reaching powers that can be exercised by guardians, there are very often few or no judicial mechanisms to enable people to appeal their involuntary admission and treatment or protect their right to exercise their legal capacity more generally.\textsuperscript{1,27}

The denial of legal capacity can also mean that a person is excluded from participation in social and political life, such as the right to vote or be elected, and to participate in the development and implementation of laws and policies that concern them.\textsuperscript{1,38}

**Evidence-based strategies to improve human rights**

Such a pervasive pattern of systemic violations of human rights of people with mental and psychosocial disabilities requires a range of strong, inclusive, and integrated strategies to be adopted in response. Unfortunately, there is a paucity of evidence for the effectiveness of such strategies in low-income and middle-income countries. We review the available evidence in conjunction with the recommended strategies suggested by respondents (panel 5) and the obligations set out in the CRPD. The CRPD is an important reference point because of its authoritative status in both informing and enforcing strategies to improve rights for people with mental and psychosocial disabilities.

Overall, there was a very good match between these three components (the existing evidence, the respondents, and the CRPD). However, respondents also identified several specific strategies relating to participation and empowerment
that have not yet been considered. These strategies emerged as consistent themes from respondents from a range of different low-income and middle-income countries and with different life experiences, and as such warrant greater attention.

At the outset, it is important to be mindful that the strategies discussed below should not exist in isolation from each other, nor can they be seen as a set of discretionary goals that receive attention by governments and development stakeholders only when it is convenient. As one respondent from Nepal pointed out, all strategies “must be interwoven within the overall planning of national development. The permanent solution to this problem cannot be imagined outside the overall development strategy of the government”.

**Information, training, and education campaigns**

The attitude of society as a whole has an important role in the way people with mental and psychosocial disabilities are treated in the community and by mental health professionals. Respondents stated that ignorance or false beliefs about people with mental and psychosocial disabilities is one of the leading reasons that human rights violations occur—a theme that is substantiated in previous reports. Studies from low-income and middle-income countries show that people with mental and psychosocial disabilities are incorrectly perceived to be violent, dangerous, or unpredictable. Such negative attitudes are held not only by the general public, but also by health professionals and policy makers.

A respondent from Georgia said that the prevailing belief in his country is that “a person with mental disabilities is not considered as a human being at all”. These perceptions are associated with greater social distance from people with mental and psychosocial disabilities. According to one respondent from Nepal: “society perceives [us] as degraded human beings facing punishment for their past actions. Wrong beliefs of illness give society an open social license to discriminate against mentally affected people. Therefore, people with mental and psychosocial disabilities experience human rights violations”.

In response, information and education campaigns are crucial. Article 8 of the CRPD mandates that State Parties adopt measures to initiate and maintain awareness campaigns and human rights training to promote a greater understanding of the “skills, merits and abilities” of persons with disabilities. Raising awareness among different stakeholders about government obligations in relation to the CRPD is also important, and efforts are being made in this direction (panel 6).
A large proportion of respondents saw education campaigns as a necessary precondition for reform. For example, one respondent from Nepal said that although a multifaceted approach is needed, “at the basic level, nothing can be done without the awareness in people, so [the] government must invest amply to spread such awareness”.

Such campaigns have already been used widely to advance public understanding on mental health, reduce stigma and discrimination, and promote human rights in high-income countries. However, there are few examples of such campaigns in low-income and middle-income countries, and fewer assessments of their effectiveness. The available evidence suggests that campaigns lead to improved public knowledge about mental health conditions, increased awareness of mental health services and effective treatment, knowledge about mental health and attitudes towards people with mental and psychosocial disabilities, and increased demand for, and use of, community-based mental health services.

Panel 6: Raising awareness of the UN Convention on the Rights of Persons with Disabilities (CRPD): the International Diploma on Mental Health Law

In 2008, the Indian Law Society in Pune, India, in collaboration with WHO, set up the International Diploma in Mental Health Law and Human Rights. The Diploma aims to build capacity in countries to promote the rights of persons with mental disabilities in line with the CRPD and other international human rights standards. Participants on the course include government officials, people with mental and psychosocial disabilities, families, health professionals, lawyers, human rights defenders, and social workers. The aim of the diploma is to equip national actors with the skills needed to be able to advocate for human rights and influence national reform efforts.

Several factors have been shown to improve the effectiveness of information campaigns. People with mental and psychosocial disabilities, their families, and carers should have an active role in identifying priority areas to be addressed by campaigns, and be involved in their design, delivery, and assessment. Research to understand the characteristics of the recipients of information campaigns makes it more likely that the messages will be targeted, and the use of appropriate media channels improves the likelihood of effectively engaging specific groups. The testimony of people with mental and psychosocial disabilities themselves has been identified to be a very significant factor in
reducing stigmatising attitudes.\textsuperscript{49} Finally, information campaigns should be conducted on a long-term, routine basis.\textsuperscript{48}

Many respondents noted that people with authority (including health professionals, government ministers, and officials) are the most resistant groups when it comes to improving the human rights of people with mental and psychosocial disabilities. Previous reports have also emphasised that negative attitudes towards people with mental and psychosocial disabilities are frequent among mental health professionals.\textsuperscript{34, 50, 51} Such attitudes must be addressed through the specific training and education of people acting on behalf of the state or with other social authority so that all sections of society are aware of the rights of people with mental and psychosocial disabilities. This view was summarised by a respondent from Sri Lanka: “the whole society needs to become aware of mental [and psychosocial disabilities]. From the President to the ordinary voter, people must become aware—especially [people] from government organisations, temples, schools, transport services, [and the] police”.

**Provision of services in the community**

As already discussed, low-income and middle-income countries face several challenges in relation to access to mental health care. Psychosocial care and rehabilitation services and essential medicines are often unavailable, inaccessible, or unaffordable, which further constrains treatment and recovery, often with cross-generational consequences.\textsuperscript{6, 7, 52, and 53}

In the limited number of low-income and middle-income countries where budgets for mental health services exist, most expenditure goes on psychiatric hospitals or other forms of custodial care associated with violations of human rights,\textsuperscript{6, 54} rather than on community-based services. An important response to this is the need for low-income and middle-income countries to provide mental health and other services in the community to improve both access and quality of services and promote independent living in society in accordance with articles 19 and 25 of the CRPD. Providing better mental health service is necessarily contingent on providing better training for mental health professionals, a view echoed by many respondents. It also entails equipping primary health-care providers with skills in evidence-based mental health treatment and care. As a respondent from Kenya noted, “Mental and physical health exist as separate entities”, and “other physicians and nurses...have no training or information on mental health. Existing medical personnel need to be trained continuously on
mental health issues so that they can...handle both issues as well as put into place referral systems”.

When mental health services are available and adequately staffed by trained professionals in primary and community settings they are known to be more acceptable, accessible, and affordable, and produce better health and mental health outcomes. As a Jordanian respondent noted: “the clinic where I get my medications and therapy sessions is close to my house and my workplace. It’s in a strategic place where anybody can get to it within [the city]”. Despite this evidence, no country in the world has yet managed to effectively provide services in the community nationwide.1, 17, 55

However, simply providing mental health services in the community is not sufficient. A broad set of services or programmes are needed to enable people to attain and maintain maximum independence and full inclusion in society in line with the CRPD. Habilitation and rehabilitation services, including vocational and life-skills development but also in-home, residential, personal assistance and other community-support services, are vital to achieving independence and inclusion. Social and health-care services need to adopt a holistic approach to meet the multiple needs of people with mental and psychosocial disabilities. Strong links are needed with other sectors to ensure that people have access to housing, education, and employment.1, 17

Employment schemes, in which people with mental and psychosocial disabilities undertake paid work with ongoing support and training, have been consistently shown in studies in low-income and middle-income countries to result in higher employment rates, better wages, more hours of employment per month, and better mental health.1,56–58 Additionally, income generation programmes and social grants have been shown to benefit people with mental and psychosocial disabilities, their families, and communities, but are absent in many countries with low and middle incomes.1,6,59

Successful community inclusion also relies on making educational opportunities available and accessible to children with mental and psychosocial disabilities, and ensuring that barriers preventing their attendance at schools are removed. Once in the educational system, school-based mental health programmes can prevent the onset or worsening of mental health conditions into adulthood, and help to maximise the number of people completing education, which improves opportunities for employment.1
Empowerment of people with mental and psychosocial disabilities

As already discussed (panel 3), marginalisation, exclusion, and discrimination against people with mental and psychosocial disabilities were seen by respondents as the most common human rights violations. One respondent from Sri Lanka noted that: “social discrepancy is high. The human rights of those who are unable to do anything are violated more”. Accordingly, empowering people with mental and psychosocial disabilities both individually and collectively is one of the key strategies for change (panel 5). The participation of people with disabilities as equal members of society in all aspects of living is one of the fundamental principles that underpins the entire CRPD. At the individual level, efforts need to focus on ensuring that people with mental and psychosocial disabilities are able to exercise their legal capacity in line with article 12 of the CRPD. By contrast with traditional but rights-restricting models of plenary guardianship, the CRPD requires that State Parties recognise the right of people with disabilities to enjoy legal capacity on an equal basis with others in all aspects of life. Additionally, the CRPD puts forward a supported decision-making model. This model enables people to retain their legal capacity and at the same time choose to receive support in exercising this right when they desire it and when it is needed.  

The person remains at the centre of decision making on issues that affect him or her, and when necessary, support can be on-hand to explain relevant issues and interpret and communicate the signs and preferences of the individual. Types of support might include advocates, a Personal ombudsperson, community services, personal assistants, peer supports, and advance planning.

Public and collective participation can be encouraged by establishing or strengthening organisations of people with mental and psychosocial disabilities. In most low-income and middle-income countries, there are few organisations made up of and run by such people. The resultant lack of social support creates a sense of isolation and powerlessness for many people. A respondent from Belize commented that “[people with mental and psycho-social disabilities] are vulnerable and are still camouflaged in the community; they are not a strong and united group”, while a respondent from Egypt commented that “they cannot defend themselves and they cannot speak out for themselves out loud”.

In fact, the lack of independent organisations of people with mental and psychosocial disabilities was seen by some respondents as a principal reason that human rights violations occur. This is consistent with respondents’ view.
that the establishment of such organisations would be a crucial way of promoting acceptance and positive change in attitudes. Empowering people with mental and psychosocial disabilities to self-organise and advocate for their interests and needs promotes their recognition and develops their strengths, resources, and skills. Such empowerment also ensures that people with mental and psychosocial disabilities are given a collective political voice to influence and lobby for policy and legislative reform. One respondent from Tajikistan said that belonging to such an organisation “[has] made my life more positive and useful despite the huge stigma and discrimination I experienced before and a bit now. The positive side is that I can understand users and their feelings so that...we [can] help each other”.

States have an obligation, under article 29 of the CRPD, to “promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others”. This can be achieved by encouraging people’s participation in or forming of NGOs and political parties. The participation of people with mental and psychosocial disabilities is a key strategy to ensure that their personal experience and knowledge drives reform and that laws, policies, and services are acceptable, address their needs, and respect their human rights in accordance with article 4 of the CRPD. Such steps must be carried out together with a dismantling of overarching legal barriers such as restrictions on the exercise of legal capacity, which prevents people from joining associations and exercising their political rights.

A systematic review on the effect of involving people with mental and psychosocial disabilities in the training of mental health service providers and in the assessment of mental health services found that involvement improved service users’ quality of life and social functioning and resulted in trainees having a more positive attitude towards people with mental and psychosocial disabilities. Participation also leads to assessments that are more likely to address people’s requirements and concerns. Additional benefits include the development of more relevant outcome indicators, a better quality of information obtained from service recipients, and practical change strategies to improve services. Despite these benefits there is little evidence of countries involving people with mental and psychosocial disabilities in service assessment.
Panel 7: Key UN and regional human rights instruments

UN instruments

• Convention on the Rights of Persons with Disabilities
• International Covenant on Economic, Social and Cultural Rights
• International Covenant on Civil and Political Rights
• Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and its Optional Protocol

Regional instruments

• African Charter on Human and Peoples’ Rights
• American Convention on Human Rights
• Additional Protocol to the American Convention on Human Rights in the area of Economic, Social, and Cultural Rights
• Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities
• European Convention for the Protection of Human Rights and Fundamental Freedom
• European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment

Law and policy reform

Law and policy reform is a key strategy identified in previous reports and by respondents to promote human rights. Well formulated policies and laws can promote the development of accessible services in the community, stimulate advocacy and education campaigns, and establish legal and oversight mechanisms to prevent human rights violations. Mental health policies and laws in low-income and middle-income countries are absent in many cases, and where they exist they fail to incorporate current international human rights and best practice standards, in some cases actively violating human rights. In reference to legislation specifically, one respondent from Nepal said that “[our] laws are discriminatory. They encourage the authorit [ies] to imprison and then [forcibly] start treatment on mentally affected persons”. It is therefore
crucial that policies and laws are introduced in line with international human rights standards including the CRPD and other instruments (panel 7). This requires the active involvement of people with mental and psychosocial disabilities in the policy-making process. Historically, the development of policies and laws has excluded people with mental and psychosocial disabilities, which has meant that their needs have not been adequately addressed.

There are opportunities to codify human rights standards and proscribe violations and discrimination not only in specific mental health policy and legislation, but also in laws and policies on anti-discrimination, general health, disability, employment, social welfare, education, housing, and other areas. However, well-formulated policies and laws are of no use if they are not put into effect. Indeed, respondents highlighted lack of enforcement as a significant reason why human rights violations occur, and that government commitment is essential in order to establish mechanisms for implementation and monitoring.

**Establishment of legal and oversight mechanisms**

The establishment of legal and oversight mechanisms to protect the rights of people with mental and psychosocial disabilities is mandated under articles 13–16 of the CRPD. In many low-income and middle-income countries, there is no well-defined independent judicial procedure or mechanism that can be accessed by people admitted involuntarily to mental health facilities to contest their detention. In addition to judicial review mechanisms, regular visits by independent bodies to mental health facilities and other places of detention to inspect the conditions in which residents live is crucial to prevent abuses and ensure that fundamental rights are being respected. One respondent from Georgia said that “specific cases of the violation of patients’ rights should be highlighted. Regular monitoring of human rights observance [must] be carried out at psychiatric institutions”. Such monitoring mechanisms are required by the CRPD and the Optional Protocol of the UN Convention against Torture. This role can be undertaken by a dedicated independent visiting committee or integrated into the functions of existing monitoring mechanisms and organisations such as national human rights institutions, national ombudsperson offices, or NGOs.

Complaints mechanisms also need to be established and made accessible to persons with mental and psychosocial disabilities. Part of the reason why violations continue unabated is that they are unreported. Legal mechanisms therefore need to be in place to enable and encourage people with mental and
psychosocial disabilities, their family members, friends, and advocates to report any human rights violations freely and securely.

**Examples of successful legal action**

Legal remedies are being undertaken by local NGOs and disabled people’s organisations. For example, Action for Mental Illness (ACMI) is an Indian NGO that, in addition to its other advocacy activities, has undertaken litigation representing the needs and rights of people with mental and psychosocial disabilities at provincial and national levels. In its ongoing litigation in the High Court of Karnataka, ACMI’s actions have successfully led to legislative and policy reforms, including setting minimum standards for hospitals and nursing homes, converting a state psychiatric hospital to an open-ward system (i.e., where patients are free to move around the ward without their movements being restrained in any form or manner), and establishing a budget for mental health in the state. ACMI also continues to lobby for mental health legislation to be made consistent with the CRPD, and runs legal literacy workshops for people with mental and psychosocial disabilities and their families.  

However, in many countries legal remedies are absent, and in the absence of effective regulatory and oversight mechanisms within the domestic sphere, many people in low-income and middle-income countries have relied on international and regional human rights systems and organisations for justice and redress. Although the jurisprudence of these bodies is in its infancy, the African Court on Human and People’s Rights and the Inter-American Court on Human Rights have all ruled on matters related to the rights of people with mental and psychosocial disabilities. The European Court of Human Rights has a more developed case-law on rights issues, and the European Committee on Social Rights has decided on two collective complaints concerning the education of children with intellectual disabilities. The European Committee for the Prevention of Torture also visits all places of detention—including psychiatric institutions—within member states, and reports its findings and recommendations.

International NGOs also have a crucial role in oversight and redress. The Mental Disability Advocacy Center (MDAC), for example, has been successful in strategic litigation at international and national levels that has brought about legislative reform. In the case of Shtukaturov v Russia, the European Court of Human Rights found that Russia had violated several rights of the European Convention on Human Rights, which subsequently led to the Russian Constitutional Court
striking down three provisions about capacity and consent relating to people with mental and psychosocial disabilities in Russian domestic law that the MDAC argued were unconstitutional.89

However, although such international mechanisms can be effective for facilitating reform and empowering the people and groups involved, they should not be the primary method for addressing human rights violations. Oversight mechanisms, judicial review, and access to legal remedies in domestic law must be available to people with mental and psychosocial disabilities on an equal and accessible basis.

Conclusions

People with mental and psychosocial disabilities in low-income and middle-income countries continue to experience a wide range of human rights violations, including the inability to access adequate mental health services in a safe, therapeutic, and affordable setting. Rights violations also include being subjected to stigma and discrimination in the community, particularly in relation to employment, and being denied the opportunity to exercise legal capacity and civil, social, and political rights. Abuse, and inhumane and degrading treatment, are also sadly still commonplace.

Because the spectrum of violations against people with mental and psychosocial disabilities is so wide, the realisation of these rights depends on various entities including the public and private sector, groups of professionals, political and judicial bodies, and society as a whole. As the CRPD makes clear, preventing human rights violations and promoting a rights-compliant society for people with mental and psychosocial disabilities needs the cooperative participation of all stakeholders. This begins with educating all parts of society, including all sectors of government, health and mental health professionals, the media, and of course people with mental and psychosocial disabilities and their families about mental health and human rights.

The CRPD and other international human rights standards require states and the international community to empower people with mental and psychosocial disabilities, their organisations, and civil society. Civil society must be enlisted as advocates and agents for change, holding governments accountable for meeting their obligations with regard to human rights. To rectify this historic and ongoing neglect and mistreatment, it is essential to create clear benchmarks or indicators of tangible progress, with rigorous monitoring and assessment at the state and international level. Additionally, more research must be devoted to
examining the effectiveness of strategies to prevent violations and promote the rights of people with mental and psychosocial disabilities. This research must be informed by the expertise, knowledge, and opinions of people with mental and psychosocial disabilities. However, lack of research cannot be an excuse for complacency: sufficient evidence exists to spur governments, civil society, and other development stakeholders into taking action to end violations and promote the rights of people with mental and psychosocial disabilities.

Contributors

ND, MF, ST, and BS were involved in the conception of this article and the design of the consultation methodology. ND, MF, ST, JL, EC, and SK were involved in the data collection process. ND, MF, SP, and OL did the review of the literature. ND, MF, ST, LG, and BS did the qualitative data analysis and interpretation. All authors were involved in the drafting, revision, and finalisation of the article.

Conflicts of interest

We declare that we have no conflicts of interest.

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Part 2

Chapter 5

A. Mental health: a legislative framework to empower, protect and care. A Review of Mental Health Legislation in Commonwealth Member States

B. The need to review mental health legislation in Commonwealth countries
A REVIEW OF MENTAL HEALTH LEGISLATION

IN

COMMONWEALTH MEMBER STATES

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COMMONWEALTH FOUNDATION
EXECUTIVE SUMMARY

Introduction
Mental health and human rights are linked in three important ways. First, mental health affects human rights; second, human rights violations affect mental health and third, positive promotion of mental health and human rights is mutually reinforcing, as they are complementary approaches to advancing the well-being of persons worldwide (Gostin & Gable 2009).

One way to prevent human rights violations from occurring is by reforming mental health laws to be more in line with the promotion of human rights of persons with psychosocial disabilities. Internationally, the Convention on the Rights of Persons with Disabilities (CRPD), which entered into force in 2008, serves as a comprehensive and legally binding framework for promoting and protecting the rights of persons with mental disorders (Drew et al. 2011). Globally, the CPRD has been celebrated as being the universal standard for human rights of persons with disabilities (Drew et al. 2011).

At the country level, law and policy reform has been identified as a key strategy to promote the human rights of persons with mental disorders. A well-formulated mental health law is necessary to be in place for protection of human rights of persons with mental disorders (Drew et al. 2011).

We reviewed mental health legislation in the Commonwealth member states to obtain an insight as to how mental health laws in the Commonwealth complies with the CPRD and adopts a rights-based approach. We conclude by putting forward several recommendations resulting from the findings of this report.

Methodology
We used the provisions of the United Nations Convention on Rights of Persons with Disabilities (CRPD) to enable systematic comparison of legislation from different countries. We restricted analysis to dedicated mental health legislation. Most countries do not have 'consolidated' legislation covering all areas relevant to persons with mental disorders, but used a 'dispersed' style of legislation. Thus provisions related to issues such as employment, housing, social security for
example are usually not covered in mental health legislation but may be covered in other relevant legislation on these topics. These 'dispersed' provisions are not analysed in this report, as the focus of this research was an analysis of dedicated mental health legislation.

We searched for mental health legislation in 53 of the 54 countries of the Commonwealth, leaving out Fiji which is currently suspended from the Commonwealth. We were unable to obtain mental health legislation from 3 countries (St Lucia, St Kitts & Nevis and St Vincents & the Grenadines) and an official English translation for the mental health law of Cyprus. Therefore these four countries are not included in the analysis. An extensive online search and correspondence with Commonwealth Health Professions Alliance (CHPA) partners suggests there is no dedicated mental health legislation in four countries namely Cameroon, Maldives, Mozambique and Rwanda. Thus we obtained mental health legislation from 45 countries and these are included in the analysis.

Summary of Findings

Brief summary of the findings is as follows:

1. Mental health legislation in 20 per cent of Commonwealth member states was enacted prior to 1960 when modern medical treatments became available and before many of the international human rights instruments came into force.

2. Mental health legislation in only 11 per cent of the Commonwealth member states specifically included provisions that state mental health care should be provided on an equal basis with physical health care.

3. Mental health legislation in only 9 per cent of Commonwealth member states promoted voluntary admission and treatment as the preferred alternative for treatment of mental disorders.

4. Mental health legislation in 29 per cent of Commonwealth member states gives persons with mental disorders the right to be informed of their rights when receiving mental health care or treatment.

5. While laws in 24 per cent of member states had some provisions promoting community care, no legislation met all the criteria to be rated as promoting community care and deinstitutionalisation.

6. Mental health legislation in only four Commonwealth member states had
provisions for supported decision making including the provision of Advance Directives in their mental health legislation

7. Mental health laws in all Commonwealth member states allowed involuntary admission to a mental health facility. Only half (51 per cent) of country mental health laws require the person to be discharged as soon as they do not meet criteria for involuntary admission. 80 per cent of mental health legislation in commonwealth countries does not apply the principle of least restrictive alternative to involuntary admission.

8. More than two-thirds of the mental health laws do not have a judicial/quasi-judicial body to review involuntary admissions and treatment.

9. Provisions for protection from cruel, inhuman and degrading treatment are included in the legislation in 23 (51 per cent) countries.

10. Informed consent of persons with mental disorders for participating in clinical and experimental research is specifically mandated in mental health legislation in only 5 (11 per cent) countries.

11. Mental health laws in 9 (20 per cent) countries include a provision on protection of confidentiality and in 8 (18 percent) countries a provision on privacy for persons with mental disorders is included.

12. Legislation in only three (7 per cent) countries specifically outlaws forced or inadequately remunerated labour within mental health facilities.

13. Very few laws have specific provisions for the involvement of families and care-givers. Legislation in 12 (27 percent) countries provides for information to be given to families and care-givers; in 10 (22 percent) countries families and care-givers are encouraged to participate in the formulation of treatment plans.

14. Mental health laws in most Commonwealth countries provides very little protection to minors and children. Laws in only two (4 percent) countries restrict involuntary admission of minors with mental health problems, and laws in only three (7 per cent) countries ban any irreversible treatments on children with mental health problems.

15. The word “Lunatic” is used in the mental health laws of 12 countries; the term “Insane” is used in the mental health laws in 11 countries; the term “Idiot” is used in the mental health laws in 10 countries; two mental health laws use the term “Imbecile”; and two mental health laws use the term “Mentally defective”. Overall 21 (47 per cent) laws use one of the above terms.

16. The law in only one Commonwealth country mandates that users of mental health services are involved in mental health policy, legislation development and service planning.
Conclusions

Based on the findings above, the conclusions are as follows:

1. Mental health legislation in many Commonwealth member states is outdated and does not fulfil member states international human rights obligations toward persons with mental disorders.

2. Mental health legislation in many Commonwealth member states is not compliant with the Convention on Rights of Persons with Disabilities. Substantive and procedural provisions related to guardianship in mental health laws are particularly problematic in this regard.

3. Many mental health laws reviewed in this report treat persons with mental disorders as needing protection rather than as subjects with rights. As a result, mental health legislation, instead of protecting the rights of persons with mental disorders is likely to lead to violation of rights.

4. Mental health legislation in many countries is based on an outdated understanding of mental disorders; ignores advances in the care and treatment of mental disorders and denies the capacity of persons with mental disorders to manage their lives.

5. Provisions and language of mental health laws in many instances adds to negative perceptions and further stigmatisation of persons with mental disorders.

6. Most mental health laws pay little attention to protecting the rights of vulnerable groups with mental health problems such as minors, women and minorities and the special needs of such vulnerable groups.

7. Many mental health laws do not address the issue of (lack of) access to mental health care in many Commonwealth countries, in particular, making care and treatment easily available; provided in a manner which enhances the capacities of individuals and protects and promotes their rights; and enable them to live and participate in their communities.

8. There is little participation of persons with mental disorders and their families and care-givers in the development and implementation of legislation.

Recommendations

1. Commonwealth member states should urgently undertake reform of mental health legislation.

2. Member states should ensure that the legislation meets their obligations under international human rights treaties, in particular the Convention on Rights of Persons with Disabilities.
3. The Commonwealth should consider providing financial and technical support to Low and Middle income member states to undertake mental health law reform.

4. Commonwealth member states need to thoroughly review all legislation to comprehensively address all civil, political, economic, social and cultural rights of persons with mental disorders.

5. Commonwealth member states should introduce provisions to promote supported decision making in mental health legislation.

6. Commonwealth member states must involve persons with mental disorders and care-givers, apart from other stakeholders, in the mental health law reform process.

Introduction

Mental health and human rights are linked in three important ways. First, mental health affects human rights; second, human rights violations affect mental health and third, positive promotion of mental health and human rights is mutually reinforcing, as they are complementary approaches to advancing the well-being of persons worldwide (Gostin & Gable 2009). Despite the powerful relationship between the two fields, and despite international attempts to protect the rights of persons with mental disorders, violation of human rights are experienced by persons with mental disorders worldwide, irrespective of society or income level. Human rights violations adversely affect mental health and can limit participation in economic, social, and cultural activities as well as negatively impact treatment and recovery. One way to prevent human rights violations from occurring is by reforming mental health laws to be more in line with the promotion of human rights of persons with psychosocial disabilities. Internationally, the Convention on the Rights of Persons with Disabilities (CRPD), which entered into force in 2008, serves as a comprehensive and legally binding framework for promoting and protecting the rights of persons with mental disorders (Drew et al. 2011). Globally, the CPRD has been celebrated as being the universal standard for human rights of persons with disabilities (Drew et al. 2011).
At the country level, law and policy reform has been identified as a key strategy to promote human rights of persons with mental disorders. It is necessary to have in place a well-formulated mental health law for the protection of the human rights of persons with mental disorders (Drew et al. 2011). Legislation promoting a rights-based approach is important for countries as it is an important safeguard against the abuse of rights of persons with mental disorders (Gostin & Gable 2009).

We reviewed the status of mental health legislation in Commonwealth countries to obtain insight as to how mental health laws in these countries comply with the CPRD and adopt a rights-based approach. We conclude by putting forward several recommendations resulting from the findings of this report.

**Methodology**

We obtained copies of the mental health laws of the Commonwealth countries from various sources including online international legal databases such as WorldLii ([www.worldlii.org](http://www.worldlii.org)) and regional legal databases such as Paclii ([www.paclii.org](http://www.paclii.org)), from online legal resources maintained by many countries (New Zealand; [www.legislation.govt.nz](http://www.legislation.govt.nz)), from the World Health Organization, from individual partners of the Commonwealth Health Professions Alliance in various countries and other professional colleagues in different countries. This was cross-checked with other online documents referring to mental health legislation in those countries to ensure that we had the current mental health legislation for each country.

We restricted our search and subsequent analysis to dedicated mental health legislation. Most countries do not have 'consolidated' legislation covering all areas relevant to persons with mental disorders, but use a 'dispersed' style of legislation. Thus provisions related to issues such as employment, housing and social security for example are usually not covered in mental health legislation but may be covered in other relevant legislation on these topics in a particular country. These 'dispersed' provisions are not analysed in this report, as the focus of this research was an analysis of dedicated mental health legislation.
We used the provisions of the United Nations Convention on Rights of Persons with Disabilities (CRPD) to enable systematic comparison of legislation from different countries. We also referred to questions from the WHO Checklist on Mental Health Legislation (WHO, 2005) to elaborate the rights included in the CRPD. Recognizing that the WHO Checklist antedates the CRPD and may not be compliant with some of the CRPD provisions, we selected and modified the questions accordingly. We also prepared a set of questions and criteria for issues of relevance from the CRPD perspective (e.g. plenary and limited guardianship) which are not covered adequately in the WHO Checklist.

We used the World Bank classification of countries by income into Low income, Lower-Middle income, Upper-Middle income and High income economies (see http://data.worldbank.org/about/country-classifications/country-and-lending-groups for details).

Results and Discussion

We searched for mental health legislation in 53 of the 54 countries of the Commonwealth, leaving out Fiji which is currently suspended from the Commonwealth. In spite of the best efforts and assistance from the Commonwealth Health Professions Alliance (CHPA), we were unable to obtain mental health legislation from three countries (St Lucia, St Kitts & Nevis and St Vincents & the Grenadines) and an official English translation for the mental health law of Cyprus. Therefore these four countries are not included in the analysis. An extensive online search and correspondence with CHPA partners suggests there is no dedicated mental health legislation in four countries namely Cameroon, Maldives, Mozambique and Rwanda. Thus we obtained mental health legislation from 45 countries and these are included in the analysis below.

For Australia, Canada and United Kingdom there is no single federal mental health legislation and states, countries and territories in these Commonwealth member states have their own mental health legislation. This means there are 10 mental health laws from Australian States and Territories, 13 mental health laws from different Canadian states and territories and 3 mental health laws from the United Kingdom. We did not include all these state legislation in the
analysis, as we felt this would skew the findings. State legislation in these 26 states across Australia, Canada and United Kingdom (all High income states by World Bank classification) if included in the analysis would constitute nearly 40 per cent of the laws being analysed (26/68) while the 3 countries only made up 6 per cent of the countries included in the analysis (3/45). We therefore included the mental health legislation from a representative state/territory/country from each of these member states. Mental health legislation from Ontario was included as representative of mental health legislation of Canada, from South Australia as representative of Australia and from Scotland as representative of the United Kingdom. Mental health legislation from Ontario and Scotland is regarded as progressive in their respective countries and South Australia has the most recently enacted legislation (2009) amongst all Australian states and territories.

We are aware there is an ongoing mental health law reform process in many countries (e.g. India, Sri Lanka and Western Australia) and draft mental health bills are available for these countries and states. We have not included these draft bills for analysis for the obvious reason that these are not yet law and the final legislation when passed may be very different from the present draft bills available for consultation.

1. **Year of enactment of Mental Health Legislation:**

   **Table 1 : Year of enactment of legislation**

<table>
<thead>
<tr>
<th>Year of Enactment</th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre- 1960</td>
<td>3 (42%)</td>
<td>3 (17%)</td>
<td>2 (20%)</td>
<td>1 (10%)</td>
<td>9 (20%)</td>
</tr>
<tr>
<td>1961- 1991</td>
<td>2 (28%)</td>
<td>10 (56%)</td>
<td>3 (30%)</td>
<td>3 (30%)</td>
<td>18 (40%)</td>
</tr>
<tr>
<td>1991-2008</td>
<td>2 (28%)</td>
<td>4 (22%)</td>
<td>4 (40%)</td>
<td>3 (30%)</td>
<td>13 (29%)</td>
</tr>
<tr>
<td>Post 2008</td>
<td>1 (5%)</td>
<td>1 (10%)</td>
<td>3 (30%)</td>
<td></td>
<td>5 (11%)</td>
</tr>
</tbody>
</table>
Modern treatment of mental disorders with psychotropic drugs started in the 1950s which significantly impacted the care and treatment of persons with mental disorders. People could now receive treatment and continue to live in the community. We used 1960 as a cut off to identify legislation from the pre-psychotropic medicines era.

The United Nations General Assembly in 1991 adopted the “Principles for the Protection of Persons with Mental Illness and Improvement of Mental Health Care” also known as the MI Principles. The MI Principles were the first international attempt to set minimum human rights standards in mental health care and treatment practice and we therefore used it as another cut-off to identify legislation from the pre-MI Principles era. It is important to note that the MI Principles are disputed by many user-survivor organizations and have also been criticised by the UN Secretary General as affording a lesser degree of protection than existing human rights treaties (United Nations 2003) and particularly the rights protection available in the Convention on Rights of Persons with Disabilities (CRPD).

The Convention on the Rights of Persons with Disabilities (CRPD) entered into force on 3rd May 2008. The Convention represents a paradigm shift from seeing persons with disabilities as objects of charity to subjects with rights who are capable of claiming and exercising these rights. The CRPD represents a landmark in the protection of the rights of persons with disabilities and this includes persons with mental disabilities. Hence we used this as another cut-off to identify mental health legislation from the pre-CRPD era. It is important to note that, as a binding Convention, the CRPD supersedes the MI Principles.

Mental health legislation in 20 per cent of Commonwealth countries was enacted before 1960, while legislation in 60 per cent of countries was enacted prior to MI Principles and legislation in nearly 90 per cent of countries was enacted prior to the CRPD coming into force. The oldest legislation enacted in any Commonwealth country and still in force is from 1902, while the newest legislation enacted and in force is from 2012.
There is a clear gradient from Low income countries to High income countries of the Commonwealth with low income countries more likely to be using pre 1960 enacted legislation (42 per cent) while high income countries had the largest proportion of mental health legislation enacted after the CRPD (30 per cent) (see Figure 1).

The date of enactment of legislation is important as it is unlikely that legislation before 1960 will be influenced by the movement toward community treatment and is likely to have a custodial emphasis, while legislation prior to 1991 is unlikely to incorporate rights protections outlined in the MI Principles and most laws prior to 2008 are unlikely to take a rights based perspective as required by the CRPD and therefore compliance with the CRPD.

Figure 1: Year of enactment of legislation

![Year of enactment of mental health legislation clustered by country income level](chart.png)

- Low (n=7)
- Low-middle (n = 18)
- Upper-middle (n=10)
- High (n=10)
- Total (n=45)
2. CRPD Status

Table 2: CRPD Status

<table>
<thead>
<tr>
<th></th>
<th>Low (n=7)</th>
<th>Low-middle (n=18)</th>
<th>Upper-middle (n=10)</th>
<th>High (n=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ratified/Accession</td>
<td>5 (71%)</td>
<td>11 (61%)</td>
<td>6</td>
<td>6</td>
<td>28 (62%)</td>
</tr>
<tr>
<td>Signed</td>
<td>0</td>
<td>5 (28%)</td>
<td>2</td>
<td>3</td>
<td>10 (22%)</td>
</tr>
<tr>
<td>Neither signed/ratified</td>
<td>2 (29%)</td>
<td>2 (11%)</td>
<td>2</td>
<td>1</td>
<td>7 (16%)</td>
</tr>
</tbody>
</table>

Two thirds (62 per cent) of the Commonwealth member states have ratified the CRPD while 7 member states have neither signed nor ratified the CRPD.

**What it means to sign the CRPD:** By signing the Convention or Optional Protocol, States or regional integration organizations indicate their intention to take steps to be bound by the treaty at a later date. Signing also creates an obligation, in the period between signing and ratification or consent to be bound, to refrain from acts that would defeat the object and purpose of the treaty.

**What is meant by ratification of CRPD:** In order to become a party to the Convention and the Optional Protocol, a State must demonstrate, through a concrete act, its willingness to undertake the legal rights and obligations contained in these two instruments. In other words, it must express its consent to be bound by the Convention and the Optional Protocol.

Under the Convention and the Optional Protocol, States may express their consent to be bound in several ways:

- **Ratification** (for States)
- **Accession** (for States and regional integration organizations)
- **Formal confirmation** (for regional integration organizations)

From: UN Enable (http://www.un.org/disabilities/default.asp?id=231)
3. **CRPD Article 25: Health**

This Article relates to the right to enjoyment of highest standard of physical and mental health by persons with disabilities. Article 25 of the CRPD builds on the 'right to health' as included in the Universal Declaration of Human Rights (UDHR, 1948) and Article 12 of the International Convention of Economic, Social and Cultural Rights (ICESCR, 1966) and elaborated by the Committee on Economic, Social and Cultural Rights (CESCR) in General Comment 14 (2000). Article 25 of the CRPD needs to be read together with Article 19 and Article 26 to fully understand the health related obligations under the CRPD.

(A) **Article 25 (2)** requires States to provide persons with disabilities with the same range, quality and standard of free and affordable health care and programmes as provided to other persons.

We used three specific criteria to assess if mental health legislation in Commonwealth States met the criteria for Article 25 (2):

(i) Does mental health legislation state that mental health care should be provided on an equal basis with physical health care?

**Table 3: Mental health care on an equal basis with physical care**

<table>
<thead>
<tr>
<th></th>
<th>Low ((n_1=7))</th>
<th>Low-middle ((n_2=18))</th>
<th>Upper-middle ((n_3=10))</th>
<th>High ((n_4=10))</th>
<th>Total ((N=45))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>2 (11%)</td>
<td>1 (10%)</td>
<td>2 (20%)</td>
<td>5 (11%)</td>
</tr>
<tr>
<td>No</td>
<td>7 (100%)</td>
<td>16 (89%)</td>
<td>9 (90%)</td>
<td>8 (80%)</td>
<td>40 (89%)</td>
</tr>
</tbody>
</table>

Mental health legislation in only 11 per cent of the countries specifically included provisions that meet this criteria, there being little difference between countries from different income groups.
Examples

South Africa - Mental Health Care Act 2002

Section 10 (2): Every mental health care user must receive care, treatment and rehabilitation services according to standards equivalent to those applicable to any other health care user

Malta – Rights of mental health users

Section 3 (1) (b) receive treatment of the same quality and standard as other individuals;

(ii) Does the legislation promote access to psychotropic medicines?

Table 4: Access to psychotropic medicines

<table>
<thead>
<tr>
<th></th>
<th>Low ((n_1=7))</th>
<th>Low-middle ((n_2=18))</th>
<th>Upper-middle ((n_3=10))</th>
<th>High ((n_4=10))</th>
<th>Total ((N=45))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>17</td>
<td>10</td>
<td>10</td>
<td>44 (98%)</td>
</tr>
</tbody>
</table>

Mental health legislation in only one Commonwealth country had specific provisions promoting access to psychotropic medicines. However other countries may have provisions for access to medicines (including psychotropic medicines) in their general health laws which were not analysed in this report.

Example

Ghana – Mental Health Act 2012

Section 57 (4): A person with mental disorder shall have access to psychotropic drugs and any other psychosocial rehabilitative interventions at different levels of care as appropriate
(iii) Free Care

While Article 25(2) requires states to provide free and affordable health care to persons with disabilities, we found that mental health laws in 18 (40 per cent) Commonwealth member states gives the Government the right to recover costs of treatment (including involuntary treatment in public mental health facilities) from the property or estate of the person with mental disorders or from their relatives, friends or care-givers.

There are ethical and legal questions on the justification for recovery of costs of treatment by the State especially when the State has the right to admit the person involuntarily without their consent.

**Example from one country legislation**

S 20.(1) If any patient detained in a psychiatric institution under the provisions of this Act has an estate applicable to his maintenance, or if any person legally bound to maintain the patient has the means to maintain him, the principal officer of the institution may apply to the court for an order for the payment of the cost of maintenance of the patient.

(2) The court shall inquire into the matter in a summary way, and on being satisfied that the patient has an estate applicable to his maintenance, or that any person is legally bound to maintain and has the means of maintaining the patient, may make an order for the recovery of the cost of maintenance of the patient, together with the costs of the application, out of the estate or from the person.

(3) An order made by a court under subsection (2) shall be enforced in the same manner and shall be of the same force and effect and subject to the same appeal as a judgment or order made by that court in a suit in respect of the property or person mentioned in that subsection.

(B) Article 25 (3) of CRPD requires health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent.
We assessed whether mental health legislation met the requirements of this CRPD provision using the following criteria:

(i) Whether voluntary admission and treatment is the preferred alternative in mental health legislation:

**Table 5: Promotion of voluntary admission and treatment as preferred alternative**

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>3 (17%)</td>
<td>0</td>
<td>1 (10%)</td>
<td>4 (9%)</td>
</tr>
<tr>
<td>No</td>
<td>7 (100%)</td>
<td>15 (83%)</td>
<td>10(100%)</td>
<td>9 (90%)</td>
<td>41 (91%)</td>
</tr>
</tbody>
</table>

Overall mental health legislation in only 4 (9 per cent) Commonwealth member states had provisions which met this criteria.

**Example**

**Samoa – Mental Health Act 2007**

Section 5 Voluntary Care Support and Treatment:

(1) In providing care, support, and where required, treatment and protection for persons with mental disorder, the Minister, Chief Executive Officer, the Ministry, the Court, health professionals and all other persons providing care, support, treatment or protection, shall, where possible, give preference to the provision of care, support, treatment or protection: (a) on a voluntary basis;

(2) For the purposes of this Act “voluntary basis” means that the person with a mental illness is provided with care, support, treatment and protection only;

(a)Where the person is given information and explanations about the care, support, treatment or protection in a language, style and manner which the person is most likely to understand; and
(b) Where options and choices of care, support, treatment or protection are available, information about the options and choices and the right to choose which options and choices are given to the person; and

(c) Where the person is competent to freely and voluntarily agree to or refuse care, support, treatment, or protection and the person’s agreement or refusal is respected and given effect to without unreasonable pressure or influence.

(ii) Does the law clearly state that all persons admitted voluntarily to a mental health facility can only be treated after obtaining informed consent?

Table 6: Informed consent before treatment for voluntary admissions

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>2 (29%)</td>
<td>5 (28%)</td>
<td>3 (30%)</td>
<td>3 (30%)</td>
<td>13 (29%)</td>
</tr>
<tr>
<td>No</td>
<td>5 (71%)</td>
<td>13 (72%)</td>
<td>7 (70%)</td>
<td>7 (70%)</td>
<td>32 (71%)</td>
</tr>
</tbody>
</table>

Mental health laws in only 29 per cent of countries clearly specify that persons voluntarily admitted to a mental health facility can only be treated after obtaining informed consent. Interestingly there is no difference between countries based on income classification. Most other laws do not contain a specific provision stating that persons admitted voluntarily shall only receive treatment with their informed consent.

In some laws there are paradoxical provisions – for example, legislation in a few countries contains a provision titled “Voluntary patient not to be detained for more than forty days” which further goes on to say “If any person received into a mental hospital as a voluntary patient... becomes at any time incapable of expressing himself as willing or unwilling to continue to receive treatment, he shall not be retained as a voluntary patient for a longer period than forty days”.

On the other hand, there are examples of good practice (see below)
Example

Malta – Mental Health Act 2012

Section 3 (i) give free and informed consent before any treatment or care is provided and such consent shall be recorded in the patient’s clinical record. This is without prejudice to the patient’s right to withdraw consent.

Pakistan – Mental Health Ordinance 2001

Section 51 Informed consent - (1) Before commencing any investigation or treatment a psychiatrist or nominated medical officer shall obtain written informed consent, on a prescribed form, from the patient or if the patient is a minor, his nearest relative or a guardian, as the case may be.

Ghana – Mental Health Act 2012

Section 40 (2) The consent of a voluntary patient shall be obtained before treatment is given; (3) A voluntary patient reserves the right to refuse treatment.

(iii) Does the law state that voluntary admission and treatment also implies the right to voluntary discharge/refusal of treatment?

Table 7: Right of voluntary admissions to voluntary discharge/refusal of treatment

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>2 (29%)</td>
<td>10 (56%)</td>
<td>7 (70%)</td>
<td>5 (50%)</td>
<td>24 (53%)</td>
</tr>
<tr>
<td>No</td>
<td>5 (71%)</td>
<td>8 (44%)</td>
<td>3 (30%)</td>
<td>5 (50%)</td>
<td>21 (47%)</td>
</tr>
</tbody>
</table>
Although mental health legislation in many countries does not promote voluntary admissions as a preferred alternative, there is provision for voluntary admission in many country laws. 24 (53 per cent) country laws allow persons who voluntarily admit themselves to a mental health facility to discharge themselves from the facility when they wish to do so.

Unfortunately in most instances this is not an unfettered right to discharge. Many laws put time limits before voluntarily admitted persons can be discharged and most laws allow the mental health professionals to detain the person in the mental health facility if in their opinion the person meets criteria for involuntary admission. The fact that persons who are admitted voluntarily may not be allowed to voluntarily discharge themselves leads to the question of whether the admission can truly be regarded as a voluntary admission.

**Examples**

**Malaysia - Mental Health Act 2001**

Section 9 (4) to an order made under subsection (5), a voluntary patient whose discharge has been requested under subsection (3) shall not be kept in the psychiatric hospital for more than seventy-two hours from the date of the notice given under that subsection.

**Botswana - Mental Disorders Act 1971**

Section 36 (4) Any person received as a voluntary patient under this section may leave the institution or other place if he is of the age of 16 years or over upon giving to the superintendent one week's notice in writing of his intention to do so, or if he is a person under the age of 16 years, upon such notice being given by his parent or guardian; but the superintendent of such institution or other place may at any time permit the patient to leave before the expiration of the said period of one week.

**Trinidad and Tobago Mental Health Act 1975**

Section 9 (4) A voluntary patient may, on giving notice in writing to the Psychiatric Hospital Director or the duly authorised medical officer, request his
discharge; in the case of a patient who is under the age of eighteen years, such notice shall be given by a parent, guardian or other person in loco parentis.

(5) A voluntary patient who has given notice as required by subsection (4) shall not be kept in a hospital for more than seven days from the date of the notice.

Since laws give mental health professionals such powers to bar discharge of persons admitted voluntarily, we also checked whether legislation had provisions to inform persons at the time of admission of this possibility. Unfortunately, legislation in only 3 countries specifically state that voluntary persons should be informed at the time of admission that they may be denied the right to leave if they meet conditions for involuntary care (see examples below).

**Examples**

**Ghana – Mental Health Act 2012**

Section 40 (5) At the time of admission, a voluntary patient shall be informed that a personal request for discharge may not be granted if the patient meets the requirements of involuntary admission at the time the request is made

**Tonga – Mental Health Act 2001**

Section 12 A person who has been admitted voluntarily may leave the mental health facility at any time unless he satisfies the criteria for involuntary admission and shall be informed of that right.

**Malta – Mental Health Act 2012**

Section 7 (2) (d) shall be informed on admission that medical personnel may exercise the authority to prevent his discharge should he meet involuntary admission criteria, unless the responsible specialist decides that it is not in the interest of the patient to be informed of such authority in which case such information shall be passed to the responsible carer.
(iv) Does the legislation provide patients free and full access to information about themselves (including access to their clinical records)?

Table 8: Free and full access to information including clinical records

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>3 (16%)</td>
<td>3 (30%)</td>
<td>6 (60%)</td>
<td>12 (27%)</td>
</tr>
<tr>
<td>No</td>
<td>7 (100%)</td>
<td>15 (84%)</td>
<td>7 (70%)</td>
<td>4 (40%)</td>
<td>33 (73%)</td>
</tr>
</tbody>
</table>

Legislation in only 12 (27 per cent) Commonwealth countries allows persons with mental disorders access to information. In some instances, this is not full access but limited to information about their admission. Access to information and medical records is most likely in High income countries (60 per cent) and least likely in low income countries (nil).

**Example**

**South Australia - Mental Health Act 2009**

Section 7 (1) (i) patients (together with their family or other carers or supporters) should be provided with comprehensive information about their illnesses, any orders that apply to them, their legal rights, the treatments and other services that are to be provided or offered to them and what alternatives are available.

In some jurisdictions, the law permits mental health professionals to deny persons access to their medical records under certain conditions (example, see legislation from South Africa below)
Section 13 (3) A mental health care provider may temporarily deny mental health care users access to information contained in their health records, if disclosure of that information is likely to-

(a) seriously prejudice the user; or

(b) cause the user to conduct himself or herself in a manner that may seriously prejudice him or her or the health of other people.

We also examined whether countries where the law gives professionals the right to withhold information also provided for persons and their personal representatives the right to ask for judicial review of or appeal against this decision. We could find only one instance (see below) where this was provided for in mental health legislation. The lack of this provision is also likely to contravene Article 13 of the CRPD.

Malta - Mental Health Act 2012

Section 3 Access to their clinical records unless, in the opinion of the responsible specialist revealing such information may cause harm to the person’s health or put at risk the safety of others. When any information is withheld, the patient or the responsible carer, may contest such decision with the Commissioner;

It may be argued there are provisions in general health laws, at least in a few countries, which give persons with mental health problems the right to access their medical records and also give them a right to appeal any refusal by mental health professionals to give such access. As we did not review general health
legislation in all the Commonwealth countries, it is difficult to either support or refute this assumption.

(v) Are the health authorities compelled by the law to inform patients of their rights?

Table 9: Provision of information on rights

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>3 (17%)</td>
<td>5 (50%)</td>
<td>5 (50%)</td>
<td>13 (29%)</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>14 (83%)</td>
<td>4 (50%)</td>
<td>5 (50%)</td>
<td>32 (71%)</td>
</tr>
</tbody>
</table>

Many persons who receive treatment from mental health services either are unaware of their rights or are not in a position to ask health care professionals about their rights. A provision in legislation that mandates health authorities to inform persons of their rights, will help users of mental health services to exercise their rights.

Mental health legislation in 13 (29 per cent) jurisdictions in the Commonwealth gives persons with mental disorders the right to be informed of their rights while receiving mental health care or treatment. As with many other provisions, this is most likely in laws from High income and Upper Middle income countries.

**Example**

**Mauritius - Mental Health Care Act 1999**

Section 25 A medical officer or psychiatrist shall inform every patient or his next of kin of the patient's rights and freedoms as specified in the Fourth Schedule, in a language which he understands
4 CRPD Article 19: Living independently and being included in the community & Article 26 Habilitation and Rehabilitation

Article 19 (1) of the CRPD requires that persons with disabilities should have access to a range of in-home, residential and other community support services. Article 26 requires countries to organize, strengthen and extend habilitation and rehabilitation services and programmes, particularly in the areas of health.

We therefor examined country legislation for the following:

(A) Does the legislation promote a rehabilitative, psychosocial approach?

**Table 10: Promotion of a rehabilitative, psychosocial approach**

<table>
<thead>
<tr>
<th></th>
<th>Low (n=7)</th>
<th>Low-middle (n=18)</th>
<th>Upper-middle (n=10)</th>
<th>High (n=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes</strong></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Possibly/Partly</strong></td>
<td>0</td>
<td>3 (20%)</td>
<td>4 (40%)</td>
<td>4 (40%)</td>
<td>11 (24%)</td>
</tr>
<tr>
<td><strong>No</strong></td>
<td>7 (100%)</td>
<td>15 (80%)</td>
<td>6 (60%)</td>
<td>6 (60%)</td>
<td>34 (76%)</td>
</tr>
</tbody>
</table>

We used the following criteria to decide whether legislation had a psycho-social and rehabilitative approach:

1) Whether the law specifically stated this as an objective,

2) Whether the law had provisions for range of in-home, residential and community based services,

3) Whether the law had provisions for access to health and social care services in the community.

It is a matter of concern that none of the laws met all the above criteria. Mental health laws in 11 (24 per cent) Commonwealth member states met either one or other of the above criteria and were rated as 'possibly/partly' meeting this standard.
(B) Does the legislation promote community care and deinstitutionalization?

Table 11: Promotion of community care and deinstitutionalisation

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Possibly/Partially</td>
<td>0</td>
<td>3 (20%)</td>
<td>2 (20%)</td>
<td>6 (60%)</td>
<td>11 (24%)</td>
</tr>
<tr>
<td>No</td>
<td>7 (100%)</td>
<td>15 (80%)</td>
<td>8 (80%)</td>
<td>4 (40%)</td>
<td>34 (76%)</td>
</tr>
</tbody>
</table>

We used the following criteria to rate country legislation on this standard:

1) Whether this was specifically stated as an objective of the legislation,

2) Whether there were provisions for community care and treatment as an alternative to institutional care,

3) Whether there were provisions in legislation which would lead to de-institutionalization eg. restricting admissions to specific situations and short duration, promoting discharge, providing a range of community based services to prevent institutionalization, making provisions for early treatment, restricting admission only to situations when community based treatment has been tried first.

While laws in 11 (24%) of the countries had some provisions toward promoting community care (for example, the provision of community treatment orders), no legislation met all the criteria to rate as promoting community care and deinstitutionalization. Even laws which had some provisions for community-based care, the broad thrust of the legislation was towards institutional treatment and regulation of such treatment. It may be argued that community based care and de-institutionalization are matters of health policy but countries need to recognize that mental health laws may frequently be a barrier to such policies.
5. CRPD Article 12: Equal recognition before the Law

Article 12 (1) of the CRPD requires countries to “reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law”. Article 5 (1) of the CRPD also requires countries to recognize that all persons are equal before the law and are entitled without any discrimination to the equal protection and equal benefit of the law. This right is also reinforced by Article 13 (1) of the CRPD on access to justice which requires countries to “ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.”

(A) Guardianship

24 (53 per cent) countries had provisions for guardianship in their mental health laws. Low income countries (71 per cent) were most likely to have such provisions, while High income countries (30 per cent) were least likely to have guardianship provisions in mental health legislation.

Table 12: Guardianship provisions

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>5 (71%)</td>
<td>10 (56%)</td>
<td>6 (60%)</td>
<td>3 (30%)</td>
<td>24 (53%)</td>
</tr>
<tr>
<td>No</td>
<td>2 (29%)</td>
<td>8 (44%)</td>
<td>4 (40%)</td>
<td>7 (70%)</td>
<td>20 (47%)</td>
</tr>
</tbody>
</table>

(i) Provision for type of Guardianship

We further examined whether the laws of those countries which had provisions for guardianship in their mental health laws provided for limited guardianship or plenary guardianship. Nearly a third (7 countries) of the laws only allowed
limited guardianship usually restricted to property matters, while the majority (58 per cent) of mental health laws had provisions for both limited and plenary guardianship. This provision of plenary guardianship is almost certainly in conflict with the countries' obligations under Article 12 of the CRPD.

**Table 13: Type of Guardianship provision**

<table>
<thead>
<tr>
<th>Type of Guardianship Provision</th>
<th>Low (n₁=5)</th>
<th>Low-middle (n₂=10)</th>
<th>Upper-middle (n₃=6)</th>
<th>High (n₄=3)</th>
<th>Total (N=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plenary only</td>
<td>1 (20%)</td>
<td>0</td>
<td>1 (17%)</td>
<td>1 (33%)</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>Both (plenary &amp; limited)</td>
<td>3 (60%)</td>
<td>7 (70%)</td>
<td>3 (50%)</td>
<td>1 (33%)</td>
<td>14 (58%)</td>
</tr>
<tr>
<td>Limited only</td>
<td>1 (20%)</td>
<td>3 (30%)</td>
<td>2 (33%)</td>
<td>1 (33%)</td>
<td>7 (29%)</td>
</tr>
</tbody>
</table>

(ii) Procedural issues with guardianship

We then examined laws with respect to the procedures for guardianship decisions and whether these procedures met the requirements of Article 13 (1) of the CRPD.

(a) We examined whether laws required that the person is represented at the hearing.

**Table 14: Requirement for a person to be represented at a hearing**

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Low (n₁=5)</th>
<th>Low-middle (n₂=10)</th>
<th>Upper-middle (n₃=6)</th>
<th>High (n₄=3)</th>
<th>Total (N=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>2 (20%)</td>
<td>1 (17%)</td>
<td>0</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>No</td>
<td>5 (100%)</td>
<td>8 (80%)</td>
<td>5 (83%)</td>
<td>3 (100%)</td>
<td>21 (87%)</td>
</tr>
</tbody>
</table>

Many laws had provisions for the person who is the subject of the guardianship application to be produced before the Court for examination, however only 3 (13 per cent) country laws required the person who is the subject of the
guardianship application to remain present and/or be represented at the hearing.

**Example**

**Ghana – Mental Health Act 2012**

*Section 68 (5) A person for whom a guardian is being appointed has the right, in person or through a representative, to contest the application for the guardianship.*

(b) We examined whether laws had provisions for appeal to higher courts against the guardianship order. The majority of country laws (66 per cent) did not have any provisions for appeal to a higher court against the guardianship order.

**Table 15: Appeal provisions**

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=5)</th>
<th>Low-middle (n₂=10)</th>
<th>Upper-middle (n₃=6)</th>
<th>High (n₄=3)</th>
<th>Total (N=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1 (20%)</td>
<td>3 (30%)</td>
<td>3 (50%)</td>
<td>1 (33%)</td>
<td>8 (34%)</td>
</tr>
<tr>
<td>No</td>
<td>4 (80%)</td>
<td>7 (70%)</td>
<td>3 (50%)</td>
<td>2 (67%)</td>
<td>16 (66%)</td>
</tr>
</tbody>
</table>

**Example**

**Dominica – Mental Health Act 1987**

*Section 25 An appeal lies to the Court of Appeal from any decision of the High Court subject to and in accordance with rules of court relating to civil appeals from the High Court to the Court of Appeal.*

(c) We also examined if the laws provide for regular reviews of guardianship orders. The majority of country laws (79 per cent) did not have any provisions for regular time bound reviews of guardianship orders.
Table 16: Review provisions

<table>
<thead>
<tr>
<th></th>
<th>Low (n_1=5)</th>
<th>Low-middle (n_2=10)</th>
<th>Upper-middle (n_3=6)</th>
<th>High (n_4=3)</th>
<th>Total (N=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>3 (30%)</td>
<td>1 (17%)</td>
<td>1 (33%)</td>
<td>5 (21%)</td>
</tr>
<tr>
<td>No</td>
<td>5 (1005)</td>
<td>7 (70%)</td>
<td>5 (83%)</td>
<td>2 (67%)</td>
<td>19 (79%)</td>
</tr>
</tbody>
</table>

**Example**

**Grenada - Mental Health Act 1990**

*Section 51 (5) An order made under this section shall lapse after one year unless renewed by the Court after being satisfied that the reasons for the order still exists.*

On all the above procedural issues, mental health laws fall significantly short of the legal requirements for fulfilling the rights of persons with mental disorders under Article 13 (1) of the CRPD.

**(B) Supported & Substituted Decision-making**

Article 12 (3) says that States Parties shall take appropriate measures to provide access by persons with disabilities to the support they require in exercising their legal capacity

**(i) Supported Decision Making**

Supported decision-making is concerned with assisting people with impaired decision-making (due to disability) to make their own decisions (Gooding, 2012). It allows for the expression of autonomous decisions, regardless of the level of support needed. The Committee on Rights of Persons with Disabilities (ComRDP) defines supported decision-making as:

“those assisting a person may communicate the individuals’ intentions to others or help him/her understand the choices at hand. They may help others to realize
that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity... the individual is the decision maker; the support person (s) explains the issues, when necessary and interprets the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity, to the greatest extent possible according to the wishes of the individual” (UN ComRPD, undated; Gooding, 2012). Additionally, the ComRPD highlights the significance of supported decision making to laws and policy concerning disability and psychosocial disabilities, including guardianship and mental health legislation.

**Existing models of supported decision-making in Commonwealth legislation**

The two Commonwealth countries with well-developed models of supported decision-making included in legislation are Canada and Scotland. We review their models briefly below.

(Also see Pathare & Shields (2012) for more details)

**Table: 17**

**Overview of supported decision-making provisions in Canadian and Scottish Legislation**

| Alberta                  | Supported decision-making offered to mild disabilities; for more significant impairment: co-decision makers, guardians, or trustees.  
|                         | Co-decision makers (court-appointed) collaborate together with the individual. The individual still can make decisions but with support (retains legal capacity).  
|                         | Guardians (court-appointed) take legal responsibility on behalf of the individual who lacks capacity.  
|                          | Guardianship and Trusteeship Act & Personal Directives Act |
- Trustees make financial decisions for the individual who lacks capacity.
- Co-decision makers, supported decision makers, and specific decision makers cannot make mental health treatment decisions for formal patients or patients who have a community treatment order if they lack mental capacity.
- A health care provider can choose a relative to make decisions based on a ranked list if no guardian or advance directive is available for treatment decisions.
- Tools available for support are advance directives, enduring Power Of Attorney (POA), and supported decision authorizations.

<table>
<thead>
<tr>
<th>British Columbia</th>
<th>1. Representation agreements (RA’s) cover personal, health and financial affairs.</th>
<th>Representation Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. A representative (usually multiple representatives to cover different areas, and with an external monitor to ensure representatives are fulfilling duties as a safeguard to protect from abuse) helps the individual to make their own decisions, and/or makes substituted decisions. There must be a clear desire for a representative agreement and a trusting relationship between the individual and representative(s).</td>
<td>Adult Guardianship and Planning Statutes Amendment Act, 2007</td>
</tr>
<tr>
<td></td>
<td>3. The individual must have capacity to make a RA</td>
<td></td>
</tr>
</tbody>
</table>


(depending on whether it is section 7 or 9 agreement). RA’s can be amended and revoked; thus less restrictive than guardianship.

4. RA’s involve elements of supported and substituted decision-making and presume everybody has capacity until proven otherwise.

5. RA’s enable the individual to remain in control and retain decision-making rights.

<table>
<thead>
<tr>
<th>Manitoba</th>
<th>Acknowledges support networks, exercising decision-making rights, implements safeguards to prevent abuse and neglect and keeps substituted decision-making as a last resort. Only available for persons with intellectual disabilities, not for persons with mental disorder (PwMD).</th>
</tr>
</thead>
</table>
| Prince Edward Island | • Supported decision-making agreements can be made by any person over 18 years of age  
• The Act contains guiding principles (similar to Manitoba and British Columbia) endorsing the presumption of capacity  
• The use of court-ordered guardianship as a last resort and only after support and assistance have been tried/carefully considered, and the adult is involved to the best of his or her ability in decision-making that affects their lives. |
| Vulnerable Persons Living with a Mental Disability Act | Supported Decision-making and Adult Guardianship Act |
| Quebec | Curators and tutors (court-appointed) available for PwMD. Curator assignment implies that incapacity of the individual is total and permanent and tutorship implies incapacity is temporary.  
- Advisorship is also available and is least intrusive, pertains to administration of the individuals’ property; decision-making power is retained in all other aspects of life. Advisors are imposed on the individual, so the person is unable to refuse support.  
- Support tools (mandates) such as advance directives are also available. | Civil Code of Quebec |
| Saskatchewan | Hybrid between supported and substituted decision-making.  
- Guardians: court ordered, courts choose who guardian will be, supports imposed by order (rather than by choice).  
- Co-decision makers: available to assist in making decisions jointly with the individual.  
- Temporary guardians are also available for emergency situations.  
- Decision-making orders can be assigned for areas of life that an individual has particular difficulty in reaching decisions in (so capacity is intact to make autonomous decisions in other aspects of life).  
- Individuals can also refuse support, as long as they have the capacity to communicate | Adult Guardianship and Co-decision-making Act |
<table>
<thead>
<tr>
<th>Area</th>
<th>Details</th>
<th>Act/Policy</th>
</tr>
</thead>
</table>
| Yukon Territories | - Full spectrum of varying support options (supported decision-making agreements, representation agreements, substituted decision-making for health care decisions, guardianship) based on needs of the individual.  
  - Supported decision-making agreements possible if person has capacity at time of requesting agreement. If the client loses capacity, the agreement is terminated.  
  - The supported decision-making agreement involves the consent and formalization of two (or more) adults to enter into a support relationship. | Adult Decision Making and Protection Act (Yukon)                           |
| Scotland        | - Scotland’s system provides free access to independent advocacy (obligated responsibility of each Health Service/Board).  
  - Less legal approach to determining decision-making capacity; acknowledges times where decision-making capacity is retained and other times where it may be compromised due to a mental disorder.  
  - There can be no personal appointment to position of guardian (only a POA). Having a POA in place for a PwMD removes the need for guardianship.  
  - A “named” person can be nominated by the client to attend hearings and provide | Mental Health (Care and Treatment Act) 2003; Adults with Incapacity (Scotland) Act 2000 |
information for the client. PwMD have access to advance directives, particularly in treatment decisions. If a PwMD cannot consent to treatment or refuses to, a clinician is obligated to consider (and record in writing) the reason for not consenting; the views of the involuntary patient and a nominated person together with any advanced statement; and how efficacious the treatment is.

Canada

Support provisions for decision-making differ across Canadian laws (see table above). Some provincial laws only provide the option for supported decision-making to persons with intellectual disabilities and not to persons with mental disorders, as is the case in Manitoba’s The Vulnerable Persons Living with a Mental Disability Act. Similarly, in Alberta, supported decision-making arrangements are only available for persons with mild disabilities. Other provinces, like Saskatchewan, offer a hybrid system between supported decision-making and substituted decision-making. However, perhaps the most discussed and well-known example of a supported decision-making model in Canada is British Columbia’s Representation Agreement Act. Representation agreements provide a contractual agreement between two (or more) adults to formalise a support relationship. In the representation agreement, the “decision-maker” (person with disability) can appoint a person (an “associate”) to help him or her make decisions regarding personal, health and financial decisions. In this instance, a person has the right to be assisted by an associate to make health care decisions, but the associate has no authority to make decisions for the supported individual (Gooding, 2012). A typical support set-up involves a representative, or multiple representatives to cover different areas (personal, health and financial affairs) and an external monitor to ensure
representatives are fulfilling duties as a safeguard to protect from abuse. Agreements can be amended and revoked and are less restrictive than guardianship. Representative agreements do however involve some elements of supported and substituted decision-making and presume everybody has capacity until proven otherwise. British Columbia and Quebec have enacted three-tier systems of court-ordered guardianship and substitute decision-making, with the aim of distinguishing between different kinds of support and assistance and ensuring that when a court-ordered intervention occurs it is the most effective but least restrictive, least intrusive and least stigmatizing way of meeting the affected adults needs (Gordon, 2000). The Yukon Territories offer a number of support options based on the needs of the individual.

**Scotland**

Scotland’s legal system provides free access to independent advocates, a provision which is obligated by each health service in the country. Scotland’s system acknowledges that there may be times where decisional capacity is retained and other times where it may be compromised due to a mental disorder. Scotland’s legislation allows for a power of attorney (who cannot be self-elected, must be appointed by the client with a psychosocial disability), a nominated representative (“named” person) or advance directives. Scottish law also empowers carers to be actively involved in the decision-making process together with their family member or relative with a mental disorder.

**(ii) Advance Directives**

Perhaps one of the more discussed forms of supported decision-making is Psychiatric Advance Directives (PADs) (Weller, 2012).

*Brief overview of psychiatric advance directives in Commonwealth legislation*

**Canada**

Mental health law in all Canadian provinces and territories (with the exception of Nunavut) enable persons with mental disorder to complete proxy directives, however, only 6 jurisdictions in Canada have statutory provisions for the use of instructional directives like PADs (Ambrosini et al. 2012). For example, proxy
directives are used in Quebec and are mandated legal documents (outlined in the Civil Code of Quebec, 1991) where a person with mental disorder can appoint a trusted third party (e.g. a relative) to make decisions in the event of mental incapacity (Ambrosini et al. 2012). Quebec, New Brunswick, Ontario, British Columbia, and the Yukon do not have legislation which recognises instructional directives (Ambrosini et al. 2012).

Scotland

Scotland is well known for its support for advance statements. Scotland makes provisions for PADs (referred to as advance statements), outlined in the Mental Health (Care and Treatment) Act (2003). The Act states that all persons subject to a mental health order under the Act are entitled to write PADs. The client has the right to both make and withdraw the PADs. The provision has two aspects: First, it allows a person to specific treatment they want and the treatment they do not want, and second, the statement is taken into consideration when a person is to be treated under the Act (Atkinson, 2007). When the advance statement is taken into account under compulsory treatment, both the treating health care professional and tribunal need to take the statement into account (although the statement can be overridden) (Atkinson, 2007). The statement can only be overridden after reasons have been provided to the patient, the patient’s guardian, legal representative and the Mental Welfare Commission (Morrissey, 2010). The advance statements in Scotland are therefore non-binding statements.

New Zealand

New Zealand offers provisions for PADs in its Code of Health and Disability Services Consumer Rights (which came into effect in 1996) and is a regulation under the Health and Disability Commission Act of 1996. PAD’s are also recognised in the National Mental Health Sector Standards and within provisions for Powers of Attorney (POAs) under the Protection of Personal and Property Rights Act (1988). Finally, amendments to the Compulsory Assessment and Mental Health Treatment Act (1999) requires persons authorised under the Act (e.g. health care professionals and providers) to take into account client and
carer preferences, and ensure proper recognition of the patient’s beliefs (Weller, 2010).

**Australia**

Three Australian states (Victoria, South Australia, and Queensland), and two territories (the Northern Territory and Australian Capital Territory) have provisions for PADs. New South Wales, Tasmania and Western Australia do not have similar legislation however PADs may still be valid under common law in these states (Australian Government, 2007).

**(iii) Substituted Decision making:**

Australia has entered a Interpretive Declaration on Article 12 stating Australia's understanding that substituted decision making is allowed under the CRPD.

“*Australia recognises that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life. Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards.*”

Canada too has entered a Declaration and Reservation on Article 12 stating its understanding that substitute decision making is allowed under the CRPD and Canada reserves the right to continue with substitute decision making arrangements with appropriate safeguards.

“*Canada recognises that persons with disabilities are presumed to have legal capacity on an equal basis with others in all aspects of their lives. Canada declares its understanding that Article 12 permits supported and substitute decision-making arrangements in appropriate circumstances and in accordance with the law.*

To the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Canada reserves the right to continue their use in appropriate circumstances and subject to appropriate and effective
safeguards. With respect to Article 12 (4), Canada reserves the right not to subject all such measures to regular review by an independent authority, where such measures are already subject to review or appeal.”

While examining Tunisia, the ComRPD said “The Committee recommends that the State party review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making.”

(accessed on 20th April 2013

http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session5.aspx).

The ComRPD also made nearly identical recommendations while examining China “The Committee urges the State party to adopt measures to repeal the laws, policies and practices which permit guardianship and trusteeship for adults and take legislative action to replace regimes of substituted decision-making by supported decision making, which respects the person’s autonomy, will and preferences, in the exercise of one’s legal capacity in accordance with article 12 of the Convention.”

(accessed on 20th April 2013


Brayley (2009) posits a “stepped” approach to supported decision-making, based on increasing or decreasing state intervention and levels of autonomy. Bach & Kerzner (2010) suggest three levels of decision-making: autonomous, supported and facilitated decision-making, accompanied by a corresponding level of legal oversight, covering the spectrum from non-intervention to the provision of support mechanisms to help further decision-making capabilities, to a form of substitute decision-making (facilitated decision-making).

6. CRPD Article 14: Liberty
Article 14 (a) says that persons with disabilities should not be deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

Australia has entered an Interpretive Declaration on Article 14 stating Australia's understanding that CRPD allows for involuntary treatment of persons with mental disorders.

“Australia recognizes that every person with disability has a right to respect for his or her physical and mental integrity on an equal basis with others. Australia further declares its understanding that the Convention allows for compulsory assistance or treatment of persons, including measures taken for the treatment of mental disability, where such treatment is necessary, as a last resort and subject to safeguards.”

The ComRPD has not yet published its concluding observations on any Commonwealth member state (Australia is currently being examined by the ComRPD and concluding remarks of the ComRPD are awaited). However in the case of Spain the ComRPD observed “The Committee recommends that the State party: review its laws that allow for the deprivation of liberty on the basis of disability, including mental, psychosocial or intellectual disabilities; repeal provisions that authorize involuntary internment linked to an apparent or diagnosed disability; and adopt measures to ensure that health-care services, including all mental-health-care services, are based on the informed consent of the person concerned.”

(accessed on 20th April 2013)

http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session6.aspx)

Recently the UN Special Rapporteur on Torture (Mendez J, 2013) recommended that States:

(1) Impose an absolute ban on all forced and non-consensual medical interventions against persons with disabilities, including the non-consensual administration of psychosurgery, electroshock and mind-altering drugs such as
neuroleptics, the use of restraint and solitary confinement, for both long- and short-term application. The obligation to end forced psychiatric interventions based solely on grounds of disability is of immediate application and scarce financial resources cannot justify postponement of its implementation;

(2) Revise the legal provisions that allow detention on mental health grounds or in mental health facilities, and any coercive interventions or treatments in the mental health setting without the free and informed consent by the person concerned.

The UN High Commissioner for Human Rights (UNHCHR, 2009) recommended “Legislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent must be abolished. This must include the repeal of provisions authorizing institutionalization of persons with disabilities for their care and treatment without their free and informed consent, as well as provisions authorizing the preventive detention of persons with disabilities on grounds such as the likelihood of them posing a danger to themselves or others, in all cases in which such grounds of care, treatment and public security are linked in legislation to an apparent or diagnosed mental illness.”

However in the same report, the UNHCHR further says “This should not be interpreted to say that persons with disabilities cannot be lawfully subject to detention for care and treatment or to preventive detention, but that the legal grounds upon which restriction of liberty is determined must be de-linked from the disability and neutrally defined so as to apply to all persons on an equal basis.”

Currently mental health legislation in all Commonwealth member states allows involuntary admission and treatment for persons with mental disorders. We therefore examined the grounds for involuntary admission and treatment in country legislation.

(A) Involuntary Admission:

Mental health legislation in only 53 per cent of countries mandates the mental disorder should be of a specified severity to allow involuntary admission. In the
remaining countries, such a requirement is not necessary for involuntary admission. Mental health legislation in 69 per cent of countries states that involuntary admission may only be allowed if there is serious likelihood of harm to self or others and/or substantial likelihood of serious deterioration in the patient’s condition if treatment is not given. Mental health legislation in only 31 per cent of countries states that involuntary admission may be allowed if admission is for a therapeutic purpose. 60 per cent of country laws require certification by two accredited mental health practitioners for involuntary admission. 80 per cent of mental health legislation in Commonwealth countries does not apply the principle of least restrictive alternative to involuntary admission. Only half (51 per cent) of country mental health laws require the person to be discharged as soon as they do not meet criteria for involuntary admission (see below).
### Table 18: Criteria for involuntary admission

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) Does the law state that involuntary admission may only be allowed if there is evidence of mental disorder of specified severity?</td>
<td>3 (43%)</td>
<td>9 (50%)</td>
<td>7 (70%)</td>
<td>5 (50%)</td>
<td>24 (53%)</td>
</tr>
<tr>
<td>(ii) Does the law state that involuntary admission may only be allowed if there is serious likelihood of harm to self or others and/or substantial likelihood of serious deterioration in the patient’s condition if treatment is not given?</td>
<td>4 (57%)</td>
<td>11 (61%)</td>
<td>7 (70%)</td>
<td>9 (90%)</td>
<td>31 (69%)</td>
</tr>
<tr>
<td>(iii) Does the law state that involuntary admission may only be allowed if admission is for a therapeutic purpose?</td>
<td>0</td>
<td>6 (33%)</td>
<td>4 (40%)</td>
<td>4 (40%)</td>
<td>14 (31%)</td>
</tr>
<tr>
<td>(iv) Does the law state that two accredited mental health care practitioners must certify that the criteria for involuntary admission have been met?</td>
<td>4 (40%)</td>
<td>10 (56%)</td>
<td>5 (50%)</td>
<td>8 (80%)</td>
<td>27 (60%)</td>
</tr>
<tr>
<td>(v) Is the principle of the least restrictive environment applied to involuntary admissions?</td>
<td>0</td>
<td>4 (22%)</td>
<td>1 (10%)</td>
<td>4 (40%)</td>
<td>9 (20%)</td>
</tr>
</tbody>
</table>
(vi) Does the law specify that patients must be discharged from involuntary admission as soon as they no longer fulfil the criteria for involuntary admission?

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3 (43%)</td>
<td>8 (44%)</td>
<td>5 (50%)</td>
<td>7 (70%)</td>
<td>23 (51%)</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
<td>15 (83%)</td>
<td>6 (60%)</td>
<td>3 (30%)</td>
<td>31 (69%)</td>
</tr>
</tbody>
</table>

(B) Review and Oversight Mechanisms:

Article 14 (b) says, “States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of the present Convention, including by provision of reasonable accommodation.”

(i) Does the law set up a judicial or quasi-judicial body to review processes related to involuntary admission or treatment and other restrictions of rights?

Table 19: Review of involuntary admission or treatment

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>3 (17%)</td>
<td>4 (40%)</td>
<td>7 (70%)</td>
<td>14 (31%)</td>
</tr>
<tr>
<td>No</td>
<td>7 (100%)</td>
<td>15 (83%)</td>
<td>6 (60%)</td>
<td>3 (30%)</td>
<td>31 (69%)</td>
</tr>
</tbody>
</table>

Mental health legislation in 14 (31 per cent) Commonwealth member states sets up a judicial or quasi-judicial body to review involuntary admissions, treatment
and restriction of rights. Thus more than two-thirds of the mental health laws do not have a judicial/quasi-judicial body to review involuntary admissions and treatment.

(ii) We further examined the provisions of the judicial/quasi-judicial body in these 14 country laws. In general, when a judicial/quasi-judicial review body exists in country legislation, it usually meets standards outlined below (see Table 20).

**Table 20: Judicial or Quasi-Judicial Review of Involuntary Admission**

<table>
<thead>
<tr>
<th>(a) Does the body assess each involuntary admission/treatment?</th>
<th>Low (n₁=0)</th>
<th>Low-middle (n₂=3)</th>
<th>Upper-middle (n₃=4)</th>
<th>High (n₄=7)</th>
<th>Total (N=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>2 (67%)</td>
<td>1 (25%)</td>
<td>6 (86%)</td>
<td>9 (64%)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(b) Does the body entertain appeals against involuntary admission and/or involuntary treatment?</th>
<th>Low (n₁=0)</th>
<th>Low-middle (n₂=3)</th>
<th>Upper-middle (n₃=4)</th>
<th>High (n₄=7)</th>
<th>Total (N=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>3 (100%)</td>
<td>4 (100%)</td>
<td>7 (100%)</td>
<td>14 (100%)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(d) Does the law allow for appeal of this body’s decisions to a higher court?</th>
<th>Low (n₁=0)</th>
<th>Low-middle (n₂=3)</th>
<th>Upper-middle (n₃=4)</th>
<th>High (n₄=7)</th>
<th>Total (N=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>3 (100%)</td>
<td>3 (75%)</td>
<td>5 (71%)</td>
<td>11 (79%)</td>
<td></td>
</tr>
</tbody>
</table>

**7. Article 15 : Freedom from cruel, inhuman and degrading treatment and punishment**

Article 15 (1) of the CRPD says that no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.
Mental health laws in 27 (82 per cent) Commonwealth countries do not specifically include a right to respect and dignity. Provisions for protection from cruel, inhuman and degrading treatment is included in the legislation in 23 (51 per cent) countries. Prohibition on psychosurgery and irreversible treatments on persons who are being treated involuntarily is absent in 42 (93 per cent) country laws. Only 11 (24 per cent) country laws specify that informed consent should be obtained when using electro-convulsive therapy (ECT). Legislation in no country specifically bans the use of unmodified ECT or the use of ECT in minors. Informed consent of persons with mental disorders for participating in clinical and experimental research is specifically mandated in mental health legislation in only 5 (11 per cent) countries.

(i) Does the legislation include the rights to respect, dignity and to be treated in a humane way?

**Table 21: Inclusion of right to respect, dignity and to be treated in a humane way**

<table>
<thead>
<tr>
<th></th>
<th>Low</th>
<th>Low-middle</th>
<th>Upper-middle</th>
<th>High</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n₁=7)</td>
<td>(n₂=18)</td>
<td>(n₃=10)</td>
<td>(n₄=10)</td>
<td>(N=45)</td>
</tr>
<tr>
<td>Yes</td>
<td>0</td>
<td>3 (17%)</td>
<td>3 (30%)</td>
<td>2 (20%)</td>
<td>8 (18%)</td>
</tr>
<tr>
<td>No</td>
<td>7 (100%)</td>
<td>15 (83%)</td>
<td>7 (70%)</td>
<td>8 (80%)</td>
<td>37 (82%)</td>
</tr>
</tbody>
</table>

**Example**

**Mauritius - Mental Health Care Act, 1999**

Fourth Schedule: [S. 2 and S. 25]

*Patients’ Rights: “The patient shall be treated with humanity and respect for the inherent dignity of the human person.”*

(ii) Does the law specify the right to be protected from cruel, inhuman and degrading treatment?
Table 22: Right to be protected from cruel, inhuman and degrading treatment

<table>
<thead>
<tr>
<th></th>
<th>Low (n=7)</th>
<th>Low-middle (n=18)</th>
<th>Upper-middle (n=10)</th>
<th>High (n=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3 (43%)</td>
<td>6 (33%)</td>
<td>6 (60%)</td>
<td>8 (80%)</td>
<td>23 (51%)</td>
</tr>
<tr>
<td>No</td>
<td>4 (57%)</td>
<td>12 (67%)</td>
<td>4 (40%)</td>
<td>2 (20%)</td>
<td>22 (49%)</td>
</tr>
</tbody>
</table>

Example

Ghana - Mental Health Act, 2012

S. 57: Standards of Treatment

(3) A person with mental disorder shall not be subjected to torture, cruelty, forced labour and any other inhuman treatment.

(iii) Are psychosurgery and other irreversible treatments outlawed on persons being treated involuntary?

Table 23: Outlawing of psychosurgery and other irreversible treatments

<table>
<thead>
<tr>
<th></th>
<th>Low (n=7)</th>
<th>Low-middle (n=18)</th>
<th>Upper-middle (n=10)</th>
<th>High (n=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>1 (6%)</td>
<td>1 (10%)</td>
<td>1 (10%)</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>No</td>
<td>7 (100%)</td>
<td>17 (94%)</td>
<td>9 (90%)</td>
<td>9 (90%)</td>
<td>42 (93%)</td>
</tr>
</tbody>
</table>

Example

Ontario - Mental Health Act, 1990

S. 49 (1) Psychosurgery shall not be administered to an involuntary patient, to a person who is incapable of giving or refusing consent to psychosurgery on his or her own behalf for the purposes of the Health Care Consent Act, 1996, or to a person who is remanded or detained in a psychiatric facility pursuant to the Criminal Code (Canada). 1992, c.32, s.20 (39); 1996, c.2, s.72(30).
(iv) Does the law specify the need for informed consent when using ECT?

**Table 24: Requirement for informed consent for ECT**

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>3 (17%)</td>
<td>4 (40%)</td>
<td>4 (40%)</td>
<td>11 (24%)</td>
</tr>
<tr>
<td>No</td>
<td>7 (100%)</td>
<td>15 (83%)</td>
<td>6 (60%)</td>
<td>6 (60%)</td>
<td>34 (76%)</td>
</tr>
</tbody>
</table>

Example:

**Pakistan - MENTAL HEALTH ORDINANCE FOR PAKISTAN 2001**

S.56: Specialized Psychiatric Treatments.
- (1) Specialized psychiatric treatment may be carried out with the informed consent of the patient, on the orders in writing by the psychiatrist in charge of the treatment of the patient or his relative or guardian, if the patient is a minor.

(v) Does the law prohibit the use of unmodified ECT?

**Table 25: Prohibition of unmodified ECT**

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Possibly/Partially</td>
<td>0</td>
<td>1 (7%)</td>
<td>0</td>
<td>1 (10%)</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>No</td>
<td>7 (100%)</td>
<td>17 (93%)</td>
<td>10</td>
<td>9</td>
<td>43 (96%)</td>
</tr>
</tbody>
</table>
(vi) Does the law prohibit the use of ECT in minors?

**Table 26: Prohibition of ECT in minors**

<table>
<thead>
<tr>
<th></th>
<th>Low (n1=7)</th>
<th>Low-middle (n2=18)</th>
<th>Upper-middle (n3=10)</th>
<th>High (n4=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes</strong></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>No</strong></td>
<td>7</td>
<td>18</td>
<td>10</td>
<td>10</td>
<td>45 (100%)</td>
</tr>
</tbody>
</table>

(vii) Does the mental health law specifically state that informed consent must be obtained for participation in clinical or experimental research from both voluntary and involuntary patients?

**Table 27: Informed consent for participation in clinical or experimental research**

<table>
<thead>
<tr>
<th></th>
<th>Low (n1=7)</th>
<th>Low-middle (n2=18)</th>
<th>Upper-middle (n3=10)</th>
<th>High (n4=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes</strong></td>
<td>0</td>
<td>2 (11%)</td>
<td>2 (20%)</td>
<td>1 (10%)</td>
<td>5 (11%)</td>
</tr>
<tr>
<td><strong>No</strong></td>
<td>7 (100%)</td>
<td>16 (89%)</td>
<td>8 (80%)</td>
<td>9 (90%)</td>
<td>40 (89%)</td>
</tr>
</tbody>
</table>

8. Article 22: Respect for Privacy

Article 22 (b) of the CRPD requires States to protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

Mental health laws in 9 (20 per cent) countries include a provision on protection of confidentiality and 8 (18 per cent) countries include a provision on privacy for persons with mental disorders.

(i) Is the right to confidentiality regarding information about themselves, their illness and treatment included in mental health legislation?
Table 28: Right to confidentiality

<table>
<thead>
<tr>
<th></th>
<th>Low (n1=7)</th>
<th>Low-middle (n2=18)</th>
<th>Upper-middle (n3=10)</th>
<th>High (n4=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>3 (17%)</td>
<td>3 (30%)</td>
<td>3 (30%)</td>
<td>9 (20%)</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>15 (83%)</td>
<td>7 (70%)</td>
<td>7 (70%)</td>
<td>36 (80%)</td>
</tr>
</tbody>
</table>

(ii) Are there sanctions and penalties for people who contravene confidentiality?

Table 29: Sanctions and penalties for contravention of confidentiality

<table>
<thead>
<tr>
<th></th>
<th>Low (n1=7)</th>
<th>Low-middle (n2=18)</th>
<th>Upper-middle (n3=10)</th>
<th>High (n4=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>2 (11%)</td>
<td>2 (20%)</td>
<td>3 (30%)</td>
<td>7 (16%)</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>16 (89%)</td>
<td>8 (80%)</td>
<td>7 (70%)</td>
<td>38 (84%)</td>
</tr>
</tbody>
</table>

(iii) Does the mental health law insist on the privacy of people with mental disorders?

Table 30: Privacy

<table>
<thead>
<tr>
<th></th>
<th>Low (n1=7)</th>
<th>Low-middle (n2=18)</th>
<th>Upper-middle (n3=10)</th>
<th>High (n4=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>3 (17%)</td>
<td>2 (20%)</td>
<td>3 (30%)</td>
<td>8 (18%)</td>
</tr>
<tr>
<td>No</td>
<td>7 (100%)</td>
<td>15 (83%)</td>
<td>8 (80%)</td>
<td>7 (70%)</td>
<td>37 (82%)</td>
</tr>
</tbody>
</table>

9. Article 16 : Freedom from exploitation, violence and abuse

Article 16 (3) of the CRPD requires states to prevent the occurrence of all forms of exploitation, violence and abuse, by ensuring that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities

(i) Does the law set up a regulatory and oversight body to protect the rights of
people with mental disorders within and outside mental health facilities?

**Table 31: Mental health regulatory body**

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>5 (71%)</td>
<td>10 (56%)</td>
<td>5 (50%)</td>
<td>6 (60%)</td>
<td>26 (58%)</td>
</tr>
<tr>
<td>No</td>
<td>2 (29%)</td>
<td>8 (44%)</td>
<td>5 (50%)</td>
<td>4 (40%)</td>
<td>19 (42%)</td>
</tr>
</tbody>
</table>

Only 26 (58 per cent) country laws have provisions to set up an independent body to regulate mental health facilities. Mostly these bodies conduct inspection of the mental health facilities and make recommendations to the government. However persons with mental health problems and their families and care-givers are usually poorly represented in these bodies (see Table 32 below)
### Table 32: Regulatory Bodies

<table>
<thead>
<tr>
<th>Does the law require the above body to:</th>
<th>Low (n_1=5)</th>
<th>Low-middle (n_2=10)</th>
<th>Upper-middle (n_3=5)</th>
<th>High (n_4=6)</th>
<th>Total (N=26)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Conduct regular inspections of mental health facilities?</td>
<td>5 ((100%))</td>
<td>10 ((100%))</td>
<td>5 ((100%))</td>
<td>6 ((100%))</td>
<td>26 ((100%))</td>
</tr>
<tr>
<td>(b) Report and make recommendations directly to the appropriate government minister?</td>
<td>3 ((60%))</td>
<td>8 ((80%))</td>
<td>5 ((100%))</td>
<td>6 ((60%))</td>
<td>22 ((85%))</td>
</tr>
<tr>
<td>(c) Publish findings on a regular basis?</td>
<td>0</td>
<td>2 ((20%))</td>
<td>0</td>
<td>3 ((50%))</td>
<td>5 ((19%))</td>
</tr>
<tr>
<td>(e) Does the composition of the body include professionals (mental health, legal, social work), users, members representing families, advocates and lay persons?</td>
<td>Yes</td>
<td>1 ((20%))</td>
<td>2 ((20%))</td>
<td>1 ((20%))</td>
<td>1 ((17%))</td>
</tr>
<tr>
<td></td>
<td>Partially</td>
<td>4 ((80%))</td>
<td>5 ((50%))</td>
<td>2 ((40%))</td>
<td>2 ((33%))</td>
</tr>
</tbody>
</table>

10. **Article 27: Work and Employment**

Article 27 of the CRPD requires states to ensure that “persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.”

Legislation in only 3 (7 per cent) countries specifically outlaws forced or inadequately remunerated labour within mental health facilities.
Table 33: Prohibition of forced or inadequately remunerated labour

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>0</td>
<td>1 (6%)</td>
<td>2 (20%)</td>
<td>0</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>No</td>
<td>7 (100%)</td>
<td>17 (94%)</td>
<td>8 (80%)</td>
<td>10 (100%)</td>
<td>42 (93%)</td>
</tr>
</tbody>
</table>

Example

**Grenada - The Mental Health Act, 2009**

S.16: *Non exploitation of labour*

(1) No person shall exploit the labour of a patient in a mental health facility.

(2) Subject to subsection (3), a patient shall receive the same remuneration for any work which he does as if he was in the general work force.

(3) A patient shall receive a fair share of any remuneration which is paid to the mental health facility for any work to which he has participated.

11. Families

Preamble (x) of the CRPD says, “Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities.”

Very few laws have specific provisions for the involvement of families and care-givers. Legislation in 12 (27 per cent) countries provides for information to be given to families and care-givers, in 10 (22 per cent) countries families and care-givers are encouraged to participate in the formulation of treatment plans and legislation and 2 (4 per cent) countries mandates that families and care-givers are involved in mental health policy, planning and service development.
Table 34: Involvement of Families and Care-givers

<table>
<thead>
<tr>
<th></th>
<th>Low (n₁=7)</th>
<th>Low-middle (n₂=18)</th>
<th>Upper-middle (n₃=10)</th>
<th>High (n₄=10)</th>
<th>Total (N=45)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) Does the law entitle families or other primary carers to information about the person with a mental disorder (unless the person refuses the divulging of such information)?</td>
<td>1 (14%)</td>
<td>3 (17%)</td>
<td>3 (30%)</td>
<td>5 (50%)</td>
<td>12 (27%)</td>
</tr>
<tr>
<td>(ii) Are family members or other primary carers encouraged to become involved in the formulation and implementation of the person's individualised treatment plan?</td>
<td>2 (28%)</td>
<td>2 (11%)</td>
<td>3 (30%)</td>
<td>3 (30%)</td>
<td>10 (22%)</td>
</tr>
<tr>
<td>(iii) Does legislation ensure that family members or other carers are involved in the development of mental health policy, legislation and service planning?</td>
<td>0</td>
<td>2 (11%)</td>
<td>0</td>
<td>0</td>
<td>2 (4%)</td>
</tr>
</tbody>
</table>

12. Article 7: Children with disabilities

Article 7 (1) of the CRPD requires States to take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

Mental health laws in most Commonwealth countries provide very little protection to minors and children. Laws in only 2 (4 per cent) countries restrict involuntary admission of minors with mental health problems to instances
where all feasible community alternatives have been tried, and laws in only 3 (7 per cent) countries ban any irreversible treatments on children with mental health problems.

Example

**Malta - Mental Health Act, 2012**

S. 30. (1) Without prejudice to the provisions relating to involuntary admission for observation under this Act, an involuntary admission for observation of a minor suffering from a mental disorder shall only be permissible if a specialist who has clinical experience of working with minors with mental health problems and has so been appointed for the purpose by the Minister certifies on the prescribed form in accordance with the Thirteenth Schedule that community based alternatives are not available or are unlikely to be effective or have been tried and failed or are unsafe.

S. 31 (2) No psychosurgery, sterilisation, implantation of hormonal or other invasive devices to modify sexual and, or emotional and, or behavioural changes arising from mental illness shall be carried out on minors.

13. Article 8: Awareness Raising

Article 8 (2) of the CRPD requires State parties to promote positive perceptions and greater social awareness toward persons with disabilities.

We looked at the use of stigmatizing language in mental health laws. The word “Lunatic” is used in the mental health laws of 12 countries; the term “Insane” is used in the mental health laws in 11 countries; the term “Idiot” is used in the mental health laws in 10 countries; two mental health laws use the term “Imbecile”; and two mental health laws use the term “Mentally defective”. Overall 21 (47 per cent) laws use one of the above terms.
14. Participation

Preamble (o) of the CRPD requires that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them.

The law in only one country (Ghana) mandates that users of mental health services are involved in mental health policy, legislation development and service planning.

15. Other issues not directly related to CRPD

Legislation in 28 (62 per cent) Commonwealth countries had a clear definition of mental disorder and 19 (42 per cent) countries clearly specified whether intellectual disability/personality disorders/substance abuse was covered or excluded in legislation. Mental health legislation in 18 (40 per cent) countries had a requirement for accreditation of mental health facilities admitting persons involuntarily for treatment of mental disorders.

Limitations

There are a number of limitations to this report. We did not look at subsidiary legislation, namely rules and regulations arising out of the mental health legislation. Such subsidiary legislation may have important provisions on rights protection which are not included in our report. We also did not look at other related legislation for example, general health and disability legislation. In some countries, these laws may contain important provisions on protecting the rights of persons with mental disorders. Finally, we did not look at legislation related to civil (e.g. marriage and divorce laws), political (e.g. legislation related to voting), economic (e.g. legislation related to property and employment), social and cultural rights for persons with mental disorders.

We are aware of ongoing mental health law reform process in many Commonwealth memeber states and this may address some of the shortcomings identified in this report. In many countries where the reform process has progressed substantially, draft mental health bills are in the public
domain. However we did not look at these draft laws because these are working drafts and it is difficult to predict final legislation arising out of these draft bills.

It is also important to highlight that provisions in the law may not necessarily reflect actual practice in the country. In many countries, while there may be progressive legislation on the statute, professionals and others continue with customary practices and legislation is largely ignored. We have not examined this particular issue in this report.

**Summary of Findings**

Brief summary of the findings is as follows:

1. Mental health legislation in 20 per cent of Commonwealth member states was enacted prior to 1960 when modern medical treatments became available and before many of the international human rights instruments came into force.

2. Mental health legislation in only 11 per cent of the Commonwealth member states specifically included provisions that state mental health care should be provided on an equal basis with physical health care.

3. Mental health legislation in only 9 per cent of Commonwealth member states promoted voluntary admission and treatment as the preferred alternative for treatment of mental disorders.

4. Mental health legislation in only 29 per cent of Commonwealth member states gives persons with mental disorders the right to be informed of their rights when receiving mental health care or treatment.

5. While laws in 24 per cent of member states had some provisions promoting community care, no legislation met all the criteria to be rated as promoting community care and deinstitutionalisation.

6. Mental health legislation in only four Commonwealth member states had provisions for supported decision making including the provision of Advance Directives in their mental health legislation.

7. Mental health laws in all Commonwealth member states allowed involuntary admission to a mental health facility. Only half (51 per cent) of country mental health laws require the person to be discharged as soon as they do not meet
criteria for involuntary admission. 80 per cent of mental health legislation in Commonwealth countries does not apply the principle of least restrictive alternative to involuntary admission.

8. More than two-thirds of the mental health laws do not have a judicial/quasi-judicial body to review involuntary admissions and treatment.

9. Provisions for protection from cruel, inhuman and degrading treatment are included in the legislation in 23 (51 per cent) countries.

10. Informed consent of persons with mental disorders for participating in clinical and experimental research is specifically mandated in mental health legislation in only 5 (11 per cent) countries.

11. Mental health laws in 9 (20 per cent) countries include a provision on protection of confidentiality and in 8 (18 per cent) countries a provision on privacy for persons with mental disorders is included.

12. Legislation in only three (7 per cent) countries specifically outlaws forced or inadequately remunerated labour within mental health facilities.

13. Very few laws have specific provisions for the involvement of families and care-givers. Legislation in 12 (27 per cent) countries provides for information to be given to families and care-givers, in 10 (22 per cent) countries families and care-givers are encouraged to participate in the formulation of treatment plans.

14. Mental health laws in most Commonwealth countries provides very little protection to minors and children. Laws in only two (4 per cent) countries restrict involuntary admission of minors with mental health problems, and laws in only three (7 per cent) countries ban any irreversible treatments on children with mental health problems.

15. Stigmatizing language is common in mental health legislation of commonwealth member states. The word “Lunatic” is used in the mental health laws of 12 countries; the term “Insane” is used in the mental health laws in 11 countries; the term “Idiot” is used in the mental health laws in 10 countries; two mental health laws use the term “Imbecile”; and two mental health laws use the term “Mentally defective”. Overall 21 (47 per cent) laws use one of the above...
16. The law in only one Commonwealth country mandates that users of mental health services are involved in mental health policy, legislation development and service planning.

**Conclusions**

Based on the findings above, the conclusions are as follows:

1. Mental health legislation in many Commonwealth member states is outdated and does not fulfil member states international human rights obligations toward persons with mental disorders.

2. Mental health legislation in many Commonwealth member states is not compliant with the Convention on Rights of Persons with Disabilities. Substantive and procedural provisions related to guardianship in mental health laws are particularly problematic in this regard.

3. Many mental health laws reviewed in this report treat persons with mental disorders as needing protection rather than as subjects with rights. As a result, mental health legislation instead of protecting the rights of persons with mental disorders, is likely to lead to violation of rights.

4. Mental health legislation in many countries is based on an outdated understanding of mental disorders, ignores advances in the care and treatment of mental disorders and denies the capacity of persons with mental disorders to manage their lives.

5. Provisions and language of mental health laws in many instances adds to negative perceptions and further stigmatisation of persons with mental disorders.

6. Most mental health laws pay little attention to protecting the rights of vulnerable groups with mental health problems such as minors, women and minorities and the special needs of such vulnerable groups.

7. Many mental health laws do not address the issue of (lack of) access to mental health care in many Commonwealth countries, in particular, making care and treatment easily available, provided in a manner which enhances the capacities
of individuals and protects and promotes their rights and enables them to live and participate in their communities.

8. There is little participation of persons with mental disorders and their families and care-givers in the development and implementation of legislation.

Recommendations

1. Commonwealth member states should urgently undertake reform of mental health legislation.

2. Member states should ensure that legislation meets their obligations under international human rights treaties, in particular the Convention on Rights of Persons with Disabilities.

3. The Commonwealth should consider providing financial and technical support to Low and Middle income member states to undertake mental health law reform.

4. Commonwealth member states need to thoroughly review all legislation to comprehensively address all civil, political, economic, social and cultural rights of persons with mental disorders.

5. Commonwealth member states should introduce provisions to promote supported decision making in mental health legislation.

6. Commonwealth member states must involve persons with mental disorders and care-givers, apart from other stakeholders, in the mental health law reform process.

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Gordon R.M. (2000). The emergence of assisted (supported) decision-making in
the Canadian law of adult guardianship and substitute decision-making.


## Appendix

### List of Country Mental Health Legislation

<table>
<thead>
<tr>
<th>Country</th>
<th>Act</th>
<th>Enactment Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antigua and Barbuda</td>
<td>Mental Treatment Act</td>
<td>1957</td>
</tr>
<tr>
<td>Australia-South Australia</td>
<td>Mental Health Act</td>
<td>2009</td>
</tr>
<tr>
<td>Bahamas</td>
<td>Statute Law of The Bahamas Chapter 230 Mental Health</td>
<td>2010</td>
</tr>
<tr>
<td>Bangladesh</td>
<td>Indian Lunacy Act</td>
<td>1912</td>
</tr>
<tr>
<td>Barbados</td>
<td>Mental Health Act</td>
<td>1985</td>
</tr>
<tr>
<td>Belize</td>
<td>Unsoundness of Mind Act</td>
<td>2000</td>
</tr>
<tr>
<td>Botswana</td>
<td>Mental Disorder Act</td>
<td>1971</td>
</tr>
<tr>
<td>Brunei</td>
<td>Lunacy Act</td>
<td>1929</td>
</tr>
<tr>
<td>Canada-Ontario</td>
<td>Mental Health Act</td>
<td>1990</td>
</tr>
<tr>
<td>Dominica</td>
<td>Mental Health Act; Chapter 40:62; Act 29, 1987</td>
<td>1987</td>
</tr>
<tr>
<td>The Gambia</td>
<td>Lunatic Act</td>
<td>1917</td>
</tr>
<tr>
<td>Ghana</td>
<td>Mental Health Act</td>
<td>2012</td>
</tr>
<tr>
<td>Grenada</td>
<td>The Mental Health Act</td>
<td>2009</td>
</tr>
<tr>
<td>Guyana</td>
<td>Mental Health Act</td>
<td>1930</td>
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<tr>
<td>India</td>
<td>Mental Health Act</td>
<td>1987</td>
</tr>
<tr>
<td>Jamaica</td>
<td>Mental Health Act, 1999</td>
<td>1999</td>
</tr>
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<td>Kenya</td>
<td>Mental Health Act, Chapter 248</td>
<td>1991</td>
</tr>
<tr>
<td>Kiribati</td>
<td>Laws of The Gilbert Islands Revised Edition 1977 Chapter 56 Mental Treatment Mental Health Wing Management Regulations</td>
<td>1977</td>
</tr>
<tr>
<td>Country</td>
<td>Legislation</td>
<td>Year</td>
</tr>
<tr>
<td>-----------------</td>
<td>------------------------------------------------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Lesotho</td>
<td>Mental Health Act</td>
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<td>Legislation</td>
<td>Year</td>
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<td>Zambia</td>
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The need to reform mental health legislation in Commonwealth countries

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The United Nations Convention on the Rights of Persons with Disabilities (CRPD), adopted by the UN General Assembly in 2006, serves as a comprehensive and legally binding framework for countries to promote and protect the rights of persons with mental illness (PWMI). Despite being ratified by 134 countries and 35 Commonwealth countries, it is unclear whether countries have adapted or reformed their mental health legislation to reflect the binding provisions outlined in the CRPD.

Shifting the discourse of mental health legislation

In light of the CRPD, mental health laws require a general shift in terms of the perception of PWMI and the laws governing PWMI. Historically, PWMI were viewed as dangerous – this view later shifted to PWMI as being vulnerable and requiring protection by sympathetic professionals and society. Internationally, this was reflected in the adoption of the Principles for Protection of Persons with Mental illness (commonly called the MI Principles) by the UN General Assembly in 1991 (UN, 1991). More recently, the CRPD has shifted the discourse towards entitlements and rights of PWMI - a more collaborative, empowering discourse; however, our review of Commonwealth mental health legislation (Pathare &
Sagade, 2013) suggests that many countries have yet to incorporate this discourse into their mental health laws. Many mental health laws in Commonwealth countries are outdated - our review found 20% of Commonwealth country laws were enacted prior to 1960, when psychotropic medicines were introduced, 60% were enacted prior to the introduction of MI Principles, and 90% prior to the CRPD. The oldest mental health law still in force in a Commonwealth country is from 1902, while the most recent is from 2012 showcasing the wide variability in legislation throughout the Commonwealth countries. A law drafted prior to 1991 for example, is unlikely to include provisions in line with MI principles; similarly laws drafted prior to 1960 are likely to reflect a perspective when there were few treatments for severe mental illness and long-term incarceration was the norm. The outdated nature of many mental health laws is also illustrated through terminology used in mental health laws. Our review found the word “lunatic” used in laws in 12 countries, “Insane” in 11 countries, “Idiot” in 10 countries, “Imbecile” in 2 countries, and “Mentally defective” in 2 countries. Overall, 21 (47%) of laws in Commonwealth countries use one of these terms, reinforcing the incapability of PWMI and thus reinforcing stigma.

**Access to quality and acceptable mental health**

Ensuring the right to health means mental health care is equated with physical health care, access to mental health care is specified in legislation, and community-based care is mandated within law (in line with Article 19 of the CRPD). Our review found only 5 (11%) of Commonwealth mental health laws equated physical and mental health, and 11 (24%) had some provisions towards promoting community-based care. However the broad thrust of these 11 laws was toward institutional treatment and regulation. Arguably, community-based care and de-institutionalisation are matters of broader health policy and not legislation; however mental health laws themselves may be a barrier to enacting and implementing such policies.

Many persons receiving treatment from mental health services either are unaware of their rights or not in a position to ask about their rights; rights have no meaning if PWMI are not aware of their rights. Thus, a provision in legislation mandating health authorities to inform service users of their rights will help in exercising rights. Our review highlights this deficiency as only 13 (29%) Commonwealth mental health laws give PWMI the right to be informed of their rights while receiving mental health care.
The transition from guardianship to supported decision-making

Entitlement of rights means that PWMI have the right to recognition as persons before the law and are entitled to equal benefit and protection of the law (Article 12 and reaffirmed by 13 of the CRPD). Article 12 has been celebrated worldwide by disability activists as representing a ‘paradigm shift’ in our perception of PWMI. However professionals and service providers have been less enthusiastic, primarily due to concerns about decision-making capacity of PWMI and the lack of practical models for implementation. Traditionally, concern about decision-making capacity led to inclusion of guardianship provisions in mental health legislation – we found that 24 (53%) Commonwealth countries had guardianship provisions in their mental health legislation; of these, 7 (29%) only allowed limited guardianship (restricted to property matters), while 14 (58%) laws had provisions for both limited and plenary guardianship. Plenary guardianship conflicts with country obligations under the CRPD, as it does not allow for PWMI to retain decision-making abilities, rendering them non-persons before the law, contrasting with Article 12. Limited and partial guardianship are preferred over plenary (full) guardianship as PWMI retain some decision-making abilities, although, ideally, supported decision-making provisions would be in place in legislation, in line with the provisions in Article 12.

While the notion of supported decision-making is a relatively new concept and it would be premature to evaluate its implementation in legislation across Commonwealth countries, some countries (eg. Australia, Canada, Scotland) have replaced guardianship provisions in mental health legislation with supported decision-making provisions largely through separate capacity legislation. These Commonwealth countries could share lessons learned on transitioning to supported decision-making models with more resource-scarce Commonwealth Member States. Supported decision-making can be tailored to fit a country’s legislative framework and resource availability, even making use of existing community resources (e.g. peer support to become ‘supporters’). This more adaptive approach to incorporating supported decision-making into law contrasts with the argument that achieving these rights for PWMI are particularly difficult in low and middle-income countries, primarily due to fragmented public health systems and resource scarcity, based on a presumption that supported decision-making models will be resource intensive. This is not necessarily true as demonstrated by Kumar et al (2012) showing it was feasible in India for PWMI to write a psychiatric advance directive (one form
of supported decision-making) despite active symptoms and engage carers in the PAD process with little additional resources.

There are also major procedural problems with existing guardianship provisions in mental health legislation. Of the 24 countries with a provision for guardianship in mental health legislation, only 3 (13%) laws had provisions that the person who is the subject of the guardianship application has to appear before the Court at the guardianship hearing and represented at the hearing. In addition, 16 (66%) countries had no provisions for appealing to a higher court against the guardianship order, nor did 19 (79%) countries provide for regular time-bound review of guardianship orders. The lack of these procedural protections is contrary to the requirements of Article 13(1) of the CRPD.

**Involuntary admission and least restrictive care**

The last few decades have seen a movement towards voluntary care including voluntary admission, reflected in the number of countries with provisions for voluntary admission. Our review found 32 (71%) countries had provisions for voluntary admission; however, very few countries stated that voluntary admission and treatment is the preferred alternative. The majority of laws specified that persons voluntarily admitted to a mental health facility can only be treated after obtaining informed consent.

Currently all Commonwealth laws allow involuntary admission and treatment for PWMI. We found laws in only 24 (53%) countries mandate that the mental disorder be of a specified severity to allow involuntary admission; in remaining countries, such a requirement is not necessary. Often, laws allow involuntary admission only if there is a serious risk of harm to self or others, or substantial likelihood of serious deterioration in the patient’s condition if treatment is not provided, which was the case in 31(69%) of Commonwealth mental health laws. Amendment of these provisions may be necessary to comply with the CRPD. In fact, the High Commissioner for Human Rights (OHCHR) goes as far as to say that any form of involuntary admission or non-consensual treatment is considered as non-compliant with the CRPD and provisions relating to involuntary admission and treatment should be removed from all mental health legislation (Mendez, 2013).

**Moving forward**

Although there is substantial encouragement from regional, national and international actors to reform mental health legislation, as well as the shifting
discourse on rights, many mental health laws still espouse guardianship, institutionalisation, and protectionism as opposed to models of supported decision-making, community-based care, and entitlement of rights.

The key goals of mental health legislation should be facilitating better access to and quality of mental health care, promoting rights of social inclusion of PWMI. We are aware that a number of countries are currently reforming their mental health legislation, the final result of which may be a progressive mental health law. While mental health legislation by itself cannot improve the situation in the absence of well-designed and implemented policies and services, it is a necessary and important step in mental health care reform. Future work in this area should look at subsidiary legislation, which may have important provisions on rights protection, and explore civil, political, and economic laws, as well as social/cultural rights for PWMI. The Commonwealth should encourage and support Commonwealth countries with technical and financial support, in particular those with limited resources, to reform their mental health laws.

References


Part 3

Chapter 6

Gender and Mental Illness and the Hindu Marriage Act, 1955
Gender & mental illness and the Hindu Marriage Act, 1955.

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ABSTRACT

Introduction: The Hindu Marriage Act, 1955 (HMA) states in Section 5(ii) that under certain circumstances, mental illness is accepted as ground for annulment, and in Section 13(1) (iii) that mental illness is a ground for divorce. There is little data on how this provision is used and applied in matrimonial petitions. This paper assesses judicial practices in divorce cases, exploring to what extent gender and diagnosis of mental illness affect the decision to grant annulment or divorce.

Methods: Analysis of annulment and divorce judgments at the Family Court in Pune and High Court cases.

Results: In Family Court at Pune, husbands filed 85% of the cases alleging mental illness of their spouse. Medical evidence for mental illness was presented in only 33% of cases and many cases were granted divorce/nullity even in the absence
of medical evidence. 14% of judgments were granted nullity/divorce without representation of both spouses. Of Family Court cases reaching the High Court, 95% were male petitioners. High Courts reversed lower court judgments in 50% of cases.

Discussion: Our analysis highlights the need for standardized guidelines for lower courts on criteria for adequate medical proof of mental illness alleged in any petition related to nullity or divorce under HMA, and a critical review of Section 5(ii) of HMA.

INTRODUCTION

The legal scenario for marital disputes and matters in India

Family-related legal procedures in India are governed by personal laws, which are steeped in religious beliefs and cultural values. Across religions in India, legal jurisdiction of matters relating to marital issues, maintenance, alimony and custody of children in a marital dispute or divorce are tried by Family Courts or by District Courts. The Status of Women Committee in 1974 (1) together with the report of the 59th Law Commission (2) recommended that the Central Government establish a separate judicial forum to settle family disputes. Family Courts were introduced in some parts of India through the Family Courts Act, (1984) (FCA), which was initiated as part of the legal reforms related to the position of women in society. FCA enabled State Governments (in consultation with the High Court of the State) to establish a family court in any area of a particular state with a city or in areas where the population size exceeds one million. This was in an effort to separate proceedings of the Family Court from the civil courts to settle family disputes with greater speed (3). Although the Central Government issues the qualification criteria for judges working in Family Courts, administration of FCA is largely governed by High Courts, and thus Family Courts are permitted to establish their own procedures.

When a case at the Family Court is appealed, it goes to the High Court and subsequently to the Supreme Court. The High court has jurisdiction over the entire state, and has the legal power to transfer cases between Family Courts. Before the Family Courts were introduced, the Code of Civil Procedure was amended with the aim of making a special procedure for proceedings relating to the matrimonial disputes.

The role of the Family Court in the state of Maharashtra
The state of Maharashtra has 11 Family Courts (4,5) established since 1987. Family courts in Maharashtra importantly have marriage counsellors, who are expected to counsel couples and preserve the institution of marriage. Family Courts may also involve other social welfare employees in specific cases. Although the idea of a marriage counsellor is to protect women, as their primary goal is to preserve the institution of marriage, they have been criticized as working against women's interests as counsellors see their role as preserving the institution of marriage at all costs. Interestingly, reports prepared by marriage counsellors are not binding on the judiciary and are not cross-checked (3).

Nullity or Divorce on the grounds of mental illness

According to HMA, a marriage may be solemnised on fulfilment of certain conditions specified in Section 5 of the Act. When HMA was enacted in 1955, Section 5(ii) stated a condition “neither party to the marriage should be idiot or lunatic”. The Marriage Laws (Amendment) Act, 1976 amended HMA and substituted this clause with the conditions currently stated in Section 5 (ii) of HMA as “at the time of marriage, neither party is (a) incapable of giving a valid consent to it in consequence of unsoundness of mind or (b) though capable of giving a valid consent, has been suffering from mental disorder of such a kind or to such an extent as to be unfit for marriage and the procreation of children or (c) has been subject to recurrent attacks of insanity or epilepsy.” The term “or epilepsy” was deleted from this sub-section in 1999. None of the terms used here such as “unsoundness of mind” or “mental disorder” or “insanity” are adequately defined.

Under Section 12 sub-section 1(b) of HMA, a marriage is “voidable’’ and “may be annulled by a decree of nullity…” if “the marriage is in contravention of the condition specified in clause (ii) of section 5”. Thus mental illness may form grounds for annulment of a marriage. Section 12 subsection 1 (c) also allows for annulment of a marriage if “the consent of the petitioner....was obtained by force, or by fraud as to the nature of the ceremony or as to any material fact or circumstance concerning the respondent”. Petitioners may claim that concealment of mental illness prior to marriage is a ‘material fact’ and hence ask for annulment of marriage on grounds of fraud under Section 12(1) (c).

Section 13 of HMA specifies grounds for divorce. Section 13 sub-section (1) (iii) is relevant as mental illness is accepted as grounds for divorce under certain circumstances. This sub-section states if someone “has been incurably of
unsound mind or has been suffering continuously or intermittently from mental disorder of such a kind and to such an extent that the petitioner cannot reasonably be expected to live with the respondent”. Section 13(1) has an “Explanation” which states as follows “(a) the expression “mental disorder” means mental illness, arrested or incomplete development of the mind, psychopathic disorder or any other disorder or disability of the mind and includes schizophrenia; (b) the expression “psychopathic disorder” means a persistent disorder or disability of mind (whether or not including sub-normality of intelligence) which results in abnormally aggressive or seriously irresponsible conduct on the part of the other party, and whether or not it requires or is susceptible to medical treatment.”.

Such provisions in HMA are discriminatory against persons with mental illness as it is the only form of disability that may form grounds for annulment or divorce. There is also a potential for misuse of these provisions in a gender-biased manner. First, the patriarchal social dominance of men as the sole decision maker of the family in India can compromise the equal enjoyment of rights and entitlements of women; second, there is substantial stigma associated with a mental illness which reinforces the false notion that persons with mental illness are violent and dangerous to self or society and cannot be expected to continue in a marriage. Third, misconceptions about infertility and reduced childbearing capacity may be associated with mental illness, pertaining to which Section 5 (ii) (b) of HMA states “though capable of giving a valid consent, has been suffering from mental disorder of such a kind or to such an extent as to be unfit for marriage and the procreation of children”, and finally, the misconception of the genetic inheritance of mental illness may negatively impact the use of such provisions. Therefore, women with a mental illness may face double discrimination in relation to cases related to marriage laws (6,7).

The objective of this paper is to assess judicial practices to determine the role of gender and medical evidence in matrimonial proceedings in the Family Court and High Courts.

To explore this issue, we conducted an analysis of annulment and divorce judgments of the Family Court in Pune, focusing specifically on cases where annulment or divorce was being requested on grounds related to unsound mind and/or mental illness (Section 12 (1) (b) and (c) and Section 13 (1) (iii) of HMA. We also analyzed cases related to annulment or divorce on the grounds of mental illness which had been decided by various High Courts in India.
METHODS

We obtained permission from the Principal Judge at the Family Court in Pune to conduct this study. There are major practical difficulties in searching for and retrieving cases in the Family Court. Data is not computerized and all physical data is stored in a record room and which are not indexed. When a case is filed in the Family Court, basic data (including the relevant Section of HMA under which annulment or divorce is being asked for) is entered in writing in a physical register. These physical registers are maintained on a yearly basis. We first searched through the yearly registers and found details of the cases where annulment under Section 12 (1) (b) or Section 12 (1) (c) or divorce under Section 13(1) (iii) were pleaded. We then had to request the staff of the Family Court to extract out the case papers of these relevant cases. We were allowed to physically examine the case records and read through these records. We were not permitted to take copies of these case records and the records could not be moved from the records room. Although we had initially planned to search cases throughout a 20 year period (from 1993-2012), logistically this was not possible for staff of the Family Court to identify cases for earlier years, therefore only cases for decisions by the Family Court for a 17-year period (1996-2012) are included in this analysis.

Furthermore, we could collect the details of the total number of annulment or divorce cases filed in 2011 and 2012 only. For all other years only the details of the cases pleaded under Section 12 (1) (b) or Section 12 (1) (c) or divorce under Section 13(1) (iii) were collected.

Data extracted from case records was recorded manually and entered into an Excel spreadsheet. Extracted data included information on: date of marriage, date of separation, date of filing the petition, date of judgment, who had filed the petition (husband or wife), what type of relief was sought, what type of medical evidence was presented in the petition, and the final judgment of the court. No personal identifying information such as name, address, contact details were recorded from the case records.

To obtain cases at the High Court level, an electronic database search was conducted using the Supreme Court Cases Database (SCC Online) as well as Indiankanoon.org for a period from 1976 (when HMA was amended) to 2013. The first relevant judgment extracted from the search was from the year 1981. Cases were included if they were filed under the current HMA and the grounds
pleaded for nullity or divorce were mental illness (Section 12 (1) b or 12 (1) (c) or Section 13 (1) (iii)).

Descriptive statistics are presented as number and percentage and where appropriate, statistical tests were performed using SPSS version 20 (IBM 2011). Chi-squared test of independence ($\chi^2$) were used for categorical variables, and the significance level for all analyses was set at $\alpha = .05$.

RESULTS

Cases at the Family Court in Pune

Our search revealed that in 2011, of all the annulment & divorce cases filed under HMA, 61% petitioners were husbands (n=753) and 39% petitioners were wives (n=480). Similarly, in 2012, of total number of annulment & divorce cases filed under HMA, 60% petitioners (n=877) were husbands while 40% petitioners (n=575) were wives.

Our search specifically identified a total of 78 petitions filed on the grounds of mental illness under the HMA over the years 1996-2012. Of these 67 petitions were filed by husbands and 11 petitions by wives for annulment and/or divorce spanning from 1996 to 2012. Of these, 21 (husbands petitioner, n= 18, wives petitioner, n=3) petitions were for nullity, 50 (husbands petitioner, n= 43, wives petitioner, n=7) petitions were for divorce, 5 (husbands petitioners, n=4; wife petitioner, n=1) petitions were for both nullity and/or divorce and in 2 petitions (husband petitioner, n= 2) it was unclear what relief (nullity/divorce) was being sought. Surprisingly, husbands filed 85% of petitions compared to wives accounting for only 15% of petitions filed on the grounds of mental illness.

We looked for medical (psychiatric) evidence in the case papers or recorded in the judgment. Medical evidence was defined as any medical information, data, medical records or expert witness testimony to substantiate that the opposite party had a mental illness. We were able to find medical evidence in only 36% (28 out of 78) of the petitions. In the case of male petitioners, medical evidence about the mental illness of the wife was present in 39% (26 out of 67) of cases, while in the case of female petitioners, medical evidence about the mental illness of the husband was present in only 18% (2 of 11) of cases.

Table 1: Medical evidence presented at Family Court level
<table>
<thead>
<tr>
<th>Type of medical evidence</th>
<th>Witness in chief of psychiatrist</th>
<th>Certificate by psychiatrist</th>
<th>Prescription</th>
<th>Invoices for purchase of medicines</th>
<th>Copies of medical reports</th>
<th>Multiple evidence *</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of petitions filed by husbands:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annulment (n= 6)</td>
<td>1 (17%)</td>
<td></td>
<td></td>
<td>1 (17%)</td>
<td>4 (67%)</td>
<td></td>
</tr>
<tr>
<td>Divorce (n = 19)</td>
<td>4 (21%)</td>
<td>1 (5%)</td>
<td>3 (16%)</td>
<td>1 (5%)</td>
<td>10 (53%)</td>
<td></td>
</tr>
<tr>
<td>Annulment and divorce (n=1)</td>
<td>1 (100%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: Multiple evidence was defined as two or more of the following pieces of evidence: witness in chief of psychiatrist, certificate by psychiatrist, prescription, discharge summary, psychometric reports, copies of medical reports, bills for purchase of medicines

In the 26 instances where husbands provided medical evidence in the petition/Court, prescriptions of psychotropic medicines was the only evidence in 3 cases, copies of medical notes were the only evidence in one case and in one particular case, the only evidence presented was invoices for purchase of psychotropic medicines. Of the two instances where wives provided medical evidence in the petition/Court, multiple forms of evidence were presented in both instances (Table 1).

Nearly a fourth (22%) of petitions filed by husbands without medical evidence of mental illness were successful and nullity or divorce was granted on the grounds of mental illness. In contrast, more petitions were successful (36%) and divorce was granted in instances where husbands did present medical evidence for mental illness. Interestingly, a large proportion of these petitions where no
medical evidence was submitted (43%) were converted into divorce by mutual consent (Table 2). A significant number of these petitions (31%) here too were converted into divorce by mutual consent (Table 2).

**Table 2: Outcome of Petitions filed by husbands, categorised by presence or absence of medical evidence**

<table>
<thead>
<tr>
<th>Medical evidence provided</th>
<th>Type of Relief Sought</th>
<th>Nullity (n=6)</th>
<th>Divorce (n=19)</th>
<th>Nullity and divorce (n=1)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allowed (n, %)</td>
<td></td>
<td>3 (50)</td>
<td>6 (32)</td>
<td></td>
<td>9 (35)</td>
</tr>
<tr>
<td>Dismissed (n, %)</td>
<td></td>
<td>1 (16)</td>
<td>5 (26)</td>
<td></td>
<td>6 (23)</td>
</tr>
<tr>
<td>Converted to mutual consent (n, %)</td>
<td></td>
<td>1 (17)</td>
<td>6 (32)</td>
<td>1 (100)</td>
<td>8 (31)</td>
</tr>
<tr>
<td>Withdrawn (n, %)</td>
<td></td>
<td>1 (17)</td>
<td>1 (5)</td>
<td></td>
<td>2 (8)</td>
</tr>
<tr>
<td>Other (n, %)</td>
<td></td>
<td>1 (5)</td>
<td></td>
<td></td>
<td>1 (3)</td>
</tr>
<tr>
<td>Medical evidence not provided</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allowed (n, %)</td>
<td></td>
<td>4 (33)</td>
<td>5 (21)</td>
<td></td>
<td>9 (22)</td>
</tr>
<tr>
<td>Dismissed (n, %)</td>
<td></td>
<td>2 (17)</td>
<td>3 (12)</td>
<td>1 (33)</td>
<td>6 (15)</td>
</tr>
<tr>
<td>Converted to mutual consent (n, %)</td>
<td></td>
<td>3 (25)</td>
<td>11 (46)</td>
<td>2 (67)</td>
<td>18 (43) *</td>
</tr>
<tr>
<td>Withdrawn (n, %)</td>
<td></td>
<td>1 (8)</td>
<td>5 (21)</td>
<td></td>
<td>6 (15)</td>
</tr>
<tr>
<td>Other (n, %)</td>
<td></td>
<td>2 (17)</td>
<td></td>
<td></td>
<td>2 (5)</td>
</tr>
</tbody>
</table>

*Note: n=2 of the 41 cases had no available information on what type of relief was sought. In both the cases, divorce by mutual consent was granted.*
Similarly, when female petitioners failed to provide medical evidence, 2 out of 9 cases (22%) were successful and divorce was granted on grounds of mental illness. A significant number of these petitions too (66%) were converted into divorce by mutual consent. In the two cases filed by wives where medical evidence of mental illness was presented, one was successful and one was converted into divorce by mutual consent.

Three of the 6 petitions filed by husbands for annulment of marriage with medical evidence were allowed (Table 2), of which one case an *ex parte* legal proceeding was passed. Of the 12 petitions filed for annulment of marriage by husbands without medical evidence, the Family court allowed 4, of which one case was granted *ex parte*. For divorces granted to husbands who had presented medical evidence, two judgments were granted *ex parte*. Interestingly, 80% (4 of 5) divorces granted to husbands without submission of medical evidence were passed *ex parte*. For the two female petitioners granted divorce without presenting medical evidence, both judgments were granted *ex parte*. One of the 2 female petitioners who did present medical evidence was granted the divorce without her husband’s presence.

Cases in High Courts

Cases in High Court arise when a party is not satisfied with the decision of the Family Court or the District Court (in areas where there are no family courts). We were able to find 97 relevant High Court cases, starting from 1981 (the Hindu Marriage Act was amended in 1976 and the first relevant High Court case after the amendment was from 1981) where nullity or divorce was asked on the grounds of mental illness. The High Court judgments were first analyzed according to whether medical evidence was provided or not provided. Medical evidence was noted as present if it was mentioned in the High Court judgment, and absent if not mentioned in the judgment (Table 3).
Table 3: Outcome of petition by presence or absence of medical evidence

<table>
<thead>
<tr>
<th>Decision</th>
<th>ME Presented (n=77)</th>
<th>No ME presented (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nullity or divorce granted by lower court Confirmed by High Court</td>
<td>18 (23%)</td>
<td>4 (20%)</td>
</tr>
<tr>
<td>Refusal of nullity or divorce by lower court Confirmed by High Court</td>
<td>22 (29%)</td>
<td>6 (30%)</td>
</tr>
<tr>
<td>Judgment of the lower court Overturned by High Court</td>
<td>37 (48%)</td>
<td>10 (50%)</td>
</tr>
</tbody>
</table>

Surprisingly, there was no statistically significant difference in judgments taken by the High Courts with either the presence or absence of medical evidence, $\chi^2 = 0.10$, $p = 0.95$.

Table 4: Outcome of cases in High Courts

<table>
<thead>
<tr>
<th>Appellant at High Court</th>
<th>Appeal Allowed or partly allowed</th>
<th>Appeal Rejected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Husbands (n=46)</td>
<td>16 (36%)</td>
<td>30 (64%)</td>
</tr>
<tr>
<td>Wives (n=49)</td>
<td>31 (64%)</td>
<td>18 (36%)</td>
</tr>
<tr>
<td>Both Spouses (n=2)</td>
<td>2 (100%)</td>
<td>0</td>
</tr>
</tbody>
</table>

A chi-square test for significance reveals that High Court rejection of appeals was significantly higher for husbands compared to wives, $\chi^2 = 7.70$, $p = 0.00$, which points to the possibility that women are more successful in having the previous judgment of the Family Court overturned (Table 4).

For all the High Court cases, we then looked at who filed the original petitions at the Family Court/District Court level and the outcome of the petition at the Family Court/District Court. It is not practically possible to check the gender distribution of cases seeking nullity or divorce on grounds of mental illness in all the Family Courts across the country and we wanted to see whether a sample
of cases reaching the High Court from across the country had a similar gender distribution as we had found in the Family Court in Pune.

**Table 5. Gender distribution and outcome of petition at lower court level**

<table>
<thead>
<tr>
<th>Petitioner</th>
<th>At Family Court/District Court (N=97)</th>
<th>Petition Allowed</th>
<th>Petition Rejected</th>
<th>Judicial Separation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Husbands (n=92)</td>
<td></td>
<td>46 (50%)</td>
<td>43 (47%)</td>
<td>3 (3%)</td>
</tr>
<tr>
<td>Wives (n=1)</td>
<td></td>
<td>1 (100%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Both (n=4)</td>
<td></td>
<td>3 (75%)</td>
<td>1 (25%)</td>
<td></td>
</tr>
</tbody>
</table>

In 92 (95%) of the 97 cases, the husband filed the original petition. This is actually more than the 85% that we found at the Pune Family Court, but is in the same direction. Even in cases where the petitions had reached the High Court, husbands had initiated the majority of them.

**Table 6: Original outcome at lower court level for the High Court cases based on medical evidence**

<table>
<thead>
<tr>
<th>Decision</th>
<th>Medical Evidence present (n=77)</th>
<th>Medical Evidence absent (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nullity or divorce</td>
<td>42 (55%)</td>
<td>8 (40%)</td>
</tr>
<tr>
<td>granted</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nullity or divorced</td>
<td>34 (44%)</td>
<td>10 (50%)</td>
</tr>
<tr>
<td>Refused</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Judicial Separation</td>
<td>1 (1%)</td>
<td>2 (10%)</td>
</tr>
</tbody>
</table>

Table 6 shows that 40% of cases were successful at the lower court level even in the absence of medical evidence, however once these cases reached the High Court level, 50% these judgments were subsequently overturned by the High Courts (see Table 3).

Table 7 shows that while 13 of the 17 petitions filed by husbands were successful at the Family Court/District Court, the High Court decisions reversed this in more than 50% of the cases.
Figure 1. High Court ruling on judgement made at the Family Court level, when nullity or divorce was granted
Table 7. Reversal of lower court cases once brought to the High Court level

<table>
<thead>
<tr>
<th>Medical Evidence present (n=77)</th>
<th>Petitioner</th>
<th>Success at Family Court/District Court</th>
<th>Appeal at High Court (HC)</th>
<th>Result</th>
<th>HC favoured (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 petitions for nullity</td>
<td>17 petitions filed by husbands</td>
<td>13 petitions successful</td>
<td>13</td>
<td>8 appeals allowed</td>
<td>Wives (n=7) and Husband (n=1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5 appeals dismissed</td>
<td>Husband (n=5)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td>2 appeals dismissed</td>
<td>Wives (n=2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2 appeals allowed</td>
<td>Husband (n=2)</td>
</tr>
<tr>
<td></td>
<td>1 petition filed jointly by husbands and wives</td>
<td>Husband’s petition was allowed</td>
<td>1</td>
<td>Appeal allowed</td>
<td>Wife (n=1)</td>
</tr>
</tbody>
</table>

When medical evidence was presented, the petitioner in the Family Court and/or District court is male, and in cases where the lower courts have ruled in favour of the husband and granted the divorce, the High Court has overturned the judgment in the majority of cases (Figure 1). On the other hand, when the lower court has ruled against the husband and refused divorce, the High Court has confirmed (supported) the judgment in the majority of cases (Figure 1). In instances where medical evidence was absent, the petitioner in the Family Court/District Court (lower court) has been the husband, the High Courts have overturned the judgment when the lower court has granted divorce (e.g. 6 out of 7).

With regards of the type of medical evidence presented, of the 77 cases, it is interesting to note that in 10 cases the only evidence was a general doctor’s
evidence, in one case, a prescription was the only evidence, and one case a
referral letter/discharge slip was the only evidence presented to substantiate an
allegation of mental illness (Table 8).

Table 8: Type of medical evidence (n=77)

<table>
<thead>
<tr>
<th>Type of Evidence</th>
<th>Nullity (n=18)</th>
<th>Divorce (n=43)</th>
<th>Both nullity and divorce (n=16)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Witness by chief psychiatrist(s)</td>
<td>5 (28%)</td>
<td>10 (23%)</td>
<td>5 (31%)</td>
<td>20</td>
</tr>
<tr>
<td>Witness by chief of doctor(s)</td>
<td>2 (11%)</td>
<td>7 (16%)</td>
<td>1 (6%)</td>
<td>10</td>
</tr>
<tr>
<td>Examination Report</td>
<td>2 (11%)</td>
<td>2 (5%)</td>
<td>3 (19%)</td>
<td>7</td>
</tr>
<tr>
<td>Examination Report by Medical Board</td>
<td></td>
<td>1 (2%)</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Prescription</td>
<td>1 (6%)</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Referral letter/Admission/Discharge Slip</td>
<td></td>
<td>1 (2%)</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Multiple Evidence</td>
<td>6 (33%)</td>
<td>19 (44%)</td>
<td>7 (44%)</td>
<td>33</td>
</tr>
<tr>
<td>Type of ME not specified</td>
<td>2 (11%)</td>
<td>3 (7%)</td>
<td></td>
<td>5</td>
</tr>
</tbody>
</table>

**DISCUSSION**

This paper assessed judiciary practices in divorce cases in Pune, Maharashtra, India, and explored to what extent gender influences the decision to grant a divorce on the basis of mental illness. The analysis focused on annulment and divorce petitions and judgments at the Family Court and High court level in Pune, Maharashtra and nationwide, respectively.

Three main results from the analysis merit further discussion and consideration. At the Family Court level, 85% of cases filed were by husbands alleging mental illness in their wives. Corroborating this, when looking at petitions filed for divorce more generally (i.e. not specifically for mental illness) in the Family
court, 61% of petitioners are husbands. Similarly, of the cases that reached the High Court level, male petitions had filed 95% of the petitions originally at the Family Court. Synthesised, these results suggest that more men than women are filing for divorce on the grounds of mental illness, and may be using mental illness as a grounds for divorce or nullity. This is possibly reflective of the differential positions of men and women with respect to marriage, and its intersection with disability. A number of contextual factors may explain this phenomenon. First, socio-economic factors between men and women in India are disproportionate; for example, women are less likely to receive support from their natal families to divorce, and may not have the financial independence to feel confident to file for a divorce. Second, cultural expectations with regards to marriage duties may influence the number of women who file for divorce. As Addlakha (8), Ghai (9) and others (10) state, women with disabilities are considered as incapable of fulfilling their duties as a wife, homemaker, mother etc.

The second finding of interest relates to medical evidence present in the petition or in Court. Our analysis revealed that at the Family Court level, medical evidence was presented in only a third of the cases despite the fact that the basis for nullity or divorce pleaded is the presence of mental illness in the opposite spouse. When no medical evidence was presented, divorce or nullity was still granted in 22% of instances, compared to (only) a 35% success rate of petitions when medical evidence of mental illness is presented. Having said that, even when medical evidence is presented, the results show that it was often of poor quality to be considered as robust proof of a mental illness. To illustrate, in at least 20% of the 26 cases, simple prescriptions, copies of medical records, and invoices for purchase of medicine were provided as the sole piece of evidence, and were accepted by the courts. Similarly, at the High Court level, in nearly 20% of the cases no medical evidence was provided and even in cases where no medical evidence was provided, the lower courts have granted nullity or divorce to 40% of cases. This finding is disconcerting as even in the case where there is no medical evidence, the High Courts are reversing the judgment of the lower courts in only 50% of the cases. If a medical ground (mental illness) is being pleaded, then it is inconceivable how courts are making decisions without requiring substantial medical evidence to be presented. Similar to the evidence presented at the Family Court level, the evidence in cases reaching the High Court is also of poor quality. Without clear guidelines on what is considered as acceptable and sound medical evidence for proof of mental illness, judiciary practice is unlikely to change in the courts.
Furthermore, our analysis revealed that 78 (14%) of judgments at the Pune Family Court were made under exparte conditions, despite the fact that the High Court has explicitly stated that ex-parte judgments should not be given and proper representation is required (6).

One unexpected finding arising from our data was that a substantial number of petitions were converted into nullity or divorce by mutual consent. Though the underlying reasons for this figure are unclear and should be further explored, one could speculate that given the stigma associated with mental illness in the Indian context, the notion of ‘mutual consent’ might be used as a tool to pressurize the opposite spouse into agreeing to a divorce. This may reduce stigma, as mental illness is not documented in a judgment if it is determined upon mutual consent; this is not the case for nullity or divorce, which if granted on the grounds of mental illness, will be documented in the judgment. The documentation of the presence of mental illness on a judgment is problematic, as it could potentially compromise any future chances of remarriage for the opposite spouse. This is because persons with disabilities (including mental illness) are often shunned from marriage opportunities, which is well documented in both the Indian context as well as other contexts (8,10–13).

Our analysis also found that High Courts are overturning a large number of lower court-level judgments, particularly in lower court cases where the petitioner was the husband and nullity or divorce had been granted by the lower courts. On the other hand, the High Courts are confirming the judgments of the lower courts, when the lower courts have refused to grant divorce to a male petitioner. This means that the High Court’s emphasis is on preservation of marriage and/or supporting women, regardless of the presence or absence of a mental illness. This consideration of judgments made at the Family Court and High Court has gender-based implications. Approximately 5-6% of cases are appealed at the High Court level, and women in particular lack the resources to appeal to the High Court (14). Women are less likely to appeal to higher courts due to many reasons including the lack of financial resources. However, if women had the means to appeal to the High Court, our data shows they stand a very good chance of having the judgment of the lower court reversed. High Courts appear to display greater gender sensitivity with respect to mental illness and marriage; however our analysis reveals that Family and District Courts do not display this same level of gender sensitivity. Given that most cases are not appealed to the High Courts, it is imperative that lower Courts are sensitized to the social and gendered aspects of the marriage laws with respect to mental illness.
More broadly, the language of the HMA may also create conceptual confusion and be reflected in judgments. The term used in Section 13 (1) (iii) is “incurably of unsound mind”. Unsound mind is a legal concept and does not have medical equivalence (15), while curability is a medical concept. It is difficult to understand what the drafters had in mind when referring to medical curability (or lack of it) with respect to a legal term (unsound mind). Furthermore, the concept of unsoundness of mind can nullify or dissolve a marriage, which can enhance stigmatization (15). The definitions of ‘mental illness’ and ‘psychopathic disorder’ used in the HMA also do not necessarily correspond well to medical definitions and understanding of these terms. The term ‘psychopathic disorder’ in HMA encompasses intellectual disability. The term ‘psychopathic disorder’ is hardly found in modern medical literature, which tends to use the term ‘personality disorder’. However there are many concerns articulated in medical literature regarding the diagnosis of personality disorder, particularly the validity and reliability of the diagnosis (16–19). Personality disorders have long been described as deviances from social norms and values. In the Indian context where patriarchal norms prevail, any challenge to male authority has the potential to be labelled as a personality disorder, which may contribute to explaining why there are a disproportionate number of female spouses labelled to have a mental illness in divorce cases.

Taken together, the findings from the analysis presented in this paper have a number of implications for policy, practice and future research. First, there is a need for uniform guidelines for lower courts on what can be accepted as adequate medical proof of mental illness and the need to require proof of mental illness when this is alleged in any petition with respect to nullity or divorce under the HMA. Second, more awareness and research is needed on this topic to gather a sizeable evidence base to push for amendment of the HMA, and consider deletion of Section 5 (ii) and Section 13 of the HMA, as it appears to be used in a gender discriminatory manner which is detrimental to women’s interests, does not fit with modern understanding of mental illness and its curability or otherwise, taking into account the recent Supreme Court judgment (20) and also as it clearly violates the UN Convention on Rights of Persons with Disabilities, which India is a signatory to and is required to implement the CRPD in its domestic legislation. Third, sensitization for the judiciary is needed to facilitate a more gender-sensitive approach to mental illness and divorce. Sensitisation activities should focus on the social, legal, cultural and medical complexities that play a role in mental illness being used as a ground for divorce in the Indian context. Finally, it would be interesting for future research to
determine whether such patterns of mental illness being used as grounds for divorce exist in other Courts in other contexts in India, and even in South Asia. Accumulating data could then feed into potential theoretical frameworks on mental illness, marriage (and divorce), and strengthen the evidence which could be then used to prompt an amendment to the HMA and advocacy work.

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REFERENCES


Part 4

Chapter 7

Supported decision-making for persons with mental illness: a review.
Supported decision making for persons with mental illness: A review

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Abstract

Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) states that persons with disabilities should have equal recognition before the law and the right to exercise their legal capacity. Exercising legal capacity can mean making decisions about employment, medical or psychosocial treatment, property, finances, family, and participation in community activities. Persons with mental illness (PWMI) are often not afforded the same opportunity to make decisions on a par with others in society. We comprehensively review the evidence on supported decision making for PWMI, as well as look at existing decision-making models in legislation globally. Results reveal only a few countries have provisions for supported decision-making for PWMI, with a particular shortage of such provisions in legislation in low and middle-income countries (LMICs). There is also a paucity of research evidence for supported-
decision making, with the majority of research focusing on shared decision-making for treatment decisions and decision aids. This review highlights the need for additional research in this area to better guide models which can be utilised in domestic legislation, particularly in LMICs, to better implement the ideals of Article 12 of the CRPD.

**Keywords**: supported decision-making; mental illness; human rights; CRPD; legal capacity

**Introduction**
Making decisions is central to a person’s autonomy and the essence of what is regarded as personhood, and decision-making is a crucial component in enabling an individuals to have control over their lives and engage with society. Without the ability to make decisions for ourselves, we are seen as non-persons before the law and our actions and decisions no longer have any legal force. Consequently, third parties make decisions on behalf of a person who is deemed to lack legal capacity and guardianship is often appointed, either informally (i.e. a relative) or formally (i.e. court appointed representative). People with disabilities are at risk of being stripped of their decision-making abilities and rights to self-determination by having others take on the authority to make decisions for them. In particular, the presence of a mental illness is often equated with a lack of decision-making capacity. Society has historically restricted choice to persons with mental illness (PWMI) due to an assumption of incapacity. As a result, institutions “took care” of many choices for people with mental illness, removing autonomy, responsibility, and self-direction. For a person with mental illness, having a substitute decision-making or guardianship system in place can abolish rights to self-determination and take away the opportunity to enter into transactions or contracts autonomously.

The Convention on the Rights of Persons with Disabilities (CRPD) came into force in 2008 and has created an impetus for change in disability laws (including mental health laws). The CRPD demands a paradigm shift in the disability sphere, moving from a substitute decision-making model to a supported decision-making model. Article 12 has been called the core of the CRPD and states that all persons with disabilities (PWD) should have equal recognition before the law. It declares that PWD should have both the recognition of their rights, legal capacity and the right to exercise this legal capacity. In practical terms, exercising legal capacity means making decisions for oneself in all areas of life
including medical treatment, housing, employment, relationships, finances, children, family planning, and property. The CRPD recognizes that there are times when PWD may require support in making decisions and that depending on the course of the disability or illness, varying levels of support may be needed.\textsuperscript{6, 18} Accessing support, regardless of the form of support, is central to the recognition of being equal and full citizens before the law.\textsuperscript{3} Countries are expected to take measures to support PWD to exercise their legal capacity, which are tailor-made to the person’s circumstances and preferences, applying for the shortest amount of time possible, provide safeguards to prevent abuse and regularly reviewed by a legal authority.\textsuperscript{19}

In most countries, mental health legislation does not include provisions for PWMI to exercise legal capacity. A number of laws still adopt a paternalistic approach with the stated purpose of protecting the individual and society from harm.\textsuperscript{5 20} This protection has been linked to the historical view that PWMI are dangerous to others\textsuperscript{21} or violent,\textsuperscript{22} leading the state to adopt a protective role. Early laws concerned with mental health were often penalizing and concerned with taking the individual away from society,\textsuperscript{21} often prescribing institutionalised treatment and guardianship as the solution and as a means of protection.\textsuperscript{5 6} Fortunately, mental health reform in a number of countries has led to new mental health legislation that better promotes treatment in the community and inclusion of PWMI in society. Despite mental health reform, however, guardianship and substituted decision-making systems are still the prevailing norm in many countries and jurisdictions for PWMI.

Terminology used to describe decision-making capacity as it relates to mental illness differs substantially across jurisdictions, countries and even between disciplines of law and health. Decisions can be made in a number of ways in both law and health. Decisions can be made autonomously, by having a substituted decision-making, by electing powers of attorney or writing advance directives, by having court-appointed mentors or legal representatives, and by supports (e.g. information aids, decision aids, peer support). For the purposes of this review, we consider guardianship as a form of surrogate decision-making where a decision maker is appointed to make decisions on behalf of a person believed to lack mental capacity.\textsuperscript{6} Guardianship can vary in its levels of decision-making power; for example guardianship can be limited, partial or full (also known as plenary). While limited and partial guardianship are not ideal for realising legal capacity and autonomy, they allow an individual to retain some decision-making
abilities in other areas of life, thus these levels of guardianship are preferred over full guardianship.  

The concepts of mental and legal capacity differ and hold different meanings. Legal capacity can be viewed as a person’s capacity to have rights and exercise these rights without discrimination. In contrast, mental capacity can be seen as the ability to understand incoming information, considering the harms and benefits of making or abstaining from a decision, and the ability to communicate the decision to others. The correlation between the two definitions is that the cognitive requirements for mental capacity are also needed to exercise legal capacity. Often, health or law professionals decide on capacity and it is often established prior to involvement from the legal system. Full legal capacity can be understood as a phenomenon when one can understand the aspects of a decision and communicate this decision to others. However, even an individual unable to go through this decision-making process should still have the right to retain full legal capacity, instead accessing support where necessary to be able to reach the same decision autonomously.

Research on decision-making for PWMI has been largely restricted to the medical domain, focusing primarily on treatment decisions. There is limited research outside this sphere which test or evaluate supported decision-making models and assess legal outcomes as related to mental illness. Research has predominantly focused on shared decision-making (SDM). Shared decision-making not been precisely defined in the literature, although it has been extensively researched for review see . In an attempt to clarify the concept of shared decision-making, Makoul and colleagues posited that for a decision to be shared, it must involve at least two participants, have shared information and the decision must be made and agreed upon by all parties. Montori and colleagues subsequently added to this conceptual definition of SDM by stating (specific to decision making in health care) that a decision is only shared if there is an ongoing partnership and collaboration between the health care worker and patient. Adams and colleagues emphasise the patient participation angle of SDM, highlighting patients should have accessible information, enabling them to participate in an active and meaningful way. SDM enables an individual to exercise only partial autonomy over decisions and has been positioned as an intermediate option between paternalistic models and informed choice models and has been associated with improvements in patient satisfaction, treatment adherence, and improved health outcomes (e.g. reduction of severity of symptoms). Conversely, supported decision-
making is broader, and can consist of organisations, networks, provisions or agreements with the aim of supporting and assisting an individual with a mental illness to make and communicate decisions. In supported decision-making, the individual is always the primary decision maker, but it is acknowledged that autonomy can be communicated in a number of ways, thus provision of support in different forms and intervals can assist in the expression of autonomous decisions. Supported decision-making enables the individual to retain legal capacity regardless of the level of support needed. Forms of supported decision-making can therefore include advance directives, enduring powers of attorney, health care proxies, arrangements for financial decisions (e.g. payee regimes, banking systems), nominated representatives, and/or personal ombudsmen. These forms of support are more formal and offer less autonomy to PWMI on the support spectrum than less formal forms of support. Less formal but equally important forms of support can consist of support networks of family and friends and peer support. Research has extensively focused on advance directives (also referred to advance planning, joint crisis planning, advance crisis planning, anticipatory psychiatric planning, Ulysses directive). Advance directives have been defined as a supportive tool that spell out a person’s wishes and preferences for treatment decisions for the future when he or she loses decision-making capacity. In advance directives, the wishes of the client are expressed and based only on circumstances wherein the client loses decision-making capacity. Advance directives, while a valid support tool and a form of supported decision-making, offer less autonomy and can easily transition into a form of substituted decision-making depending on the authority of the other person involved in the decision-making process. Furthermore, these tools are often not offered to persons with severe mental illness as they are seen to lack capacity.

Despite the CRPD’s exhortation for supported decision-making, there has been resistance to supported decision-making, primarily due to the assumption that persons with a mental illness are unable to make the right decision and are not aware of their best interests. This is based on the “outcomes” approach to legal capacity, which infers one’s capacity from the outcomes of decisions they make. This means that there are “right” and “wrong” decisions, and someone only has capacity if they can demonstrate that they can make “right” or reasonable decisions. The bias in this approach lies in the fact that PWMI must always make “right” and reasonable decisions to be considered to have capacity, and it does not afford PWMI the right to make mistakes or wrong decisions (and to subsequently learn from experience) like others in society. Furthermore,
persons without disabilities also solicit advice from family and professionals prior to making a decision – particularly health care decisions. In this sense, the concept of supported decision-making for people with disabilities only re-emphasises the norm of seeking advice and input when making an important decision.

As no countries have fully implemented Article 12 of the CRPD, there is a need to review what progress has been made to date, particularly in low and middle-income countries (LMICs) where constrained resources required to shift legal and social sectors to a model of supported decision-making may be problematic. Reviewing the evidence and legislation will assist in guiding the research findings, delineate crucial areas for future research, and draw on the efficacy of support aids for PWMI within legislative frameworks to make the 'paradigm shift' of the CRPD a reality in practice. Therefore, the aim of this paper is to review the literature on supported decision making processes in light of Article 12 of the CRPD and examine best practices in supported decision making internationally and point towards how components of supported decision making can be implemented.

Methods

Study selection

Given that this review focuses on supported decision-making as it relates to legal capacity, we review shared decision-making only briefly and synthesise the evidence in a way that might inform supported decision-making models. We noted that as studies in decision-making are not always conducted as randomized controlled trials (RCTs), restricting inclusion to a particular study design could substantially limit relevant data, a study selection approach also employed by a recent Cochrane review. We therefore included RCTs, quasi-experimental studies, and qualitative studies. We also included grey literature (policy documents, legislation, unpublished presentations, reports) for the portion of the review identifying legislation for supported decision-making. We included all studies as long as at least 50% of the sample population had a mental illness and the intervention or research aim focused on decision-making for this population. We excluded studies if they focused on support tools which were not fully defined to be “supportive” (that is, advance directives, nominated representatives, powers of attorney, health care proxies); populations with mental retardation, intellectual disabilities, Alzheimer’s, dementia or cognitive
impairment, or focused on patients with health conditions other than mental health problems. There were no language restrictions for this review. Outcomes of interest for this review included patient satisfaction, health care outcomes (e.g. hospitalization rates post-intervention, severity of symptoms, medication adherence), effective supported decision-making models, legislation including provisions on supported decision-making (for grey literature). Relevant settings for the review of the research literature were community, primary, secondary, tertiary health care and social care settings (including inpatient psychiatric facilities).

**Search Strategy**

In order to maximize the number of possible retrieved studies from the searches, we conducted searches incorporating a number of terms related to decision-making for PWMI, including the following terms: “assisted decision-making,” “shared decision-making”, “facilitated decision-making” and “supported decision-making.” We broadened these search terms as we recognized that searching only for shared decision-making would focus primarily on medical treatment decisions, and although relevant, we wanted to additionally include articles focusing on other circumstances beyond medical decisions. For the legislative component of the review, we reviewed laws from any country regardless of its income level, as long as it incorporated provisions for supported decision-making for PWMI or included alternatives to guardianship and substituted decision-making systems. We searched in the following databases: PubMed, MEDLINE, PsycINFO, and Cochrane Library. References were searched from 1950 up until 2012. We also searched through reference lists of included studies to identify any additional references for potential inclusion which our searches might have missed. These additional references were searched in Google Scholar.

**Data collection**

From each study, we extracted the study design, setting, participant information, interventions (where appropriate), results, and limitations of the study. Both authors looked through the reference lists of included studies to identify any additional references that may have been missed by the searches. If relevant for inclusion, we obtained the abstract from the reference, and if relevant, obtained the full-text of the reference for review.

**Results**
Our initial search yielded 8041 references in total. Of those 8041 references, we assessed the references based on titles and abstracts, which yielded 511 potentially relevant studies, of which we obtained the full-text. After applying our inclusion criteria, we included 26 studies (13 studies for the research review and 12 for the legislation review). From the reference lists of the included studies, we identified an additional 134 potentially relevant studies, of which 30 were included in both the legislative and research review. A flow chart of the sifting strategy is shown in Figure 1. Common reasons for exclusion of studies include: the intervention was beyond the scope of this review (end-of-life decision-making interventions, decision-making interventions aimed at physical health problems like diabetes or cancer); topic of paper focused on legislation outside of decision-making and legal capacity (for example, on treatment orders or discharge from treatment); the population of focus in the paper was beyond the scope of this review (e.g. focused on patients with Alzheimer’s or dementia or mental retardation). In total, we reviewed 25 research studies and 30 papers providing information on legislation in 16 countries.
Figure 1. Flow chart of study selection.

Legislation review

A number of countries, all upper middle-income or high-income, include provisions for supported decision-making in national legislation. One result emerging is that advocacy services and/or community organisations (e.g. the Canadian Association for Community Living) are influential in assisting PWMI in
arranging supported decision-making agreements. In Canada, 5 provinces (British Columbia, Yukon Territories, Alberta, Saskatchewan, Quebec and Manitoba) have legislation providing for varying forms of supported decision-making. Canada and Australia, although having signed and ratified the CRPD and do have provisions for varying forms of support for exercising legal capacity, both have entered a reservation on Article 12 of the CRPD, interpreting compulsory treatment and fully-supported or substituted decision making as permissible under the CRPD, but only as a last resort. Scotland’s progressive Mental Health Act and the UK’s Mental Capacity Act have both developed a Code of Practice to assist service users and carers on interpreting the Act, which is particularly useful when it comes to outlining decision-making capabilities.

In 2012, The Czech Republic enacted a new civil code introducing supported decision-making and stating that restrictions of legal capacity are a last resort. Germany has also made use of supported decision-making agreements in various forms for persons with mental illness. The introduction of a “friend” or mentor appointed by the court has become common in a number of European countries, such as Germany, Finland, Sweden and Austria. Friends/mentors are appointed to an individual after a capacity assessment finds the individual to lack capacity. The friend/mentor has authority to make substitute decisions, is expected to elicit the preferences of the client, and can also allow for the individual to make autonomous decisions in certain areas of life.

This arrangement has been viewed as a middle ground between autonomous and substituted decision-making.

Table 1. Supported decision-making legislation internationally

<table>
<thead>
<tr>
<th>Country</th>
<th>Provisions/Progress towards Supported Decision-Making</th>
<th>Associated legislation</th>
</tr>
</thead>
</table>
| Austria [HIC] 55-56 | ▪ Guardians appointed either for one reason (e.g. financial management) or several fields (limited guardianship) or all fields (full guardianship)  
▪ Review of guardianship regime: every 5 years, revoking guardianship is possible if no longer needed (e.g. health status | Austrian Civil Law; Austrian Guardianship Law |
improves), otherwise guardianship duration is infinite

- Family friends most likely appointed as guardians.
- In absence of social network, NGOs lawyers, notaries or social workers can be appointed.
- An enduring POA removes the need for guardianship when there is a lack of capacity.
- Forms of support offered: Life planning supports; independent advocacy; communication and interpretation support; representatives; relationship-building supports (groups and networks)

| Australia [HIC] | 6. Legislation varies by state and territories  
|                 | 7. Usually limited guardianship, plenary guardianship offered, but rare.  
|                 | 8. Presence of mental illness associated with whole or partial incapacity for managing personal affairs/making decisions  
|                 | 9. Guardianship orders usually time limited (3-5 years) and review possible  
|                 | 10. Guardians: make least restrictive decisions on behalf of client and in best interests  
|                 | 11. Victoria’s Draft Exposure Bill: supported-decision making model and enables compulsory patients to make own decisions about MH treatment/care. Assumes that PWMI have capacity to make decisions unless determined otherwise. Introduces statutory mechanisms to support people to |
participate in decisions about treatment/care, and makes provisions for nominated person scheme, and substituted decision-making is a last resort.

12. New South Wales considering amendments to legal capacity legislation. NSW has no formalized support arrangements but may transfer ideas from financial decision-making capacities with trustee and financial manager to other areas. NSW submitted a proposal to conduct a research trial on supported decision-making.

13. South Australia: Completed phase 1 of research trial on supported decision making; considering amending legislation to facilitate supported decision-making

<table>
<thead>
<tr>
<th>Canada [HIC]</th>
<th>Supported decision-making offered to mild disabilities; for more significant impairment: co-decision makers, guardians, or trustees.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alberta</td>
<td>Co-decision makers (court-appointed) collaborate together with the individual. The individual still can make decisions but with support (retains legal capacity).</td>
</tr>
<tr>
<td></td>
<td>Guardians (court-appointed) take legal responsibility on behalf of the individual who lacks capacity.</td>
</tr>
<tr>
<td></td>
<td>Trustees make financial decisions for the individual who lacks capacity.</td>
</tr>
<tr>
<td></td>
<td>Co-decision makers, supported decision-makers, and specific decision-makers cannot make mental health treatment decisions</td>
</tr>
</tbody>
</table>

Guardianship and Trusteeship Act & Personal Directives Act
• for formal patients or patients who have a community treatment order if they lack mental capacity.
• A health care provider can choose a relative to make decisions based on a ranked list if no guardian or advance directive is available for treatment decisions.
• Tools available for support are advance directives, enduring POA’s, and supported-decision authorizations.

| British Columbia | Representation agreements (RA’s) cover personal, health and financial affairs. |
|------------------|---------------------------------------------------------------------------------
|                   | A representative (usually multiple representatives to cover different areas, and with an external monitor to ensure representatives are fulfilling duties as a safeguard to protect from abuse) helps the individual to make their own decisions, and/or makes substituted decisions. There must be a clear desire for a representative agreement and a trusting relationship between the individual and representative(s). |
|                   | The individual must have capacity to make a RA (depending on whether it is section 7 or 9 agreement). RA’s can be amended and revoked; thus less restrictive than guardianship |
|                   | RA’s involve elements of supported and substituted-decision making and presume everybody has capacity until proven otherwise. |
|                   | RA’s enable the individual to remain in control and retain decision-making rights |

<p>| | Representation Agreement |
| | Adult Guardianship and Planning Statutes Amendment Act, 2007 |</p>
<table>
<thead>
<tr>
<th>Province</th>
<th>Support Measures</th>
<th>Legislation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manitoba</td>
<td>Acknowledges support networks, exercising decision-making rights, implements safeguards to prevent abuse and neglect and keeps substituted decision-making as a last resort. Only available for persons with intellectual disabilities, not for PWMI.</td>
<td>Vulnerable Persons Living with a Mental Disability Act</td>
</tr>
</tbody>
</table>
| Quebec      | ▪ Curators and tutors (court-appointed) available for PWMI. Curator assignment implies that incapacity of the individual is total and permanent and tutorship implies incapacity is temporary.  
▪ Advisorship is also available and is least intrusive, pertains to administration of the individuals’ property; decision-making power is retained in all other aspects of life. Advisors are imposed on the individual, so the person is unable to refuse support.  
▪ Support tools (mandates) such as advance directives are also available. | Civil Code of Quebec |
| Saskatchewan| ▪ Hybrid between supported and substituted decision-making.  
▪ Guardians: court ordered, courts choose who guardian will be, supports imposed by order (rather than by choice)  
▪ Co-decision makers: available to assist in making decisions jointly with the individual.  
▪ Temporary guardians are also available for emergency situations.  
▪ Decision-making orders can be assigned for areas of life that an individual has particular difficulty in reaching decisions in (so capacity is intact to make autonomous decisions in other aspects of life) | Adult Guardianship and Co-decision-making Act |
<table>
<thead>
<tr>
<th>Country/Region</th>
<th>Description</th>
<th>Source</th>
</tr>
</thead>
</table>
| Yukon Territories              | - Individuals can also refuse support, as long as they have the capacity to communicate that decision.  
- Full spectrum of varying support options (supported decision-making agreements, representation agreements, substituted decision making for health care decisions, guardianship) based on needs of the individual.  
- Supported decision-making agreements possible if person has capacity at time of requesting agreement. If the client loses capacity, the agreement is terminated.  
- The supported decision making agreement involves the consent and formalization of two (or more) adults to enter into a support relationship. | Adult Decision Making and Protection Act (Yukon)                                                                         |
| Colombia [LMIC]71              | Efforts to make changes to Law 1306, which defines legal capacity by clinical diagnosis. Colombia has instituted a multidisciplinary advocacy group (La Mesa) bringing together stakeholders (universities, CSOs, lawyers, Ministry of Social Welfare and National Council on Disability) to lobby for legal reform recognising legal capacity for PWMI and PWD. | None yet; but reform of Law 1306                                      |
| Czech Republic [HIC]72         | New law introduces supported decision-making as an alternative to guardianship, recognises legal capacity, implemented safeguards to prevent abuse  
Restriction of legal capacity as last resort.  
Support mechanisms such as representatives and advance directives available | Czech Civil Code                                                      |
| Denmark [HIC] 73,74 | ▪ Guardians/representatives do not imply loss of legal capacity; belief that person with limited legal capacity should retain as much of their right to exercise legal capacity as possible.  
▪ Guardianship can only be used under legal circumstances (contractual agreements and financial decisions).  
▪ Other decisions (accommodation, participation and personal affairs) administered and supported by advocates/assistants who support the client rather than act as guardians. | Guardianship Act |
|---|---|---|
| England and Wales [HIC] 73,75,76 | ▪ The MCA (2005) is centralised around the individual and their decision-making process; supports involvement of the individual and their social network in decisions.  
▪ Everybody has capacity until determined otherwise; incapacity in one area means still retain decision-making abilities in other areas  
▪ Capacity assessments conducted on a decision-specific basis rather than globally applied to all decisions.  
▪ If guardians assigned, must take best interests approach, and are reviewed/supervised by the Office of the Public Guardian.  
▪ Support places emphasis on family, friends and professionals coupled with legislation safeguards (rather than on court-appointed support).  
▪ If no support from social network, independent mental capacity advocates (working for CSO’s) can | Mental Capacity Act (2005) |
<table>
<thead>
<tr>
<th>Country</th>
<th>Law or Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>Germany [HIC]</td>
<td>German Guardianship Law; German Civil Code</td>
</tr>
<tr>
<td>Hungary [HIC]</td>
<td>Hungarian Civil Code</td>
</tr>
<tr>
<td>India [LMIC]</td>
<td>Mental Health Care Bill 2012</td>
</tr>
<tr>
<td>Netherlands [HIC]</td>
<td>Netherlands Civil Code; Medical Treatment Act (WGBO)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Country</th>
<th>Offer Support for Decision-Making</th>
</tr>
</thead>
<tbody>
<tr>
<td>Germany [HIC]</td>
<td>No plenary guardianship and strong focus on supported decision-making. Limited guardianship (temporary orders up to 6 months, maximum orders 7 years) can be granted for court-specified duties (i.e. for financial affairs) but an individual retains full legal capacity.</td>
</tr>
<tr>
<td>Hungary [HIC]</td>
<td>Planned reform for Civil Code in 2010, Hungarian Constitutional Court has blocked the reform from being enforced. Reform was to shift from plenary guardianship to join decision-making arrangements between client and guardian. Anticipated that these reforms will be re-considered after active lobbying. Current system: plenary guardianship, limited options for reviewing or revoking a guardianship regime.</td>
</tr>
<tr>
<td>India [LMIC]</td>
<td>New draft bill acknowledges legal capacity and capacity to make mental health treatment or care decisions. A number of tools can be provided if a person is unable to make a decision autonomously (advance directives and nominated representatives).</td>
</tr>
<tr>
<td>Netherlands [HIC]</td>
<td>Mentors and protective trusts. Protective trusts: only financial decisions, so legal capacity is retained in all other areas. Mentors: limited to nonfinancial interests pertaining to care and treatment guidance. Mentors advise, update, and regularly</td>
</tr>
</tbody>
</table>
inform clients of actions taken in all non-financial matters.
- For medical care, automatic decision-making given to the partner or close relative when the individual is incapacitated.
- Advocacy services available to assist with supported decision-making. An advocacy representative can offer support (via information provision, representation, etc.) to help the individual express own views.
- For admission to a psychiatric hospital, obligatory for the treatment plan to be drawn up collaboratively between the patient and clinician, and if the patient lacks capacity at that time, the person drawing up the agreement must discuss the treatment and hospitalisation plan with either a legal representative, a named representative, a spouse, or relative.

| Norway [HIC] 70,73 | Advocates support adults with decision-making (particularly financial affairs) so legal capacity is not lost
- Legislation provides 2 levels of decision-making interventions: Assistance representative or support person
- Assistance representative only compromises legal capacity when necessary and their decisions prevail over the individuals only in extenuating circumstances
- Support person assists with helping client to express interests/wishes |
| New Zealand [HIC] \(^{55}\) | Welfare guardians (usually a family member) appointed to make or communicate decisions around personal care and welfare (if this is the only option available for the client).
- Temporary orders can be made for 3-6 months, longer orders up to 3 years.
- Welfare guardians should: promote best interests and welfare of the individual, encourage exercising legal capacity for the individual to make autonomous decisions, encourage individual to act on own behalf to furthest extent possible (and consult with the individual as much as possible), and assist in community integration of the individual. | The Protection of Personal and Property Rights Act 1988 |
|---|---|---|
| Scotland [HIC] \(^{2,5,55,61}\) | Scotland’s system provides free access to independent advocacy (obligated responsibility of each Health Service/Board).
- Less legal approach to determining decision-making capacity; acknowledges times where decision-making capacity is retained and other times where it may be compromised due to a mental illness.
- There can be no personal appointment to position of guardian (only a POA). Having a POA in place for a PWMI removes the need for guardianship.
- A “named” person can be nominated by the client to attend hearings and provide information for the client. PWMI have access to advance directives, particularly in Mental Health (Care and Treatment Act) 2003; Adults with Incapacity (Scotland) Act 2000 |
treatment decisions. If a PWMI cannot consent to treatment or refuses to, a clinician is obligated to consider (and record in writing) the reason for not consenting; the views of the involuntary patient and a nominated person together with any advanced statement; and how efficacious the treatment is.

| **Sweden [HIC]** 5,52,55,73,79,80 | ▪ No plenary guardianship but a partial guardianship as last resort. Instead, have a system of support for PWD and PWMI.  
▪ Two options: mentor or “god man” (court appointed; usually consisting of family members or community members, who acts with consent of the individual) or trustee “forvaltare” (more similar to guardians, has authority in designated matters over the incapacitated individual).  
▪ Trustee can make decisions in financial/personal welfare areas, and must approach decisions using the best interests principle. Trusteeship still incorporates elements of full guardianship and does not fully emphasize individual rights/preferences.  
▪ Personal ombudsmen (PO) for PWMI available: accessible (anyone can request PO); supports the client in personal, financial and legal affairs, no alliance with social services, authorities or carers, trained in developing rapport. | **Swedish Law/Parental Code** |
| **Switzerland [HIC]** 55,82,83 | ▪ Federal Council tends to amend Swiss Civil code support the right to choose and acknowledge legal capacity via introduction of | **Swiss Civil Code reform** |
advance directives and developing/tailoring a support package for a person who lacks capacity. The authorities tailoring the support package will conduct a needs assessment for the person concerned, to identify tasks/roles needing to be completed by official assistance.

On the way to reform

Guardianship law reform is also occurring in the Czech Republic, Hungary, France, Ireland, Portugal, Slovakia and Slovenia. Several South American countries like Colombia also offer either plenary guardianship or assistance to make decisions, where the individuals’ decision is taken into account along with a third party. Advocacy measures to implement Article 12 of the CRPD are also strong, though legal reform has yet to take place. The Hungarian Government, although in 2009 was planning to abolish plenary guardianship and offer supported decision-making as an alternative, declined to enact the new reforms in 2010. Norway and Germany have mixed systems, offering both support and substitution. Sweden has abolished plenary guardianship and offers a system of support services in favour of the support paradigm ranging from mentors to trustees allocated to support persons with disabilities. Mentors can be family members, members of the community or professionals who act only with consent of the person receiving support. Trustees, however, are similar to guardians but the individual retains the right to vote.

Research review

Supported decision-making in high-income countries

Few studies have assessed supported decision-making beyond treatment decisions, such as how supported decision-making impacts legal capacity and other life decisions. One study looked at having choice about housing and receiving support to autonomously decide about housing in the community. Srebnik (1995) found that perceived autonomy to decide about housing had a substantial impact on psychological well-being. Other authors have discussed financial capacity in persons with schizophrenia, recommending the use of advance directives to outline preferences and processes with regards to
financial matters during periods of both capacity and incapacity. Another study in Australia looked at the impact of supported decision-making. Results revealed that out of 22 adults, 8 (36%) wanted to receive support in several areas of their life (e.g. choosing services, housing, medical procedures). Social exclusion was identified as a barrier to supported decision-making, as 3 of 22 participants had nobody they could nominate in their life as a supporter, though they were keen to have support. Participants believed that an advocate or multidisciplinary team would be best to provide support for mental health care decisions, a solicitor for legal decisions, and a friend or relative for day-to-day matters. Another study conducted by Amnesty International in Ireland revealed that after interviewing 8 clients, all were unanimously in favour of writing advanced directives and expressed strong values for supported decision making. Participants acknowledged that emotional distress can impact decision-making capacity, and capacity can be further reduced by social and environmental factors, such as lack of available treatment options, lack of trust in an information provider, and inaccessible information. The participants also articulated that incapacity as it relates to mental illness is a partial rather than a total phenomenon. They stressed that assessments of capacity need to take into account how much the individual at that particular time is able to contribute to their own decision-making rather than making assumptions that they are incapable due to mental illness or relying on past episodes to infer current capacity. The Australian and Irish findings support this and highlight the need for a strengths-based approach in accord with a social model of disability to build up the decision-making confidence of the individual.

**Shared decision making in mental health care**

While a number of reviews have assessed shared-decision making we chose to review primary studies and not conduct a review of reviews. Despite the extensive research on SDM, we were unable to identify any studies focusing on SDM interventions in low or middle-income countries; therefore our review is limited to studies conducted in high-income countries.

SDM interventions have shown mixed results. Some authors have found that shared decision-making interventions had some impact on reducing the severity of substance-related and/or psychiatric problems but did not impact quality of life. Another study found SDM to have a significant impact for clients with a mental illness even when deciding on secondary decisions like lifestyle behaviours. Mahone (2008) found that participation in SDM was associated with better medication adherence rates, while a recent study found that a
computerized shared-decision making tool had no impact on medication adherence in community outpatient settings.\textsuperscript{116}

Common across the majority of the studies is the finding that people with mental illness have a higher desire for treatment decision-making than other groups within general medicine. \textsuperscript{39,93-95} In addition, participants in a number of studies declared that they had a clear desire for greater participation in decision regarding their psychiatric care compared to the current care they were receiving.\textsuperscript{39,90,92,94} To illustrate, in one study, 82\% of participants preferred a collaborative relationship with their health care provider, however only 70\% experienced this collaboration.\textsuperscript{90} Interestingly, participants articulated a clear idea of how and when to prioritise autonomy in decision-making and when to consult or defer the decision to healthcare professionals. One study\textsuperscript{96} interviewed participants who endorsed a 2-step process of decision-making; first prioritising autonomy and if autonomy is not possible then refer to the case manager to reach a decision. The desired autonomy for decision-making varied by type of decision: for example, with medication choices, 77\% prefer either autonomous or shared roles regarding their choices.\textsuperscript{44} Participants in another study\textsuperscript{94} wished for collaborative decision-making with health care professionals for medication decisions, autonomous decision-making for psychosocial treatment and a passive role in decision-making with their general health care providers. Similarly, Stacey and colleagues (2008) found that 52\% of individuals with depression preferred to make treatment decisions alone, 38\% collaboratively with the health practitioner, and 8\% wanted the practitioner to make the decision.\textsuperscript{98} More difficult decisions will elicit validation from health care professionals, like hospitalisation. Simon (2006) found that participants noticed decision-making took longer when difficult topics arose and when clients were uncertain about the benefits of a decision exceeding the harms (e.g. with medication).\textsuperscript{99} In this particular study, 75\% of patients reported ambivalence towards decision-making, and judged that when symptoms became too great, decision-making should be placed in the hands of professionals. More difficult personal circumstances of the client (e.g. severity of symptoms at the moment, perceived self-competency, experiences with health care professionals) also play a role in determining whether a client relinquishes decision-making control to the health care professional.\textsuperscript{97} Preferences for decision-making also vary when it comes to who patients prefer to make health care decisions for them. In one study, the majority preferred to make their treatment decision alone and have an active role in decision-making, followed by sharing the decision with their health care provider, and lastly, very
few wanted someone to make a substituted decision on their behalf (even if the substitute decision maker was a family member). One factor potentially influencing results is the type of treatment setting, that is, whether participants interviewed in these studies were formal or informal patients, outpatients or inpatients. This could influence the results as inpatients may feel they have less options and less autonomy to make decisions, as well as perceived reduced capacity compared to when they voluntarily seek treatment or when receiving care in the community.

Table 2. Supported and shared-decision making included study characteristics

<table>
<thead>
<tr>
<th>Study ID</th>
<th>Characteristics</th>
</tr>
</thead>
</table>
| AI2009 [87] and MCDAID2011 [88] | Country: Ireland  
Setting: public locations  
N=8 clients with direct experience of mental health in Ireland  
Method: Qualitative; semi-structured interview  
Sampling method: Snowballing |
| CAMPBELL2007 [97]               | Country: UK  
Setting: Home-based  
N=16  
Method: Qualitative interviews  
Sampling: Purposive |
Method: Intervention design/description |
| HAMANN2007 [107]                | Country: Germany  
Setting: inpatients  
N=107  
Method: Cluster RCT Pilot study  
Intervention: Decision making intervention (decision aid, planning consultation) vs. usual care |
| HAMANN2011 [92]                 | Country: Germany  
Setting: inpatients  
N=61; SDM training (N=32) or cognitive training (N=29)  
Design: RCT  
Interventions: SDM-training (intervention) or cognitive training (control) |
Setting: Outpatient clinics  
N= 98  
Method: Secondary analysis of 98 audiotaped interviews (between practitioners and patients)  
Intervention: Computer program in a decision support centre run by peers. |
| JONIKAS2011 [109]               | N= 555 adults (N=276 in experimental, N=270 in control) |

198
| Country: US; Setting: Public outpatient/peer support community services | **Method:** RCT  
**Intervention:** 8 (2.5 hrs each) sessions delivered peer-instructors in recovery in groups of participants vs. Control (wait list + usual care) |
|---|---|
| JOOSTEN2009 [89]  
Country: Netherlands  
Setting: In/outpatient addiction centres | **N=220**  
**Method:** Randomized quasi experimental (non-blinded)  
**Intervention:** SDM, brief intervention added to inpatient treatment. Vs Treatment as usual |
| KUMAR2012 [111]  
Country: India; Setting: urban outpatient | **N= 122 patients; cross-sectional writing advance directives**  
**Method:** Cross-sectional pilot study (observational) |
| LESTER2006 [101]  
Country: UK (primary care) | **N= 18 focus groups (N=45 patients, N=39 GP’s, N=8 practice nurses in 6 primary care trusts).**  
**Design:** Qualitative focus groups  
**Sampling:** Convenience |
| LOH2006 [106]  
**Country:** Germany; Setting: Primary Care | **N=20**  
**Design:** Observational (Audiotape recordings of consultations)  
**Sampling:** Convenience |
| LOH2007 [102]  
**Country:** Germany; Setting: primary care | **N= 405 clients (N=263 Intervention; N=142 Control) ; N=30 physicians (N=20 Intervention physicians, N=10 Control physicians)**  
**Method:** Cluster RCT  
**Comparison:** Physician training and patient centred-decision aid vs. treatment as usual |
| MAHONE2008 [90]  
**Country:** US  
**Setting:** community MH centres | **N= 84 with serious mental illness**  
**Design:** Cross sectional correlational study  
**Sampling:** Convenience |
| MAHONE2011 [100]  
**Country:** US; **Setting:** Public outpatient MH | **N=7 focus groups (consumers, family members, prescribers, MH clinicians & rural providers); N=44 participants in 7 focus groups**  
**Method:** Qualitative focus group |
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Setting</th>
<th>N</th>
<th>Method</th>
<th>Sampling</th>
</tr>
</thead>
<tbody>
<tr>
<td>MCMULLEN2012</td>
<td>Canada</td>
<td>primary care</td>
<td>11 physicians</td>
<td>Qualitative in-depth interviews</td>
<td>Convenience sample</td>
</tr>
<tr>
<td>ONEAL2008</td>
<td>US</td>
<td>Outpatient; residential facility</td>
<td>65 (33 OD; 32 YD)</td>
<td>Cross-sectional pilot study (observational)</td>
<td>Convenience</td>
</tr>
<tr>
<td>OPD2010</td>
<td>Australia</td>
<td>community</td>
<td>22 referred to project, 8 had signed agreements.</td>
<td>Evaluation study to test applicability of supported decision-making</td>
<td>Supported decision making for PWMI.</td>
</tr>
<tr>
<td>PATEL 2010</td>
<td>US</td>
<td>outpatient</td>
<td>60</td>
<td>Survey</td>
<td>Convenience</td>
</tr>
<tr>
<td>SIMON2006</td>
<td>Germany</td>
<td>Inpatient, outpatient, self-help</td>
<td>40 patients with depression (45% severe)</td>
<td>Qualitative; Semi-structured interviews</td>
<td>Convenience</td>
</tr>
<tr>
<td>SREBNIK1995</td>
<td>US</td>
<td>Supported housing project</td>
<td>115</td>
<td>Qualitative interviews; Quasi-experimental</td>
<td>Program offering MH and community support services with obtaining/maintaining housing</td>
</tr>
<tr>
<td>STACEY2008</td>
<td>Canada</td>
<td>Outpatient + community hospital</td>
<td>9</td>
<td>Semi-structured interviews</td>
<td>Non-randomized convenience sample</td>
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<td>STEIN2012</td>
<td>US</td>
<td>community mental health clinics</td>
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<td>Non-randomized computer intervention</td>
<td>Computerized decision support program vs. treatment as usual</td>
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<tr>
<td>WOLTMANN2010</td>
<td>US</td>
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<td>16</td>
<td>Qualitative, structured interviews</td>
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<tr>
<td>Setting:</td>
<td>Public community MH services</td>
<td>Sampling:</td>
<td>Purposive ;Sample taken from a previous RCT comparing usual care vs. electronic decision support program;</td>
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<td>WOLTMANN2011 [108]</td>
<td>Case mangers (EDSS, N=10) and Control N=10; Clients (EDSS N=40; Control N=40)</td>
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<td>Country:</td>
<td>US</td>
<td>Design:</td>
<td>Cluster RCT</td>
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<td>Setting:</td>
<td>urban community MH services</td>
<td>Comparisons:</td>
<td>Supported planning group vs. usual care planning group.</td>
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<tr>
<td>YOUNG2008 [105]</td>
<td>N = 298 interactions between 18 “clients” and 152 physicians</td>
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<td>Country:</td>
<td>US; Setting: Outpatient</td>
<td>Method:</td>
<td>Secondary analysis from an RCT. Coded 287 audio recorded interactions between physicians + patients assess SDM behaviours</td>
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Preferences in decision-making

The extent to which decision-making will be utilised by patients depends on a number of cognitive and affective factors such as individual preferences regarding involvement in the decision-making process. It is not the case that all individuals want to make autonomous decisions, however the central idea is that all individuals should have access to supported decision-making should they need and want it, and all individuals should have the opportunity to exercise their legal capacity.\(^2\)

Barriers to decision-making

Not being informed and the perceived feeling of not being supported appeared as one barrier in decision-making in mental health care in the literature. Stacey and colleagues found that of 94 participants, 67 were uncertain about their decisions regarding medication and treatment, and the uncertain group (compared to those displaying more certainty) felt less informed, less supported and less clear about how to value the benefits and risk of options.\(^98\) These participants required guidance in acquiring information, clarifying values, and support to reach a decision. Some also expressed fear about their own level of competency and were reluctant to breach the topic of SDM with their health providers after relating back to traumatic experiences from the past with health care providers.\(^100\) Another study identified that clients felt particularly uncertain about decision-making when they were perceived to not be competent due to
their mental illness. Cultural factors in help-seeking behaviour and decision-making also impact the willingness to share decision-making with health care providers. Patel (2010) found that Hispanics preferred more passive decision-making in mental health care compared to non-Hispanics who preferred a more active decision-making role. Lastly, social exclusion has also been cited as a barrier to decision-making. If clients have someone to discuss decisions with (peers, families, community members) this often contributes to mobilising a large proportion of support needed to reach a decision.

Another barrier affecting desire for decision-making is decisional conflict, which leads to increased treatment discontinuation and treatment refusal. Supported decision-making would contribute to addressing factors that influence decisional conflict such as being uninformed, having unclear values, feeling unsupported, and having low motivation. Another barrier to a more active role for PWMI in treatment decision-making is the fear and anxiety that they are “difficult” patients and challenging their health care provider and this will lead to reduced access to much needed care.Psychoeducation, having peer-staff listen and inform clients, or providing information prior to consultations with health practitioners could alleviating some of this anxiety, fear and insecurity when considering participation in mental health care.

For health care workers, a number of barriers to employing an SDM approach have been mentioned in the literature. In line with the patient perception of being perceived as difficult if engaging in SDM behaviours, a trial comparing a SDM intervention and treatment as usual by Hamann and colleagues (2011) found that even at 6 months post-intervention, although patients in the SDM group had modified their behaviour compared to baseline (more motivated, held different attitudes towards participation and decision-making), the treating psychiatrists perceived the SDM group to be more difficult to treat (in terms of stress levels for the psychiatrist) compared to control group patients. Other barriers mentioned have been difficulty in ascertaining how to respond when it comes to mental health crises, lack of system support, additional time required for SDM  although other studies, have found that SDM does not require additional time. McMullen (2012) found that physicians she interviewed often did not make used of shared decision-making principles, but rather persuaded clients to decide on empirically supported treatments which physicians themselves had some control over (e.g. therapy in their office, pharmacotherapy as administered via their prescription pad). Two other
studies found that most physicians did not try to involve patients in SDM and that physicians failed to fully participate in SDM in consultations.\textsuperscript{105,106}

\textit{Peer support and support systems}

Two randomized controlled trials conducted in Germany revealed that SDM interventions had a marginal increase in patient satisfaction and demonstrated some evidence that SDM also increased doctor facilitation of patient involvement in decision-making, and did not increase doctor consultation time. Neither of the trials found any positive effect of SDM on clinical outcomes, hospital readmission, or patient compliance with treatment.\textsuperscript{102,103,107} A more recent RCT found that an electronic decision support system did not increase patient satisfaction, however clients became more involved in treatment plans and case managers became more aware of clients concerns and needs, potentially facilitating a more collaborative and supportive relationship in the future.\textsuperscript{108} Another study had peer-educator led training for people with mental illness which emphases informed decision-making, wellbeing, and self-management.\textsuperscript{109} These long-term training sessions resulted in a greater inclination to engage in self-advocacy behaviours and these effects continued after 6-months post-intervention as well as across settings and cultures. Advanced directives have also been seen as a way to support the client in reaching a decision and facilitate collaborative partnership between doctors and patients, particularly due to the fact that it takes into account that mental capacity may fluctuate over the course of mental illness. Deegan (2010) found that even within a short 15-minute consultation, peer support and technology could be utilised to enhance psychiatric medication visits and make them more efficient for both patients and clinicians.\textsuperscript{110} The drawback to this system is the cost of developing and implementing such a system.

\textit{Supported decision making in low and middle-income countries (LMICs)}

While the literature in high-income countries is limited, research in low- and middle-income countries (LMICs) on supported decision-making is even sparser. Poor understanding of patient rights, limited education, and limited medical and legal resources have been reported as reasons for the lack of research.\textsuperscript{111} A review of advanced directives points towards several implementation barriers in LMICs. The authors take the view that the service delivery context in a country like India make implementation of supported decision-making tools problematic, as such tools are designed to be implemented in a more accessible, equitable, and organized system.\textsuperscript{50} Another barrier is the limited resource availability for
monitoring and evaluating these legislative frameworks leading to potential abuse of such progressive tools. Lastly, limited resources means that dedicated legal aid services are scarce, and make implementation of advanced directives in an affordable and accessible manner difficult.\textsuperscript{50} One study countering these opinions was the first trial on psychiatric advance directives (PAD) in India which demonstrated that persons with a long-term mental illness (even with active symptoms) can make use of supportive tools in a resource-poor setting.\textsuperscript{111} While advance directives are not a supportive tool allowing for full autonomous decision-making (although it does fall along the spectrum of support in a supported decision-making framework, this trial is a step in the right direction for shifting to more supportive-decision making models in India.

Discussion

This review aimed to assess progress made in both research and legal domains on supported decision-making models for PWMI. People with mental illness have a right, like those without a mental illness, to exercise their legal capacity and make decisions in all areas of their lives. The complex debate regarding decision-making for PWMI stems from the attribution that, PWMI lack mental capacity to make decisions. However, there are periods of time when a person with mental illness may lose capacity to make decisions. Under these circumstances, support measures must be in place to provide all information and guidance necessary to support that person to make an autonomous decision. Support can take on various forms and be directed towards a number of decisions in life, ranging from the mundane to the profound. There is inherently an element of risk for people taking decisions about their own lives\textsuperscript{112}; however a supported decision-making paradigm requires that choice and risk of making these choices is transparent in order to enable fair appraisal of the decision-making process.\textsuperscript{112}

Our findings indicate that there remains a disconnect between international conventions (CRPD), domestic legislation. We found very limited evidence on supported decision-making, and even less evidence on interventions assessing autonomy and decision-making outside treatment decisions. We found that the models of decision-making tested in the research arena are often very narrow and controlled and do not reflect the dynamic relations between health care professionals, legal professionals, clients, and carers that occur in practice. The findings from the research, predominantly on SDM, indicated that common to the majority of PWMI, there is a desire for autonomy in decision-making and support for decisions involving complex life issues, particularly when the person
is uncertain about the pros and cons of the decision, or uncertain about their competence. Some health care providers have expressed concerns about managing capacity and treatment decisions in crises, additional time, resources and infrastructure required, and difficulty in seeing clients as equals all as barriers to collaborating on decisions. However, supported decision-making should not be seen as a barrier to accessing care, but rather a facilitator of better quality care. Supported decision-making as well as SDM for treatment decisions both point towards a model of inclusion, wherein if a person has difficulty in expressing and communicating his or her wishes, the solution is not coercive and involuntary treatment or to assign guardianship but to develop a relationship in ways which make it possible for an individual to communicate what he or she wants in certain aspects of their lives. It is also important to recognise that there is no “ideal” for supported decision-making either at the professional, state, or national level; but rather a set of components, which, depending on the resources, training and cultural values of the country, can be utilised to promote legal capacity and autonomous decision-making.

From a legal point of view, countries that have ratified the CRPD have a particular impetus to modify or update their mental health legislation in light of the CRPD, particularly when it comes to provisions enabling people to exercise their legal capacity. The CRPD requires mental health legislation to be framed in such a way that presumes all persons with a mental illness have legal capacity until proven otherwise, and even with a lack of capacity, a PWMI should be offered supports and accommodations to reach an autonomous decision.

The lack of legislative frameworks and research evidence suggest that health care professionals, governments, legal systems, and guardians do not always make decisions in accordance with the best interests principle. This provides further impetus to shift from a paternalistic way of viewing PWMI to a more inclusive and supportive system embracing decisions made by PWMI. There is an expectation from the CRPD that governments have a responsibility to change their existing legislation on substitute decision-making and supplant them with a more supportive model encouraging supported decision-making. Policies and programmes should accordingly be designed to implement such legislation. This depends on how countries interpret Article 12 and interpret support for PWMI. Their interpretations and reaction to these interpretations ultimately shape practices and legislation. It is therefore important that research be conducted inform examples of how Article 12 of the CRPD can be implemented,
and additionally, governments must liaise with user organisations, peer support networks, carers, and the social sector to ensure that support aids are used in practice when appropriate. From a practical legislation perspective, instituting a law-based system of supported decision-making should focus on main decisions of legal relevance impacting a person with a mental illness, such as finances, who they live with, employment, medical decisions, community participation and choice of appropriate support services. The key for legislation is to make provisions which enable support to individuals in a way that encourages them to utilise existing support networks and access support when they feel it is necessary to reach a decision.

Adapting support models to low and middle-income countries

Several countries discussed in this paper, such as the UK, Canada, Sweden and Australia are leading the way towards inclusion of supported-decision making in their legislation; and other countries should look to these examples to identify applicable components to their own context and legal systems. LMI Countries particularly need research and applicable models in supported decision-making. To illustrate, a review of SDM training programs globally found no evidence of programs in LMICs to train health professionals in SDM. The question remains as to how supported decision-making models can be feasible for clinicians and clients, and adapted to suit the legal and medical context in LMICs.

The first issue for LMICs is re-conceptualising decision-making capacity for PWMI. For example, in a number of African countries, decision making capacity is viewed as an all or nothing phenomenon. This means that PWMI when stripped of decision-making powers, lose the ability to make decisions in all areas of their lives and rarely have an opportunity for re-assessment of capacity to change this status. Another issue is the potential for abusing supported decision-making efforts, as a person providing support may use their influence over the PWMI in a way that may not be in accordance with the best interests of the PWMI. In LMICs, there is limited availability of monitoring systems in place to pose a safeguard against such a abuse, however, non-profit organisations could perhaps enlist a guardian monitoring service. An additional consideration is, in resource-constrained settings (especially in LMICs) who and how can support be provided in the absence of family and friends? This is particularly the case, in both high-income and LMI countries, for PWMI who have been institutionalised for a significant period of time in psychiatric hospitals and have limited community support. How can supported decision-making tools be extended to this population? The Australian supported
decision-making study found that a number of people wanted supported in making decisions but did not have the network to do so. Gordon (2000) discusses how community advocacy organisations have and can experiment with the development of support networks for people without family and friends, or who are not willing or able to provide support. While this is a very positive initiative, Gordon’s concern relates to how sustainable it is to expect that non-profit organizations can handle large incoming caseloads of PWMI requiring support.  

The second issue when adapting models from high-income countries is the limited financial resources in LMICs. A personal ombudsman model like in Sweden would not be feasible in a LMIC due to the high implementation costs. Family support is crucial in LMICs and can provide a unique opportunity when considering appropriate supported decision-making models. However, despite the limited financial resources, there are ways that LMICs can provide support for people to exercise their legal capacity. It is plausible that placing emphasis on the role of families and support networks in decision-making, similar to the UK, could be beneficial in LMICs, both from a cultural and financial standpoint. Involving independent advocates, where financially feasible (perhaps from voluntary organizations in LMICs) could potentially alleviate the barrier of social exclusion that limits support for PWMI who do not have a carer or support network. This is an effective model that works in the UK.  

Brayley (2009) proposes a model of supported decision-making based on a spectrum of increasing or decreasing state intervention and autonomy. The model “steps up” options for care and intervention offered by the state, depending on need. The highest state intervention involves the appointment of a state official as a guardian of last resort, whereas the step with the lowest state intervention is autonomous decision making. Steps in between involve a support team assisting with decision making; single one-off decisions being made by a tribunal (wherein the client retains decision-making power for all other matters with this exception of this one-off decision); enduring guardianship which the client sets out prior to losing capacity; guardianship by a family or friend with government support or overview. This is similar to a sliding scale of support, which would be beneficial in LMICs but also in high-income countries. Offering a number of support mechanisms on a spectrum based on need, and based on
existing resources of the state or country and which build upon the values of the
given society would be most effective to accommodate diverse needs of people
with disabilities. In addition, particularly in low and middle-income countries,
but not exclusively, people turn to informal support networks when they realise
they need support. As a result, peers and social networks can be invaluable in
providing accommodations and support to those who would like to reach a
decision while also utilising existing resources in a country, when the addition of
legal advocates and representatives might be costly, particularly in resource-
constrained settings. This could entail training people on the path to recovery
from mental illness in peer-support training who can provide support or
resources to those who require it to make decisions. This would indeed translate
action to implementation Article 12 of the CRPD by strengthening and extending
informal networks rather than substituting them with professional legal and
medical services. There is no single best practice for supporting people with disabilities to reach
decisions, as systemic factors impact the provisions of these accommodations
(resources, legal system, implementation of legislative frameworks, availability
of support networks) as well as individual factors (level of need of the individual,
accessibility to support networks and services, capacity at the time of need).
Furthermore, the decision making process in mental illness is complex (largely
due to the chronicity and course of illness) and dependent on circumstances and
context. However, certain components from successful models which embody
the support paradigm, as well as a social model of disability, could be extracted
and utilised in systems and settings wishing to shift away from a guardianship
model. It is therefore important that research pinpoints components of
supported decision-making which facilitates exercising legal capacity but which
could be used in different countries, and then tailored to reflect the context.
Research is therefore urgently needed in light of the fact that guidelines, policies
and international conventions like the CPRD advocate for supported decision-
making, with little evidence of effect.

Limitations

There are of course limitations of this paper that need to be addressed. Perhaps
most importantly, the terminology with regards with decision-making is highly
heterogeneous and loosely defined, impacting the results of our review with
regards to the numbers of included studies. It is possible we may have missed a
number of studies due to our search terms. For example, we did not look at
patient participation in mental health care as a search term, which could have
yielded some studies focusing on SDM. Our hand search identified a number of more relevant studies than did our database searches, potentially due to the grey literature which we included in the legislative review. In addition, the reviewed literature was primarily observational or pilot studies with a small, narrowly focused sample size which is not generalizable to the wider population. It is also debated that there is a substantial gap between supported decision-making models and actual practice – it has been acknowledged that an actual decision-making process rarely fits any of these idealised models. Similarly, while there is no problem in understanding the ideals of Article 12 of the CPRD, truly shifting from substitute decision-making to a more supportive mode is an entirely different problem. Deciding upon which model of decision-making depends on the circumstances of the decision being made within the preferences of the clients and other decision-making parties, and the available information and knowledge resources. An illustrative example is a consumer health survey which found that although a large majority of respondents did not endorse health care professionals to solely make decisions, general practitioners conversely believed that their task was to relieve patient anxiety and comply with patient expectations rather than involve them in the decision making process. Third, in many settings, to provide supported decision-making options for clients, it is necessary that there is a paradigm shift to approach disability from a social model, involving the assumption that people with disabilities have the capacity to make their own decisions.

Conclusion

The paucity of research in supported decision-making models for PWMI highlights the need for tested models, not only in high-income countries, but also in low and middle-income countries. Furthermore, we note that in order for the ability to exercise legal capacity to become a lived reality for PWMI, there needs to be an increase in research output assessing which components of supported decision-making could be used in legislation and in practice. A disconnect still exists between national and/or state legislation and the CRPD provisions. While a government may be in favour of the idea of supported decision-making, their mental health and/or guardianship legislation is not conducive to exercising legal capacity. It is important that mental health laws be updated to reflect CRPD provisions, as mental health legislation can shape, empower, and regulate the entire mental health system, including services, policies, and relationships between professionals and end users.

Conflicts of interest: None declared
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Part 4

Chapter 8

A Review of Barriers to Using Psychiatric Advance Directives in Clinical Practice
A Review of Barriers to Using Psychiatric Advance Directives in Clinical Practice

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A J Van der Ham
Joske Bunders

Abstract

Despite advocacy and demand for psychiatric advance directives (PADs), uptake and implementation in clinical practice is low. We examine why PAD implementation has been difficult globally by reviewing barriers in existing evidence. The review includes 30 studies, and identified 13 barriers, clustered into system level barriers, health professional level barriers, and service user level barriers. The considerable barriers to uptake and implementation hamper PAD use. We propose several potential strategies for overcoming some of the barriers. In order to realise these strategies, additional research is needed, particularly more field-based and operational research to understand processes and difficulties experienced in clinical practice.

Key words: psychiatric advance directives; mental health legislation; decision-making; literature review

Introduction

Psychiatric Advance Directives (PADs) are legal documents detailing a person’s preferences for future mental health treatment and care in advance of decisional incapacity (Campbell & Kisely, 2009; Elbogen et al. 2006; Henderson, Swanson, Szmukler, Thornicroft, & Zinkler, 2008) Traditionally, PADs have been used to document preferences in advance of a psychiatric crisis (Backlar, 1997; Henderson et al. 2008; Swanson, Swartz, Ferron, Elbogen, & van Dorn, 2006) but can be extended to plan for future routine care. PADs are seen as a tool for service users to exercise autonomy, choice, and control over treatment for their mental health problems (Atkinson, Garner, Stuart, & Patrick, 2003; Thara &
PADs can specify treatment preferences (e.g. preference for a particular medication or refusal of a medication), treatment setting (e.g. preference for a particular hospital or type of care), methods for de-escalating crises, life decisions (e.g. what to do with pets or the home while hospitalized, who to contact in case of emergency) or other care preferences (e.g. restraint and seclusion preferences, existing treatment details for comorbidities) or preferences/guidance for staff (e.g. staff should be friendly and understanding) (Srebnik & Russo, 2007; Swanson et al. 2006).

Apart from exercising autonomy, empowerment, and choice (Backlar, McFarland, Swanson, & Mahler, 2001; Jankovic, Richards, & Priebe, 2010; Kim, van Dorn, Scheyett, Elbogen, & Swanson, 2007; Peto, Srebnik, Zick, & Russo, 2004), PADs offer some additional advantages. They can increase service user motivation to continue with planned treatment, thus improving treatment adherence (Elbogen, Swanson, Swartz, et al. 2007; Srebnik, 2005; Swanson, Tepper, Backlar, & Swartz, 2000), improve the patient-provider relationship, address practice-based issues in the organization of mental health care, and reduce coercion and involuntary care (Jankovic et al. 2010; Srebnik et al. 2005; Srebnik, Russo, Sage, Peto, & Zick, 2003; Swanson et al. 2006). Advance directives are also seen as a form of supported decision-making (Weller, 2010) and therefore in line with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2008) which emphasises equal recognition before the law and the right to exercise legal capacity.

PADs do not necessarily require collaboration or agreement with health professionals, and are seen to enhance autonomy and choice in decision-making for the person with mental illness. A number of other advance planning tools are available (e.g. joint crisis plans, crisis cards, advance statements) requiring various degrees of collaboration with health care professionals, and some offer the ability to be legal binding, similar to PADs.

Legislation in a number of countries have provisions for PADs, however, only a small minority of people with mental illness actually write a PAD. Previous research on usage of PADs in the United States (US) shows that between 4-7% of those surveyed have completed a PAD (Swanson et al. 2003; Swanson et al. 2006), and only 12.5% of health care professionals had seen clients with an existing PAD (Swanson et al. 2003). Despite the low completion rate of PADs, demand is high in the US, ranging from 66 to 77% of service users surveyed (Swanson et al. 2006; Wilder, Swanson, Bonnie, Wanchek, McLaughlin, &
Richardson, 2012). Similar data are not available for other countries, but given that the US is at the forefront of encouraging PADs completion and use, the situation in other countries is likely to be less developed.

This raises questions on two issues. First, why is the uptake of psychiatric advance directives so low despite the high demand from service users? Second, if PADs are seen as empowering for service users and promote the CRPD's goal of supported decision making, why are they not implemented more in practice? The gap between interest in and completion of PADs has been attributed partially due to the barriers facing service users and health professionals (Swanson et al. 2006). The perceived barriers to implementation and use of PADs in practice differ depending on the models of care they are based on, as well as the legislative and service contexts they have been developed in (Henderson et al. 2008).

The aim of this review is to obtain greater understanding as to why it has been so difficult to implement psychiatric advance directives globally. We aim to do this by reviewing the barriers highlighted in the existing evidence base and conclude with putting forward potential research suggestions, which could be tested to inform how particular barriers could be alleviated and how PAD uptake could be scaled up. In this paper we will only focus on barriers to using and implementing PADs and facilitated PADs. Facilitated PADs, for the purposes of this review, refer to support or assistance in completing a PAD, provided by someone who has received training on PADs and how to facilitate such a process for a person with a mental illness. Other forms of advance planning tools (e.g. joint crisis plans, crisis cards, advance agreements, treatment plans, wellness recovery plans) will not be covered in this review. The interactions between health care professionals and service users are different for PADs compared to other advance planning tools, as the power distinctions are different. In a situation where there are power differentials between different stakeholders, it is quite conceivable that the 'voice and desire' of the service user can be lost. PADs give the service user the greatest level of autonomy to have his/her wishes heard and respected. We endeavour to explore the controversies surrounding the legal backing of PADs, and whether this presents more barriers at a particular level (service user level, health professional level, or system level).

Methods

Search strategy. We conducted a systematic search in the following databases: PubMed, PsycINFO, and Cochrane Library. Search terms included: advance
directives, advance directive adherence, advance statements, advance agreements, Ulysses AND psychiatry, mental health services/legislation, mental competency, commitment of mental illness, crisis intervention. We also systematically searched through reference lists of included studies to identify any additional references for potential inclusion that our searches might have missed (See Figure 1)

**Inclusion Criteria.** We restricted our search to inclusion of papers focusing on PADs (facilitated and non-facilitated), and we did not include studies on any other type of advance agreements or treatment planning tools. As studies in this field are often not conducted as randomized controlled trials, we broadened our inclusion criteria to include qualitative studies. We included studies as long as at least 50% of the sample population reported having a mental illness. We included primary data and did not include reviews in the analysis. Included studies were restricted to English.

**Exclusion criteria.** We excluded studies if they: focused on a sample population with predominantly physical health conditions or cognitive impairment (Alzheimer’s, dementia); focused on enduring powers of attorney; focused on other forms of advance planning tools (i.e. anticipatory psychiatric planning, joint care plans, joint crisis plans, crisis cards, and advance care planning).

**Study selection.** One reviewer (LS) conducted the search and screened the abstracts of all publications obtained by the search strategy and sifted through the references to exclude irrelevant studies. Two authors (LS and SP) screened the remaining relevant abstracts to identify which papers met eligibility criteria. Disagreements were resolved by consensus and where necessary involving the third author. Records were kept for study exclusions. References were managed Reference Manager (version 11) on Windows.

**Data extraction and Study Appraisal.** Study characteristics (Study ID, setting, population characteristics, interventions and comparisons (if applicable) and outcome measures were extracted from all included studies and inputted into evidence tables in Microsoft Word. Two authors (LS and LVDH) extracted the data independently and SP checked for accuracy. LS and AVDH appraised the studies for methodological quality using a methodological checklist for qualitative studies. Disagreements were resolved by consensus or by consulting with external researchers.
Results

3853 references were identified from the search, of which 403 were assessed based on full-text. Of those, 30 were included in this review (see Table 1 for included study characteristics). Common reasons for exclusion were: the article did not highlight concerns or barriers to PADs uptake or implementation, the article focused on other types of treatment planning tools or advance agreements aside from advance directives, or the article focused on medical advance directives and not on PADs. The study flow outlining the review process can be seen in Figure 1.

Barriers were assessed at three levels: the system (both legal and health system) level, the health professional level, and the service user level. We describe the barriers at each level emerging from the evidence, as well endeavoured to capture tensions and conflicting barriers between levels.

What are the barriers to PAD implementation/uptake at the system level?

Three main themes emerged from the literature on barriers to PAD implementation at the system level (including both the health and legal system): legal liability, legal provisions to override PAD, and resource implications associated with PAD implementation.

Legal liability. Legal liability was one of the main barriers voiced by health professionals in 5 studies. The legal liability concern is two fold: First, health professionals are concerned that overriding provisions made in a PAD in line with community practice standards could result in a potential lawsuit by the service user or nominated representative (Srebnik & Russo, 2008). These findings were corroborated by 18% of professionals surveyed in a later study (Wilder et al. 2012). Second, there is a worry that if health professionals honour a PAD, it could lead to poor treatment outcomes and a potential legal liability for this poor outcome. It is interesting that these barriers were identified in studies conducted in the US, where clinicians have the legal right to override PADs if (a) the PAD is incongruent with acceptable community practice standards, or (b) if the service user poses a risk to themselves or others (e.g. high risk of suicide or violence). Results from Swanson et al. (2007) revealed that psychiatrists concerned about being sued for adverse outcomes from treatment decisions were more likely to override the PAD. In addition, psychiatrists most likely to override treatment refusals outlined in a PAD were more resigned to the necessity of involuntary treatment and held more negative views about the
availability of community-based mental health services for people with mental illness (Swanson, Van McCrary, Swartz, Van Dorn, & Elbogen, 2007).

In this same study, 48% of mental health professionals articulated that involuntary treatment would rarely be necessary if quality services were available and accessible in the community (Swanson et al. 2007). This pertains to the perceived lack of quality and accessible community-based services in that particular health care system. Should these services exist, involuntary treatment
would be infrequently required, creating less legal liability for health professionals and less need to override PADs due to involuntary treatment.

In some countries, an involuntary admission overrules a PAD. This provision in the law has been said to weaken the utility of PADs overall (Swanson et al. 2003). The laws authorising PADs are the same laws enabling health care professionals to decide to ignore PADs. In the United States, for example, the laws on involuntary treatment and admission overrule PAD laws in nearly every jurisdiction (Swanson et al. 2003). Service users in another study (Atkinson et al. 2003) held the view that unless PADs are legally binding, clinicians would not devote attention to them. This view differed from the clinician views in the same study, who stated that PADs would be unworkable if made legally binding in the United Kingdom (Atkinson et al. 2003).

Table 1. Included studies in the review

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<th>Study</th>
<th>Method</th>
<th>Country (State)</th>
<th>Sample/Stakeholders</th>
<th>Sample characteristics</th>
</tr>
</thead>
</table>
| Ambrosini et al 2008 | Qualitative interviews | Canada (Ontario and Quebec)          | Legal professionals and mental health professionals       | N=200  
N=50 legal professionals, N=150 mental health professionals |
| Amering et al 1999   | Questionnaire     | Austria                                | Mental health professionals at a university-affiliated teaching hospital | N=174 mental health professionals (N=34 psychiatrists, N=140 nursing staff) }
<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Methodology</th>
<th>Location</th>
<th>Participants</th>
<th>Sample Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amering et al 2005</td>
<td>Field observation sessions from PAD training sessions, open-ended interviews; focus groups</td>
<td>US (New York)</td>
<td>Service users interested in completing a PAD</td>
<td>N=20 in Interview Group, N=9 in Focus Group</td>
</tr>
<tr>
<td>Atkinson et al 2003</td>
<td>Focus groups; interviews</td>
<td>Scotland</td>
<td>Service users, professionals, carers</td>
<td>N=28 interviews; (N=10 psychiatrists, N=6 service users, N=4 other mental health professionals, N=3 carers, N=2 representatives from voluntary organisations, N=3 not stated interest group)</td>
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<tr>
<td></td>
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<td></td>
<td>N=17 group discussions (N=10 with service users; N=6 with</td>
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<tr>
<td>Study</td>
<td>Methodology</td>
<td>Country/Countries</td>
<td>Participants</td>
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<tr>
<td>Backlar et al 2001</td>
<td>Qualitative interviews</td>
<td>US</td>
<td>Service users and their providers</td>
<td>40</td>
</tr>
<tr>
<td>Elbogen et al 2006</td>
<td>Questionnaire</td>
<td>US</td>
<td>Mental health professionals</td>
<td>N=597 (591 in results) professionals (N=164 psychiatrists, N=234 clinical psychologists, N=193 clinical social workers)</td>
</tr>
<tr>
<td>Elbogen et al 2007</td>
<td>Follow-up data after 1 year of PAD intervention (quantitative and qualitative measures)</td>
<td>US</td>
<td>Service users with severe mental illness</td>
<td>Subpopulation from a larger project on PADS (Swanson et al, 2006) N=125 Subset for these analysis 125 participants who completed PAD via facilitation. Have had a PAD for at least 1 year to examine long-term effects of PADS</td>
</tr>
<tr>
<td>Foy et al 2007</td>
<td>Survey</td>
<td>UK</td>
<td>Service users</td>
<td>N= 58</td>
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<tr>
<td>Henders on et al 2010</td>
<td>Delphi method; questionnaire</td>
<td>US</td>
<td>Within the US Veteran Affairs Administration: Service users who have made PADs, consumer advocates who have helped others to do so, caregivers named as health care agents, clinicians support of PAD and researchers working on PAD.</td>
<td>N=55</td>
</tr>
<tr>
<td>Kim et al 2007</td>
<td>Qualitative interviews</td>
<td>US (North Carolina)</td>
<td>Service users</td>
<td>Data collected as part of a larger longitudinal RCT examining FPAD (N=469, Swanson et al 2006) N=28</td>
</tr>
<tr>
<td>Kim et al 2008</td>
<td>Online self-report survey</td>
<td>US</td>
<td>Social workers providing services to adults with severe mental</td>
<td>N=193</td>
</tr>
<tr>
<td>Study</td>
<td>Methodology</td>
<td>Setting</td>
<td>Participants</td>
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<tr>
<td>O’Connel &amp; Stein 2005</td>
<td>Self-report survey</td>
<td>US (Ohio)</td>
<td>Law professionals, health care professionals, clergy, mental health professionals, consumers, family members</td>
<td>272</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>N=64 Legal professionals; N=52 health care professionals; N=44 clergy; N=66 mental health professionals; N=32 consumers, N=14 family members</td>
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<tr>
<td>Peto et al 2004</td>
<td>Follow-up Analysis of earlier study; Online interviews via PAD program, survey</td>
<td>US (Washington)</td>
<td>Service users (outpatients) with severe mental illness</td>
<td>106</td>
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<tr>
<td></td>
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<td></td>
<td>N=106 (consists of those who completed a PAD, drawn from larger sample of N=303)</td>
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<tr>
<td>Sbrenik et al 2003</td>
<td>Interviews, and quantitative analysis of</td>
<td>US (Washington)</td>
<td>Service users</td>
<td>303</td>
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<td>Study</td>
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<tr>
<td>Scheyett, Vaughn, Francis (2010)</td>
<td>Qualitative interviews; Phone survey; part of a larger survey of North Carolina Jail administrators</td>
<td>US</td>
<td>Jail administrators N=80</td>
<td></td>
</tr>
<tr>
<td>Srebnik and Brodoff, 2003</td>
<td>Field notes from 24 structured meetings on PAD</td>
<td>US</td>
<td>Mental health professionals N=296</td>
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<td></td>
<td>N=115 outpatient participants at 2 community mental health centres; N=78 inpatient staff (nurses, social workers, medical staff, administrators) at 4 community psychiatric hospitals,</td>
<td></td>
</tr>
<tr>
<td>Srebnik and Russo, 2008</td>
<td>Interview; Chart review; Case history; Quantitative analysis of larger study sample</td>
<td>US (Washington)</td>
<td>Service users who completed a PAD and had a psychiatric crisis event post-PAD completion</td>
<td>N=303 (larger study, of which N=106 completed a PAD). This analysis focuses on N=69 of the N=106 who had at least ( N=39 ) inpatient staff from 1 state hospital, N=16 crisis service staff, including 1 triage unit, N=13 from an after hours crisis program for 2 mental health centres, N=6 crisis mental health program in a county jail, N=29 county-designated mental health professionals in 2 counties.</td>
</tr>
<tr>
<td>Swanson et al 2003</td>
<td>Interviews with service users and family members; mailed self-report questionnaire for clinicians</td>
<td>US</td>
<td>Service users with severe mental illness, family members (carers), clinicians who treat persons with severe mental illness</td>
<td>N=272 N= 104 service users; N= 83 family members; N=85 clinicians</td>
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<tr>
<td>Swanson et al 2008</td>
<td>Prospective study</td>
<td>US (North Carolina)</td>
<td>PAD completers vs non completers (service users)</td>
<td>N= 147 (PAD completers) and N=92 (PAD non-completers)</td>
</tr>
</tbody>
</table>
| clinician attitudes | Swartz et al 2006 | Follow-up quantitative analysis of F-PAD RCT | US | Service users | Additional analysis based on original F-PAD trial (N=469) (Swanson et al. 2006) to look at preferences for completed PAD

This analysis used two samples: A) Full sample with non-missing data for preference measure (N=456) B) Subsequent analyses (N=381) who were those who indicated prior to randomization that they did not already |
<table>
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<tr>
<th>Study</th>
<th>Design</th>
<th>Location</th>
<th>Participants</th>
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<tbody>
<tr>
<td>Van Dorn et al 2006</td>
<td>Survey</td>
<td>US</td>
<td>Mental health professionals (psychiatrists, psychologists, social workers) N=591 (N=167 psychiatrists, N=237 clinical psychologists, N=193 clinical social workers)</td>
</tr>
<tr>
<td>Van Dorn et al 2009</td>
<td>Researcher-administered questionnaire</td>
<td>US</td>
<td>Service users coming from a Latino background in the US and their family members and their treating clinicians N=140 (N=85 service users, N=25 family members, N=30 clinicians)</td>
</tr>
<tr>
<td>Study</td>
<td>Methodology</td>
<td>Country</td>
<td>Participants</td>
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<tr>
<td>Varekamp 2004</td>
<td>Qualitative interviews</td>
<td>Netherlands</td>
<td>Service users and carers, psychiatrists</td>
</tr>
<tr>
<td>Wilder et al 2007</td>
<td>Mailed self-report or online questionnaire</td>
<td>US</td>
<td>Mental health professionals</td>
</tr>
<tr>
<td>Wilder et al 2012</td>
<td>Internet based self-report questionnaire</td>
<td>US</td>
<td>Administrators, Clinicians, Consumers, Family Members, Advocates</td>
</tr>
</tbody>
</table>
Difficulty communicating about PADs. There were 4 studies identifying difficulty with communication between staff working in clinical settings once PADs are accessed (Kim et al. 2007; Kim et al. 2008; Srebnik & Brodoff, 2003.; Van Dorn et al. 2006). These studies found that mental health professionals in the United States (US) were concerned about how staff could access PADs, how crisis/inpatient staff would know whether someone has a PAD, how the PAD would be made available, and who informs the crisis/inpatient staff that a service user has a PAD (Van Dorn et al. 2006; Kim et al. 2007). For example, 66% of health professionals in one study cited this as a barrier between different cadres of staff (e.g. between emergency room (ER) and psychiatric unit) (Van Dorn et al. 2006), whereas another study found that limited communication between outpatient and inpatient providers and limited communication between outpatient and ER was a highly significant barrier perceived by both consumers and non-consumers (on a scale of 1 to 9, 1 being highly significant barrier, 9 = insignificant, this barrier received a mean score of 2.4 (1.7) and 2.3 (1.6) respectively) (Henderson, Jackson, Slade, Young, & Strauss, 2010).

Resource implications. A third barrier concerns resource implications resulting from PAD implementation. This was primarily expressed in terms of taking into account the time that PADs will cost to complete. Different stakeholders (71% of administrators and 52% of clinicians) believed clinicians will not have sufficient time to help consumers with severe mental illness understand and complete PADs, or manage the extra paperwork they perceived to be associated with PADs (57% and 48%, respectively) (Wilder et al., 2012). Logistical difficulties (e.g. storing and retrieving PADs at the critical time, incorporating PADs into routine documentation and making them easily accessible) was another system-level barrier identified by 25% of respondents in O’Connell & Stein’s study (O’Connell & Stein, 2005). In another study, 80% of the sample showed little confidence in the ability of institutions (e.g. clinics, hospitals) to have a system in place to facilitate access to PAD information (Backlar et al. 2001).

What are the perceived barriers to PAD implementation/uptake at the health professional level?

Lack of knowledge and training. A lack of knowledge and awareness about PADs among mental health professionals emerged as one of the most frequently cited barriers in the literature, both from the health professional and service user perspective. O’Connell and Stein (2005) found that 55% of health professionals had never heard of PADs, and only 11% considered themselves “very familiar”
with PADs. (O’Connell & Stein, 2005) Similar results emerged from another study finding that 37% of health professionals correctly answered the question that the PAD statute in North Carolina does not require a clinician to follow a patient’s advance refusal of treatment inconsistent with community practice standards (Elbogen et al. 2006), showing that 67% of health professionals were therefore not familiar with PAD-relevant provisions in the law. O’Connell and Stein (2005) found that health professionals in the region which did not receive PADs education had significantly higher scores on the Obstacles to Success scale compared with informants in the pilot region (who received PAD education) ($p < .001$) (O’Connell & Stein, 2005). Thus, health professionals who received training on PADs perceived fewer obstacles to PAD implementation.

Six studies (Amering, Denk, Griengl, Sibitz, & Stastny, 1999; Van Dorn et al. 2006; Ambrosini, Crocker, Perreault, & Israël, 2008; Kim et al. 2008; Wilder et al. 2012) found that between 29% and 54% of health care professionals had prior knowledge of PADs. The extent of PADs knowledge appears to differ by health care professional, as social workers and nursing staff had more PADs knowledge compared to psychiatrists and psychologists (Amering et al. 1999; Van Dorn et al. 2006). Furthermore, inpatient and outpatient clinicians received less training compared to inpatient and outpatient administrators (30% and 100%, respectively (Wilder et al. 2012). More administrators (100% of inpatient and 88% of outpatient) had heard of the relevant law governing health care decisions in the US compared to clinicians (67% of inpatient and 62% of outpatient) (Wilder et al. 2012). However, administrators working in specialized mental health contexts (e.g. prisons) reported limited knowledge of PADs; only 10% of administrators surveyed in one study reported having any knowledge of PADs (Scheyett, Vaughn, & Francis, 2010). Finally, emergency care and inpatient care providers having limited knowledge of PADs was cited as a significant barrier to PAD implementation (on a scale of 1 to 9, 1 being highly significant barrier, 9 = insignificant, this barrier received a mean score of 1.7(0.9) and 1.9 (1.1) respectively) (Henderson et al. 2010).

**Fear of complete treatment refusals.** Mental health professionals in two studies expressed concern that PADs will be used by persons with mental illness as a tool to refuse all treatment (Backlar et al. 2001; Srebnik & Brodoff, 2003). In one study this was articulated as a fear that PADs might be used to refuse either all medications or hospitalizations, which could compromise treatment (Srebnik & Brodoff, 2003). Another study found that 45% of professionals believed that the benefits of PADs could be outweighed by the disadvantages of a patient...
potentially using PADs to refuse medications (Elbogen et al. 2006). Professionals who accepted and emphasized service user autonomy were most likely to follow a PAD where treatment was refused (Elbogen et al. 2006). In two studies (Kim et al. 2008; Van Dorn et al. 2006) 41% of psychiatrists, 36% of psychologists, and 33% of social workers believed that there could be a risk of violence arising from treatment refusal in a PAD, determined by their agreement on a scale assessing obstacles to PADs implementation. In this same study, 51% of psychiatrists, 44% of psychologists and 31% of social workers believed that inappropriate treatment requests in a PAD would constitute a substantial barrier.

*Fear that PADs will interfere with clinical aspects of care.* Several studies found that health professionals felt PADs could interfere with various aspects of care. For example, 31% of mental health professionals in one study agreed with the statement that people with mental illness would not take responsibility for updating their PAD over time (O’Connell & Stein, 2005).

Health professionals also appeared to fear that once a PAD is completed, the service user will not be able to change their mind and update their PAD, compromising care and clinical outcomes (Kim et al. 2008; O’Connell & Stein, 2005; Van Dorn et al. 2006). To illustrate, 96% and 81% of crisis staff and inpatient clinicians (Wilder et al. 2012) and 55% of psychiatrists, 46% of psychologists and 48% of social workers (Van Dorn et al. 2006) surveyed believed that the service user would request to change their mind about PAD content in a crisis, posing a barrier to PAD implementation. Related to this was the fear that the service user will not be able to receive “current” or “up to date” treatment as they are bound to the outdated treatment listed in the PAD (Srebnik & Brodoff, 2003).

*Professionals’ reluctance to facilitate PAD.* Srebnik & Brodoff found that mental health professionals were reluctant to spend a substantial amount of time to create PADs with service users (Srebnik & Brodoff, 2003). This is likely linked to health professionals’ worry that they may influence the PADs process, as well as service user choices articulated in a PAD. This was found in a qualitative study conducted in the Netherlands (Varekamp, 2004). Fourteen percent of mental health professionals highlighted that it would be difficult to help people fill out a PAD in an unbiased manner (O’Connell & Stein, 2005). Front line workers’ resistance towards sharing power with the service user (Kim et al. 2008) and reluctance to work with PAD models allowing service users to opt out of
treatment (Atkinson, Garner, & Gilmour, 2004) were also mentioned as barriers to professionals facilitating PADs.

**Concerns about service user capacity.** Three studies found mental health professionals to be concerned whether service users have decisional capacity to complete a PAD and make treatment decisions (Srebnik & Brodoff, 2003; Swanson et al. 2007; Wilder et al. 2012). Ninety percent of professionals surveyed thought that a service user might be too psychotic during a crisis to remember to notify staff that they have a PAD. Accordingly, patient insight was among the most important facts that clinicians considered when deciding whether or not to support patient preferences (Wilder et al. 2012).

**What are the perceived barriers to PAD implementation/uptake from the service user perspective?**

**Trust.** One theme emerging from the service user perspective was trust. Several studies cited that service users did not have someone they trust enough to make a decision on their behalf. This translates to electing someone as a surrogate decision maker, a healthcare power of attorney, or appointing a nominated representative to make decisions as stated in an advance directive. The lack of having someone to trust is also associated with a low preference for surrogate decision-making, another barrier mentioned in two studies (Swanson et al. 2003; Swartz, Swanson, van Dorn, et al. 2006). To illustrate, 43% of service users did not feel they had someone they could trust to help them complete a PAD (Van Dorn, Swanson, & Swartz, 2009). Service users expressed that they had limited trust in their health care professional (Swanson et al. 2003; Swartz et al. 2006). In one Dutch study, 11% of service users did not trust their mental health providers enough to draw up a Ulysses directive\(^4\) (Varekamp, 2004). This distrust was related to the doubt that PADs would have any treatment effect (Swartz, Swanson, van Dorn, et al. 2006; Van Dorn et al. 2009).

**Lack of support.** Lack of support from others (e.g. from health care workers) was also mentioned as discouraging access, completion or demand for PADs in 3 studies. One study found that 24% of the population found it hard to get help with a PAD (Swartz et al. 2006). Elbogen et al. (2007) found that 94% of those

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\(^4\) The authors define a Ulysses directive as a subset of PADs, where a client with recurrent psychiatric episodes not yet deemed dangerous provides permission in advance for admission and treatment, thus forfeiting the right to refuse them. The key issue with Ulysses directives is the notion of irrevocability (Varekamp, 2004).
surveyed indicated they would be unable to complete a PAD without assistance or having a facilitator (Elbogen, Swanson, Swartz, et al. 2007). The tendency to support PADs can directly influence the interest level of the service user. In one study, case managers’ support for PADs was positively related to service user interest in PAD (Srebnik et al. 2003).

*Lack of knowledge of PADs.* Another main barrier that emerged was a lack of knowledge and information about PADs, how to complete a PAD, and what to put in a PAD. This lack of knowledge and information could stem from limited access to PADs. There was a general lack of knowledge among service users and their carers about the existence of a PAD, how PADs could benefit them and their treatment, and how to access a PAD once the service user is interested. For example, as little as 9% - 58% of service users were aware of the existence of PADs (Foy, Macrae, Thom, & Macharouthu, 2007; Swanson et al. 2003; Van Dorn, Swanson, Swartz, Elbogen, & Ferron, 2008). The comparative figures for advocates and carers was 72% and 52%, respectively (Van Dorn et al. 2008).

*Understanding and completing a PAD.* Some service users (56 and 50% of those sampled) had problems with understanding and comprehending the PAD (Swartz, Swanson, van Dorn, et al. 2006.; Van Dorn et al. 2009). Once interest is expressed, some service users were uncertain as to what to write or articulate in a PAD (Foy et al. 2007; Swanson et al. 2003; Van Dorn et al. 2009). Some also felt that PADs posed too much of a burden, expressed by 79% of clients interviewed in one study (Van Dorn et al. 2009). Finally, four studies (Foy et al. 2007; Swanson et al. 2003; Swartz, Swanson, van Dorn, et al. 2006.; Van Dorn et al.2009) highlighted a reluctance to sign legal documents, which is necessary when signing legally binding PADs.

*Fear of health professionals negative attitudes.* Service users mentioned that a key barrier was getting their health care professional to actually use and access the PAD they had completed. A follow-up study on a randomized controlled trial found that among participants with PADs who experienced episodes of decisional incapacity, only 35% reported being aware that a clinician had read their PAD (Swanson et al., 2008). These tie in with the notion that patients are afraid or reluctant to tell their doctor they even have a PAD. One study found that service users were apprehensive to tell their doctor they have a PAD (Elbogen, Swanson, Swartz, et al. 2007), whereas in another study, discomfort was expressed in even mentioning the existence of a PAD, for fear of a negative response from the doctor or involuntary treatment during future
hospitalisations (Kim et al. 2007). Health professionals’ negative attitudes towards PADs in general was rated by both service users and professionals as a significant barrier (on a scale of 1 to 9, 1 being highly significant barrier, 9 = insignificant, this barrier received a mean score of 3.4 (SD=1.4) (Henderson et al. 2010). Service users went on to further express that they were afraid to inform hospital staff they had a PAD for fear of not being paid attention to, or receiving a punishment for broaching topics such as seclusion and restraints. Service users were reluctant to approach their doctor in the first place in another study, fearing rejection (Amering, Stastny, & Hopper, 2005). A later study found that service users communicated the fear that clinicians might intimidate them during a psychiatric crisis, deterring them from introducing their PAD (Kim et al. 2007).

Revocability and enforceability of PADs. Service users who were uncertain about what to document in a PAD expressed a higher preference for irrevocability (Swartz et al. 2006). In another study, 74% of participants were concerned about the enforceability of PADs and whether they carried any legal weight (Srebnik & Russo, 2008). Building on this, participants in the same study worried about the legal validity of PADs, particularly as to whether the remaining parts of a PAD were still legally valid if health care professionals had overridden others (Srebnik & Russo, 2008). Conversely, in one Dutch study, all 18 service users interviewed mentioned that a specific disadvantage of the Ulysses directive is being committed to something agreed on in periods of decisional capacity (Varekamp, 2004).

Discussion

This review aimed to capture the barriers to psychiatric advance directive uptake and implementation from a broad group of stakeholders within the research literature. The purpose of conducting such a review was to better understand the barriers blocking the uptake of PADs and implementation despite high demand and extensive advocacy. The results from this review point to a number of barriers expressed at the system, health professional and service user level.

Capacity as a barrier to completion of PADs? The discrepancy between the interest in and completion of PADs have been attributed to a wide range of barriers such as the service user’s understanding of PAD documents, scepticism about whether PADs will be beneficial, and difficulty obtaining proxy decision-
makers (Swanson et al. 2003). Health professionals felt that a service user’s competency to complete a valid PAD could be a barrier. This is despite nearly all service users in a number of studies being able to complete a valid PAD (for example, Backlar et al. 2001; Peto et al. 2004). In low-resource settings like India, it is possible to complete a PAD, both facilitated and independently, even when service users have active symptoms (Kumar et al. 2012). In this particular Indian pilot study, 65% of service users completed a PAD without assistance, 29% required prompts, and 6% required assistance to write the PAD (Kumar et al. 2012). This study lends support to the view that decisional incapacity is not an ‘all or nothing’ phenomenon, but rather a fluctuating occurrence throughout the course of mental illness (Patel & Bloch, 2009). PADs embrace the idea of decisional incapacity as a transitory phenomenon, as they are specifically intended for completion during a period in which the service user has decisional capacity, to plan for periods when they may experience decisional incapacity.

**Legal tensions and impact on PAD use and implementation.** In many states in the US, involuntary care or admission gives the health professional the right to ignore or overrule PADs. The paradox with this provision is that a PAD is most valuable precisely in crisis situations and in situations when the person is not in a position to make decisions. If PADs are overruled in these situations, what is the motivation for service users to write a PAD? The basic philosophy that laws enable this to happen points to a sort of discriminatory practice towards people with mental illness. The objective of having a PAD is that in times of crisis, when a person with a mental illness lacks decisional capacity, the PAD and preferences come into effect. It is therefore counter-productive to overrule a PAD precisely in the times that it’s intended to be utilised. There is also an inconsistency between medical advance directives and PADs – while medical advance directives enable someone to refuse potentially life-saving procedures based on personal reasons, this logic is not applied to PADs (Atkinson et al. 2003). Medical treatments can be refused based on personal beliefs (based on emotional decision-making rather than on scientific facts) or based on religious beliefs (e.g. Jehovah’s Witnesses refusing blood transfusions) and persons with mental illness are often not offered a similar option for refusing specific treatments, even when the PAD is written in periods when the person has full decisional capacity. In this light, the law’s ability to override competently made decisions made by persons with mental illness can be seen as discriminatory (Atkinson et al. 2003). It is not the case however that all mental health professionals want to overrule PADs that refuse some form of treatment. In Wilder et al. (2007), a number of mental health professionals endeavoured to honour their patients.
wishes outlined in a PAD, particularly if the PAD presents evidences of conventional medical reasoning behind treatment refusal. The study points to the notion that mental health professionals are more sophisticated in their decision making as opposed to automatically overriding treatment refusals (Wilder, Elbogen, Swartz, Swanson, & Van Dorn, 2007). Furthermore, clinicians do have a responsibility to act in the best interests of the service user and society, particularly if the service user is harmful to themselves or others and may require treatment.

In other countries, where involuntary commitment legislation may not always overrule PADs, legal formalities and processes may reduce the attractiveness and accessibility of PADs. For example, in the Netherlands, findings show respondents were content with self-binding directives, despite the complex and time-consuming procedure. Several advantages were highlighted, such as more autonomy and empowerment for the patient; more trust in health care professionals; a better bond between the patient and psychiatrist; more responsibility for one’s own life, and treatment and protection against deterioration and serious harm. Many respondents were afraid that admission would actually be too late due to the legal formalities (in the Netherlands, requirement of a court decision beforehand) (Berghmans & Van der Zanden, 2012).

The difference between advance directives and other types of advance agreements lies inherently in the fact that it is the expressed wish of the person with mental illness which is legally binding, which ultimately offers substantial autonomy to the service user (Atkinson et al. 2003). Furthermore, a legally binding PAD may require both competence and consideration about potential risks, whereas a non-legally binding agreement often requires a discussion with health professionals and service users and their carers, and involves more agreement and compromise. Non-legally binding types of advance agreements potentially offer less perceived risk to health care professionals (and have more of a focus on communication and collaboration). Legally binding PADs are perceived to potentially impose restrictions on the influence of the health professional by offering more power to the service user in the client-patient relationship (Atkinson et al. 2003). However, Atkinson and colleagues (2003) comment that service user autonomy is only supported so far as health care professionals accept their client’s preferences. It may be imperative to change both service user behaviour and health professional behaviour (Atkinson et al. 2003). Wauchope (2011) suggests that the amount of legal weight attributed to
PADs constitutes a complex issue and requires more debate (Wauchope, O’Kearney, Bone, & Urbanc, 2011).

Provisions for PADs in global mental health legislation. Another consideration is that a number of countries have outdated mental health legislation, and close to no laws in low and middle-income countries (LMICs) offer the option of PADs. Although the legislative barriers were not mentioned in the literature, it is important to highlight. This is particularly relevant in LMICs, where the absence of mental health legislation means that advance directives are not offered as a support tool in mental health care settings. It is crucial that a strong policy and legislative framework is in place (and implemented) as a backbone to support treatment and care structures in a country. Another potential consideration not exclusive to LMICs but poignantly so is that in order to optimally implement PADs, a strong public health system and linkages are necessary, as well as good continuity of care (Thara & Rameshkumar, 2012). It is therefore important that the provisions for PADs and strategies to enable completion and uptake are adapted to reflect the local health, legal and social context (Thara & Rameshkumar, 2012). As an example, the current Mental Health Care Draft Bill in India specifically covers the issue of liability, serving as an example of overcoming the barrier of legal liability expressed by mental health professionals.

Furthermore, the roles and responsibilities that health professionals hold and the extent to which individual rights and principles such as autonomy vary by both context and by country. For example, in some states in the US, health professionals are required by law to discuss the topic with service users, while in India the draft Mental Health Care Bill does not mandate PADs but offers it as an option for service users. Underlying this are also differentiations in prioritising autonomy and individual rights, which differ between Western and non-Western countries. In non-Western contexts and in more collectivist societies, the smallest autonomous unit is often the family as opposed to the individual (Alem, Jacobsson, Lynöe, Kohn, & Kullgren, 2002; Hanlon, Tesfaye, Wondimagegn, & Shibre, 2010). This means that family members are often responsible for their family member’s ongoing mental health care (Hanlon et al. 2010) and thus are key stakeholders in facilitating and assisting their relative with a mental illness in drafting a PAD. These types of differing support structures and contextual factors impacting autonomy need to be viewed in light of provisions for, and facilitating access to, PADs. One study in India found that there was strong evidence of coercion; 73% of relatives believed that electroconvulsive therapy (ECT) would have been administered by professionals with force even if they had refused
(Hanlon et al. 2010; Rajkumar, Saravanan, & Jacob, 2006). This highlights the importance of mental health sensitization for both families and service users in such contexts, to communicate the added value of creating a PAD.

**Health professional and service user tensions as a barrier to PADs use and implementation?** A key finding in this review is that there are underlying power differentials between health professionals and service users when it comes to PADs uptake and implementation. Particularly in countries like the United States, ultimately the health professionals decide what is best and hold an effective veto over the PADs through the use of involuntary care. On a more fundamental level, it appears that health professionals exhibit reluctance to acknowledge autonomy and rights particularly in the context of PADs, and especially when the service user having autonomy has legal backing, impacting the role of health professionals. This becomes particularly problematic when the reluctance of the health professional discourages PADs use and completion overall among service users who could benefit from more involvement and say in their treatment and care. However, undeniably, health professionals face a number of ethical dilemmas with regards to balancing service user autonomy with duty of care, which needs to be appreciated.

Despite the worry that PADs may be used to refuse some or all treatment, a number of studies report that service users do not refuse all treatment. Several studies (Amering et al. 2005; Elbogen, Swanson, Swartz, et al. 2007; Kim et al. 2007) found that none of the participants refused all treatment, or refused very few treatments, and Kumar et al (2012) found that out of 92 PAD completers, all wanted to continue treatment, while Reilly and Atkinson (2010) found that only one person refused all treatment (out of 55 PADs) completed in Scotland (Reilly & Atkinson, 2010). In fact, Swartz et al (2005) found that service users placed the highest value on continuity of care, doing so by taking treatment recommendations of their doctors (Swartz et al. 2006). This interest in following treatment recommendations sharply contrasts with the fears of health professionals that a high proportion of patients will use PADs to refuse recommended treatment. This is also supported by studies showing that treatment preferences were consistent with practice standards over 95% of the time PADs were reviewed (Srebnik et al. 2005; Swartz et al. 2005).

From the service user perspective, another issue is the degree to which the service user wants their doctor involved in drafting a PAD (Ambrosini, Bemme, Crocker, & Latimer, 2012). Service users can sometimes complete a PAD in order to limit the doctor’s freedom to make decisions (Atkinson et al. 2004). Health
professional involvement in PADs may therefore depend partially on the level of trust in the doctor and dynamics arising from prior interactions (Laugharne & Priebe, 2006). Scheyett and colleagues in the US found that social workers struggle with power, responsibility and professional tensions that exist between using PADs and supporting autonomy of their clients (Scheyett, Kim, Swanson, & Swartz, 2009). From the health professional side, if PAD implementation barriers are to be reduced, it must be acknowledged that there may be valid reasons for mental health professionals to be reluctant to change their established practices and alter their responsibilities to embrace PADs (Backlar, 1997). Yet, years after Backlar’s critical observation, Wilder et al. (2012) found that still, only 24% of administrators and 5% of clinicians in American outpatient facilities assist service users with PADs completion (these figures translate to 35% and 0% in inpatient facilities) (Wilder et al. 2012). It seems therefore that despite the advocacy for PADs and existing legislative framework for PADs, the anticipated widespread benefits of PADs have yet to materialize, largely in part due to the aforementioned barriers and the lack of buy-in from health care professionals (Amering et al. 2005; Atkinson et al. 2004; Backlar et al. 2001; Miller, 1998; Srebnik & Brodoff, 2003.; Swanson et al. 2007; Swanson et al. 2003). In an effort to further action on PADs implementation and acceptance, we attempt to synthesise a number of potential solutions to the barriers we examined in this review.

Potential solutions to perceived barriers. A number of barriers can be overcome with critical reflection and a deeper knowledge and understanding of the basic utility of a PAD for service user empowerment and autonomy. For example, lack of support and concerns from health professionals that additional time is required to help patients complete PADs could be tackled by offering facilitators or peer support workers to facilitate and assist with completing a PAD, as has been demonstrated in studies evaluating the efficacy of facilitated psychiatric advance directives (Elbogen, Swanson, Appelbaum, et al.2007; Swanson et al. 2006)). While facilitated PADs can be seen as resource intensive, one solution could be to utilise non-professional health workers or support workers as a facilitator. Henderson and colleagues (2010) found that service users preferred a non-medical setting for an advance directive (Henderson et al. 2010). A more recent study in the Netherlands found that quality aspects (completeness and specificity) of crisis plans were better when the plan was facilitated by a patient advocate than by a clinician alone (70% vs. 57% completion rate, respectively) (Ruchlewska, Mulder, Van der Waal, Kamperman, & Van der Gaag, 2012). Patient advocates confirmed that a completion rate of 70% was consistent with crisis
plans facilitated outside of a controlled trial setting. Using non-health professionals to facilitate crisis cards was also found to be effective in the Netherlands (Van der Ham, Voskes, van Kempen, Broerse, Widdershoven, 2013). This solution reduces burden on health professionals, offers opportunities for informal support in the care process, while offering therapeutic benefits for the client and carer and enabling autonomy and increasing PADs completion to match high demand from service users. Facilitation can reduce a number of the reported barriers (Peto et al. 2004; Van Dorn et al. 2006) especially system-level barriers such as hampering clinician time, interfering with care, and reluctance from the service user side to approach their doctor about a PAD.

In terms of accessibility to PAD at the systems level, having information systems in place (e.g. computerised medical records that will alert the present of a PAD) seem a promising route to making PADs more accessible, however, this does not influence the reluctance or attitudes of mental health professionals to use PAD or see them as valid documents. This may be a significant barrier in under-served settings or in countries where there is a poor public health information management system. However, working on attitude changes and acceptance of PADs by mental health professionals needs to happen simultaneously with investing in a information system to store/retrieve PADs (Srebnik & Russo, 2008).

One way to solve the lack of knowledge and awareness of PADs is brief, practice-based training programmes targeted at sensitising a broad range of health and law stakeholders on the utility and implementation of PADs (e.g. social workers, administrators, community health workers, general practitioners, psychiatrists, psychologists, lawyers, judicial officers, policymakers). Increasing awareness of tools like PADs could additionally help reduce stigma as they improve perceptions around the capacity of people with mental illness to be involved in their treatment (Wauchope et al. 2011). Training can also help service users and health professionals to understand the conditions under which PADs can be optimally used, as well as conditions where PADs need to be overridden.

While effective strategies need to be realised in order to alleviate barriers, future research exploring these strategies requires some thought. Perhaps PADs require more field-based and operational research in order to recognise under which conditions and in what contexts PADs can be feasible and consistently used. Practice-based trials can help to better understand what type of training benefits health professionals and service users best, whether PADs can be completed and used in non-Western contexts where autonomy is understood differently, and which logistical issues can be tackled when it comes to
communicating the existence of a PAD among different cadres of health professionals (e.g. emergency and primary care professionals). After developing a better understanding of how PADs work in systems of care in different countries, effectiveness studies will be then be more beneficial. Outcome measures could aim to focus more on service-user centred measures such as quality of life, participation in care, and empowerment post-PAD completion.

In sum, it appears that while some barriers are relatively straightforward to address (such as the lack of knowledge and training issue for service users and health professionals), other barriers, such as changes to legislation are more difficult and require more debate and input from multiple stakeholders. Changes to legislation such as laws allowing overriding PADs in the case of involuntary care will require substantial input, as it is related to attitudinal change about power equations in client-provider relationships. If the more addressable barriers are tackled, it leaves more room to negotiate and deliberate the more difficult barriers.

Limitations. There are several limitations to this review. First, it is possible that our narrow search may have missed some studies and in addition, reviewing other forms of advance planning tools (which we excluded from this review) could have yielded more studies providing insight into barriers experienced by stakeholders. Second, the methodologies in systematically reviewing both quantitative and qualitative studies need further refining and examination. It is possible that the barriers/concerns reported across the studies were the most significant themes, and others were not highlighted, as has been found in other systematic reviews of barriers in health care (Mills, Jadad, Ross, & Wilson, 2005). Third, some barriers were explicitly cited in the literature, whereas others were implicitly stated in the form of statements in a questionnaire that stakeholders agreed or disagreed with, or expressed concerns rather than explicit barriers. Thus, there is a substantial amount of variance and heterogeneity in the compilation of the barriers in this review. Fourth, all studies were from select high-income countries, primarily the UK or US, with very few studies from other middle or high-income countries and none from low and middle-income countries. Consequently, this biases our review and limits the ability to make explicit recommendations to countries with legal and health care systems different than high-income, Western countries. Fifth, generalizability beyond these studies can be seen as limited, as many papers use the same sample population or employ small sample sizes. Finally, while we assessed barriers at 3 levels, they are in actuality interlinked, and the categorization we used in this
review is in a sense quite artificial. The barriers should be viewed not as three distinct levels of barriers but rather as lying along a continuum.

Conclusion

Reviewing the barriers to PAD uptake and implementation adds great understanding to the debate on how we can develop strategies to address these barriers experienced by service users, carers, health professionals and policymakers. Evidently, tensions exist between service users and health care professionals that appear to concentrate around dilemmas concerning power relations, capacity and reluctance to use PADs. There are potential strategies that can be applied to alleviate these tensions and dilemmas, although additional research (especially field-based and operational research) will be useful to capture the processes and challenges experienced in clinical practice as well as point to best practices in countries with existing PAD provisions.

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Part 4

Chapter 9

Unpacking the psychiatric advance directive in low-resource settings: an exploratory qualitative study in Tamil Nadu, India
Unpacking the psychiatric advance directive in under-served settings: An exploratory qualitative study in Tamil Nadu, India

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Abstract

Background

Psychiatric advance directives, a tool to document preferences for care in advance of decisional incapacity, have been shown to benefit persons with mental illness in a number of countries through improving medication adherence, reducing symptoms from escalating in a crisis, accelerating recovery, and enhancing service user autonomy and empowerment. While concepts such as autonomy and empowerment are important in a number of high-income country settings, it remains unclear whether tools like psychiatric advance directives are suitable in a different context. The recent introduction of the psychiatric advance directive into draft legislation in India prompts the question as to how feasible psychiatric advance directives are in the Indian context. The aim of this study is to explore the feasibility and utility of PADs in India, with a focus on the need for individual control over decision making and barriers to
implementation, by analysing views of the central stakeholders, service users and carers.

Methods

Qualitative semi-structured interviews (n=51) with clients (n=39) and carers (n=12) seeking mental health treatment at outpatient clinics in urban and rural settings in the Chennai area, Tamil Nadu, India.

Results

Clients engaged in a number of forms of decision-making (passive, active, and collaborative) depending on the situation and decision at hand, and had high levels of self-efficacy. Most clients and carers were unfamiliar with PADs, and while some clients felt it is important to have a say in treatment wishes, carers expressed concerns about service user capacity to make decisions. After completing PADs, clients reported an increase in self-efficacy and an increased desire to make decisions.

Conclusions

The introduction of psychiatric advance directives in India appears to be associated with positive outcomes for some service users, however, there is a need to better understand how this tool can be adapted to better suit the care context in India and hold meaning and value for service users to complete.
Background

Globally, the way we perceive disability is changing, from seeing persons with disabilities as objects of charity to subjects with rights, capable of claiming these rights and participating actively in society [1]. Article 12 of The Convention on the Rights of Persons with Disabilities (CRPD) (Equal Recognition before the Law) is representative of this paradigm shift, stressing that systems should shift from models of plenary guardianship to models of supported decision-making to enable persons with disabilities to exercise their legal capacity. Legal capacity includes access to the civil, political and juridical system, legal independence to speak on one’s behalf, autonomy to make choices, and support to make these decisions where necessary [1]. However, persons with disabilities are not always able to exercise their legal capacity, thus there is a need for tools to enable supported decision-making.

Psychiatric Advance Directives (PADs) are a legal tool for recording and implementing preferences in advance of periods of decisional incapacity [2]. PAD’s outline personal choices (finances and housing), preferences for care, and/or the appointment of a proxy decision maker (nominated representative). These preferences can be expressed independently or with support from facilitators, including health professionals or peer support workers (e.g., see Swanson et al., 2006). PADs could potentially mitigate the risks of coercive treatments to persons with severe mental illness during vulnerable periods when their autonomy is most compromised.

PADs in high-income countries such as the US and UK are associated with restoring service user autonomy and empowerment, as well as improved medication adherence, reducing escalation of symptoms in a crisis, increase satisfaction with treatment, accelerating recovery, and enhancing dialogue with health care professionals [3–6]. However, autonomy and empowerment are not necessarily the most dominant principles in many low and middle-income countries (LMICs), where cultural emphasis centres more on reciprocity, family, community, and joint decision-making [7]. In many LMICs, for example, the family often assumes the role of decision-maker, instead of the individual, responsible for ongoing mental health care [8].

This is also the case in India, where mental health care often aims to do what is best for the family [8, 9]. This is also embedded in India’s Mental Health Act of 1987, which recognises the importance of family as the primary decision-makers; however this system has been criticised as it leaves the potential for
family members to abuse these decision-making powers [8]. Currently, a new Mental Health Care Bill (2013) has been cleared for parliamentary review. The revised Bill adopts a more rights-based approach to care and has made an explicit provision for PADs as a way to promote supported decision-making. While the draft law in India could empower persons with mental illness, there are substantial barriers to overcome, most notably sparse finances and human resources as well as a lack of awareness among health care workers, families and service users about ethical frameworks, weakening the value of available tools for protection of human rights of persons with mental illness [8].

In this article, we describe initial experiences with a trial of PADs in India; a tool that previously has not been used in cultures that espouse family rights over individual decision-making rights. It can be anticipated that many barriers occur while implementing PADs, thus it is crucial to explore the perspectives of stakeholders to understand the feasibility and utility of PADs [10]. Therefore we specifically aim to explore the feasibility and utility of PADs in India, with a focus on the need for individual control over decision making and barriers to implementation, by analysing views of the central stakeholders, service users and carers. This aim raises several questions relevant to the Indian context. First, what underlying beliefs concerning decision-making do service users hold? Second, what do service users and carers think about the concept of PADs? Third, can a tool originally developed as a way to exercise autonomy be valued and used in the Indian context? Fourth, does completing a PAD have any impact for service users?

Methods

Design

This qualitative study was part of a larger study assessing the feasibility and utility of PADs India, including the process and content of PADs. This study presents the results from interviews conducted before and after completing a PAD with clients and carers.

Sample and Setting

The study was conducted at outpatient clinics run by the Banyan, a non-profit mental health services organisation, in Chennai and Kovalam, Tamil Nadu, India. A random sampling method was used to select clients attending routine outpatient clinics at three sites (one rural clinic, two urban clinics). We stratified
the sample by gender and location (i.e. equal numbers of clients living in urban and rural settings).

Clients were included in the study if they were diagnosed with a mood disorder, psychosis, or schizoaffective disorder (with or without active phase symptoms) and the client was able to understand, speak, and or/write in Tamil or English. Participants were excluded if they had a diagnosis of mental retardation, organic psychosis, or comorbid alcohol and/or substance abuse, as well as any person acutely ill to the extent that it would be unethical to have them participate in the study. In the results, we use the term clients to reflect the study sample accessing services at The Banyan, whereas the term service user is used throughout the remainder of the text.

Data collection

A total of 51 semi-structured interviews took place between March and June 2013, carried out by 2 masters-level trained researchers. Both researchers received training on PADs by a psychiatrist (SP), and additional, context specific, qualitative research training. Interview guides and concepts to be used in the interviews were translated from English to Tamil and back translated to English to ensure concepts retained the same meaning during translation. A translator carried out interviews in Tamil, which were audio recorded, and translated into English. Interviews were carried out in three phases with different samples. Prior to introducing PADs, 26 interviews were conducted with clients to explore notions of decision-making (Part 1 of this study). Then, clients and carers (n=25) were interviewed on their knowledge and attitudes towards PADs (Part 2). Third, after completing a PAD, 18 clients (of 26 interviewed in Part 1) were interviewed on the perceived impact of PADs. As the other clients were not available for a follow-up interview (n=8) post-PAD completion, it was only possible to interview 18 clients. Interviews post-PAD completion was carried between 1-8 weeks after PAD completion to allow time for reflection (depending on the client’s next scheduled appointment at the outpatient clinic). A training programme was conducted to train PAD facilitators working at the implementing service organisation. The participants of the training programme were all health workers at The Banyan (case managers, social workers, psychologists, nurses, psychiatrists). These facilitators assisted in PAD completion, if requested by the client.

Ethical Considerations
Local ethical approval was obtained for this study from the external research review committee for the Banyan. Consent to participate in the interviews and to complete a PAD was obtained and recorded from every participant either through signature on informed consent forms, or by thumbprint. To ensure confidentiality during the data analysis, names were replaced with unique ID codes. Furthermore, identifying factors associated with the interviewees were omitted from the data analysis and from this paper.

Analysis

For clients, basic demographic and clinical characteristics were collected and tabulated (age, sex, gender, and diagnosis, if known). Basic demographic characteristics (age, sex, gender, relation to relative with a mental illness, urban/rural location) were collected for carers. These demographics were available through client records maintained by the organisation.

For the qualitative data we used a thematic analysis approach [11]. The coding process consisted of several stages. Stage one involved two researchers familiarising themselves with the interview data. Stage two entailed two researchers independently coding the data inductively, creating a list of emergent codes. Codes were generated, collated, and refined into themes relevant to the research questions. A third researcher independently coded the interviews as an additional quality check. Disagreements were resolved through discussion or involvement of a fourth researcher on the project team. All interviews were analysed in MaxQDA, version 11 [12].

Results

The majority of clients were between 18-49 years of age, while the majority of the carers were over the age of 60. Males and females, and urban and rural living contexts were equally represented across clients and carers (see Table 1).

Notions of decision-making

PADs aim to enhance control over decisions and choices related to daily life and health care. Prior to the introduction of PADs, clients reflected on their ability to make decisions in their lives. From the interviews, a number of themes emerged: self-efficacy, control over circumstances, and types of decisions made.
Table 1. Characteristics of clients (n=39) and carers (n=12)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Phase 1: Client interviews (N=26)</th>
<th>Phase 2: Client interviews (N=13)</th>
<th>Carer interviews (N=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (male)</td>
<td>N=12</td>
<td>n=6</td>
<td>N=6</td>
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<tr>
<td>Age group</td>
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<tr>
<td>18-29</td>
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<td>2</td>
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<td>30-39</td>
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<td>40-49</td>
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<td>50-60</td>
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<td>60+</td>
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<td>1</td>
<td>6</td>
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<tr>
<td>Living environment (rural)</td>
<td>13</td>
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Clients conceptualised self-efficacy as setting goals and attaining them. All clients have had periods in their lives where they experience high levels of self-efficacy regarding their personal lives and medical needs i.e. feeling committed to achieving a particular goal, capable of making decisions, and influencing their circumstances. In addition, all clients, irrespective of gender, felt motivated about attaining a state of good health, “getting well”, and, recovery. Clients who felt highly self-efficacious were also more likely to feel that they possessed the ability to make decisions independently and achieve goals.

“I think I can accomplish any goals I have in life, I have confidence in myself that I can achieve them” [ID 19, Female, Client]

Yet, a number of clients, women and those living in rural areas in particular, felt they had low levels of self-efficacy, especially regarding setting individual goals. Women often set goals driven by family matters, such as ensuring family cohesion, well-being, and taking care of educational and marriage arrangements for their children. Seven clients,
mostly women, indicated that they had never thought of setting individual goals. Clients also talked about “leaving behind” goals or decisions they wanted to pursue, largely due to pressure from family, or symptoms from their mental illness. In practice, this was described as having to leave a job due to recurrent symptoms or relapse, not having funds to send their child to school, or wanting to pursue a career but having a career choice decided for them by family members. Some clients thought that goals only pertained to “larger” goals, and did not consider smaller, more mundane attainable goals.

“I have no goals in my life. When I was young I had a lot of goals..I wanted to get my own house and I wanted to be very happy. But now I do not have any goals of that sort, the only goal I have is to get my son married. There are no other goals, I just left all that I had before” [ID 12, Female, Client]

The degree to which clients made decisions independently was again context-specific, where, across the interviews, the type of decision appeared to determine the level of required support or consultation with others. Clients described engaging in three forms of decision making: active (operationalised as making decisions independently), passive (choosing to hand over decision-making powers to someone else for a particular decision) and collaborative forms of decision-making (joint decision-making).

“I make decisions for myself, and do not depend on anybody else. Although I discuss decisions with my sons, I make decisions for myself. I got my sons and daughter educated, got them a job, and got them married. This is a very big achievement and very important decisions I’ve made in my life.” [ID 11, Female, Client]

“I usually make decisions for myself, but in the middle of my life when I was in a psychological depression, I approached another person for decisions and suggestions. Usually, I make my own decisions and it has always been like this for me. When I make decisions, and I am concerned about whether my choices are right or wrong, then I ask for suggestions from my friends and family” [ID 8, Male, Client]

“I do not take any kind of decisions individually, I consult with my husband and we make decisions together” [ID 14, Female, Client]
Five clients (all women) felt unable to make decisions independently or jointly, often due to their guardians (families) making decisions on their behalf without consulting them. Barriers to decision-making were attributed to dominant family members, or distress that impeded the ability to make decisions clearly. All clients described that there were few perceived barriers to sharing their preferences for care with family and/or health care professionals they frequently consulted with at the Banyan. Similarly, all clients described moments when they negotiated aspects of their care or daily living activities with others. This involved consulting with health care professionals, family or friends about their personal problems they were experiencing, particularly in relation to their mental illness (e.g. side effects from medication, tensions with the health care worker, working conditions).

“I take the courage to talk with others and tell the doctor what I am feeling, even when I feel like I can’t. I take courage to do this because I think that I need treatment to be fine, so I discuss everything” [ID 14, Female, Client]

Fourteen clients (of 26) currently felt in control over circumstances (described as being in control over thoughts, emotions, and reactions), especially over their health and treatment adherence, both at present and in the future. Despite accounts of low self-esteem and goal-setting behaviour, women described feeling in control over circumstances. Lack of control was attributed to the internal factors arising from their mental illness, either related to symptoms, or lack of confidence at the time to control emotions. External factors were also discussed as leading to loss of control, such as low-income or unanticipated life events (losing property or money). Poverty led many (n=17) to feel not in control of resources (food, transportation, resources required to get a job, study, marry), contributed to low self-esteem, and made it difficult to envision goals. This led clients to feel sad and tense. A minority of clients felt no necessity to control situations, believing that it is not possible to control their fate:

“I wanted to get my own house for myself, but then situations were such that things did not happen the way I wanted. Situations were very bad, now I have lost a lot of money because of that, and the situation was out of my control. I still had the courage to make decisions, but I still did not feel that the situation was in my control” [ID 12, Female, Client]
Clients felt more stable and in control when receiving care (e.g. medication or counselling), as it equipped them with a better understanding of the situations occurring in their lives, and stabilised their emotions:

“Now, since I am receiving treatment, I feel better and able to control situations. I used to feel very angry, upset and very depressed... Had I taken treatment at the time [of an incident from his past] I could have controlled the situation and handled it better” [ID 23, Male, Client]

What are the perceptions of PADs among clients and carers (families)?

Awareness of PADs

Clients were either unaware of PADs or its use, or were unable to describe and interpret the purpose of the PAD. Yet, all clients described situations in which they had been asked about their treatment wishes (for example, if they would like to see a particular doctor, or if they liked their medication).

“I’ve been asked about what medicine I prefer to take. I’ve been asked this every week, whenever I come here [to the outpatient clinic]” [ID 27, Female, Client]

Similarly, 11 (of 12) carers were largely unaware of the existence of PADs, with only one carer saying she had heard about PADs during a monthly meeting for clients and carers at the Banyan.

Attitudes towards PADs

Clients were asked about whether they felt they should have a say in their treatment and whether they would hypothetically like to have a PAD. Ten clients were ambiguous in their responses, with only one client explicitly liked the idea of having a PAD:

“It would be better if the doctor asked me, and I have a say. I think that since I have an education, I can give projections on how I feel and how and what kind of treatment I prefer to have, but I have not been asked on that. The doctor doesn’t ask me, but I think the doctor should ask.” [ID 32, Female, Client]

Two clients stated PADs would be helpful both for treatment plans and as a way to encourage empowerment. However, they indicated that it is ultimately the
doctors’ decision to determine treatment, and did not feel that one “should” have a say in their own treatment:

“How can I decide on the treatment? The doctor has to decide that. The doctor knows whatever he is doing and I do not have a problem with it and I’m fine with it. I think it’s fine even if I am not asked about my opinion about my treatment wishes” [ID 36, Female, Client]

Carer views on service user capacity

Only one carer felt her mother should make decisions about her own treatment. This carer attributed her mother’s capacity to make independent decisions to her recovery. In the past, her mother was unable to make independent decisions due to the severity of her mental illness; however, since recovery, her decision-making abilities evolved:

“I want my mother to fill in the PAD document, because if she can express her wishes better then it’s good for her. It can help her in recovery. Because my mother has already worked as a nurse, she knows better about injections and treatment and all that. She knows better about taking treatment, so it is better if she is the one who fills the PAD document” [ID 5, Female, Carer]

Six carers were uncomfortable with the idea of their family member having a PAD and having a say in their treatment. Two primary reasons for this emerged from the interviews: Carers felt PADS were not useful and would not bring any additional sense of control to clients, or carers felt their family member had limited or no decision-making capacity. Other carers articulated that clients could make smaller decisions independently but were dependent on others for larger decisions:

“I don’t think she [client] should be given a say, because she will not know what will happen in the future and she will not be able to decide on what kind of treatment would be good for her in the future” [ID 3, Male, Carer]

“Even the small decisions, he [client] consults with me [mother], and he depends on me whether he wants to go out or not, so he is not able to take decisions individually. He is always dependent on me” [ID 2, Female, Carer]
“She’s not capable at all [of writing a PAD]. She was once [capable], but now it’s just not as good as it was some five or six years back. I don’t think she would be able to express her wishes, or that she’s capable… Her ability is not to that extent.” [ID 1, Male, Carer]

Interestingly, while clients themselves felt able to make decisions, especially about future care and treatment, it appears that carers did not always share this view. However, seven carers felt capable to assist their relative/friend in writing a PAD. Nonetheless, carers indicated they require support from health care staff as they have limited knowledge on the illness and treatment options.

**Perceptions about health care workers adhering to PADs**

Most of the clients (9 of 13) and carers (9 of 12) receiving care at The Banyan expected health workers to follow wishes and preferences, if documented. However, when asked to envision whether health care workers in other services (outside The Banyan) would adhere, the reaction was less positive, as there was a general sense of mistrust (based on previous negative experiences) in other care providers adhering to treatment wishes.

**Client perceptions after PAD completion**

Of the 18 clients interviewed after completing a PAD, 13 were able to articulate their treatment decisions independently without support from carers. Sixteen (of 18 clients interviewed post-PAD completion) felt that the PAD helped improve their abilities to make decisions about future treatment and feel more self-efficacious, and felt that the process of developing a PAD was easy. Sixteen clients articulated that they were able to openly express their preferences to the facilitator, and knew what kind of care they wanted to receive:

“I was able to express my preferences freely, I expressed everything, whatever medicines or tablets or counselling I am taking, or would like to take, freely to the counsellor. Before filling the PAD I did not feel this way, but during filling out the PAD I felt it was important because I felt that others have to know what I am thinking about the treatment I am taking. So, I thought the PAD is important to fill and safe for me to fill out” [ID 24, Female, Client]

However, while the PAD helped to fuel confidence in decision-making about care and treatment, it did not appear to additionally help clients with feeling more confident about decision-making in other domains.
“I cannot take decisions in my life, but treatment is different, because I know what kind of medicine is good for me, what treatment is good for me, I can take decisions on that. But life decisions are different, I always have to depend on my husband and I don’t have anybody else, it is good that I actually consult my husband and decide. I think I can make [treatment] decisions, but it is difficult to make life decisions, I see both as different” [ID 14, Female, Client]

Two clients felt PADs should only be reserved for people capable of answering questions posed by the PAD facilitator. The majority (16 of 18) felt happy with the opportunity to document what they wanted from care in their PAD, and appreciated that their wishes were inquired about:

“You asked me some very relevant and important questions in the PAD, which other people don’t ask. If you go to other doctors they want to treat you according to the way they want. And you got some very valuable information on what sort of treatment I would prefer and what treatment I would not.. what sort of doses and medication and what is useful and what is not..Writing the PAD is quite thoughtful, and down the line..it will help me to make some choice in case I need hospitalization or I need to be at a good place..or need different or more treatment...I think, definitely it could help other people to complete a PAD..I think a PAD would be helpful. I think it will be helpful if people have a say in their own life” [ID 21, Male, Client]

Overall, emerging from the interviews, PADs were found to have positive impact in 3 main areas: increased self-confidence, increased motivation to participate in treatment choices, and restoring perceived control over circumstances.

“I think writing the PAD will help me have control over future treatment, because I wrote it like a will, for my safety in the future. I liked it and think it will help me have control” [ID 2, Female, Client]

The PAD was mentioned to be important to secure future care, safety and health, and facilitate the process of speaking out about preferences, which was motivating for clients. Specific to treatment, PADs were found to be helpful in highlighting the importance of preventing relapse, and adhering to treatment more than before. The interviews revealed two negative associations with PADs. The first was the PAD served as a reminder of painful memories from past experiences, and the second was scepticism about the value and utility of completing a PAD and whether it would be used in future care. The latter
experience was linked to the feeling that the PAD was just a series of ‘answering of questions’, or redundant to document preferences and decisions that would otherwise be allocated to carers or health care professionals.

“I don’t know if it [the PAD] is important for me. Because I now know that only in the future the PAD might be implemented. I only gave answers because I was asked questions, so I don’t think it is very important” [ID 8, Male, Client]

Discussion

The aim of this study was to explore the perspectives of clients and carers to understand the feasibility and utility of psychiatric advance directives in India. To do this, we explored notions of decision-making, knowledge and attitudes towards PADs, and whether completing a PAD had any impact on clients with mental illness.

We found clients generally had high levels of self-efficacy, which is a facilitating factor for completing PADs, as clients can concretise their self-efficacious behaviour and link it to future actions and decisions. Self-efficacy was compromised by the loss of control over decisions and resources. This loss of control appeared to impact the client’s sense of stability, and was exacerbated when experiencing active symptoms of mental illness. In spite of this, we found that many clients remained motivated and able to achieve goals despite the adversity endured throughout their trajectories (e.g. domestic violence, homelessness, poverty). Although this study did not explicitly highlight client trajectories, the Banyan generally caters to populations afflicted with a number of adverse life events such as poverty, homelessness, and violence. In this regard, this population can be seen as representative of a lower socio-economic background compared to a previous study examining the feasibility of PADs in a population with a higher socio-economic status [13].

Furthermore, our findings indicate that service users engage in a number of forms of decision-making (active, passive, collaborative) depending on the situation. In India, decision-making roles (e.g. about food, education and employment) are often situated within pre-determined norms in society. It is thus important to contextualise decision-making and decision-making powers. For example, choosing to give up decision-making powers to a relative in India can be a decision in itself. Therefore it is not that clients do not make decisions, rather, the operationalisation of a decision in some domains is different compared to the context in which PADs were originally developed.
Nevertheless, within these pre-defined roles, we observed that some, but not all clients felt they had the space to exercise their decision-making capacity with varying degrees of support. The reasons for reluctance or inability to make decisions remains unclear, thus it is important to find out the barriers to making decisions (i.e. is it that they are unaware of how to demand the right to articulate decisions, reluctance to take responsibility for this decisions) etc. In order to alleviate these barriers, prior to introducing PADs, the dialogue between health care workers, staff, and clients should be opened up.

The finding that carers had a negative view of service user capacity to articulate preferences and decisions demonstrates the importance to work with carers in developing strategies to help support their relative to make decisions, even if only in certain domains. This is in contrast to findings from another study on PAD in India, which found carers to be very supportive of PADs [13]. The role of family in PADs is a delicate one, as carers may influence preferences articulated in a PAD, or may lead to tense relations if the client and carer preferences differ. However, the role of the family is an important one to consider and discovering a way for involving carers in the PAD process constructively is essential.

Overall, our findings show that PADs are promising for some clients, but in order to increase the value of the tool for clients in India and ensure smoother implementation of PADs in practice in light of the new Mental Health Care Bill, it needs to be adapted to better suit the local context. Prior to this, a number of barriers will arise to adaptation and implementation of this tool. First, the current state of the public health system is fragmented, particularly at the systems level. In a pluralistic health context like India, where it is common to concurrently use services from a number of practitioners from different systems of medicine (e.g. faith-based and biomedical practitioners), it is still unclear how a PAD will be coordinated and honoured across multiple care platforms. Our study is based in an organisation emphasising service user involvement, thus clients may have been more open to such a tool, which differs from processes in the public health system. Furthermore, barriers at the professional level could impact PAD uptake in India. The hierarchical structure of doctor-patient relationships in India means that consultations are often dominated by the doctor’s knowledge, and the client is subordinate [14]. In this type of interaction, clients may be reluctant in expressing preferences for fear of insulting the doctor, or doctors may be hesitant to use PADs for fear of compromising their status or power. On a conceptual level, one thread interwoven throughout all interviews was the difficulty of navigating through culturally-constructed
concepts and placing these concepts into context. It was apparent across interviews that the struggle to identify with concepts related to PADs made it difficult to see the value and meaning of PADs or link them to future outcomes. We observed a mismatch between local conceptual formulations compared to the values and principles underscoring a PAD (e.g. autonomy) as well as PAD-related outcomes (e.g. quality of life). In order for PADs to become more meaningful and useful for clients a better understanding of cultural formulations, and how these attributions relate to decision-making is required.

There are several limitations of this study. While this study population is representative of clients coming from a low socio-economic background with mental health problems, the standard of care this population received is not representative of the broader help-seeking population. The clients in this study received a good standard of care from a private, non-profit organisation emphasising service user involvement, which may have translated into clients being more positive about services, and made them more receptive and open to the introduction of PADs as compared to other care contexts. Second, there was variation in the way health workers facilitated PADs; at times, the PAD was used more as a checklist during consultations rather than as a tool to encourage decision-making. Providing additional training on different aspects of PADs could alleviate this. Thirdly, relying on translated interviews potentially poses a threat to the validity the results, as there were semantic miscommunications, specifically with regards to concept formulation between English and Tamil. To mitigate this, the translator participated in the PAD training and had regular evaluations and discussions with the research team on interview style and concepts. Finally, there may have been a social desirability bias inherent in the interviews. Social norms in India foster politeness and agreement; thus disagreement is rare, for fear of being disrespectful or fear that negative answers may compromise care.

There are several future research avenues for PADs in India. First, it would be interesting to delineate how PADs can be meaningful in India, and what areas in life are PADs most useful for. Second, it is necessary to understand the skills necessary to enable dialogue between health professionals, carers, and clients to encourage decision-making, especially given the hierarchical relationship between providers and clients. Third, exploring the perceptions of implementing PADs in India from the lens of a health professional is important. Finally, it would be interesting to compare the feasibility of PADs in a public health context, such as a primary health care centre or tertiary government-run hospital.
Conclusions

In summary, if adapted to suit the local context, the PAD could potentially have meaning and value for some persons with mental illness in India, particularly in situations where the voice of the service user is masked by family or health care professionals. Our findings show preliminary evidence that the PAD could be beneficial for some service users, specifically in increasing self-efficacy and desire to engage more in decision-making. Our exploratory study highlights some intriguing areas for further exploration and consideration by practitioners and researchers, particularly developing strategies for translating the concepts underscoring a PAD to the Indian context.

Competing interests

The authors declare that they have no competing financial interests. SP is a member of the National Task Force for the National Mental Health Policy, Ministry of Health and Family Welfare, Government of India, and has been involved in the drafting of the new proposed mental health legislation, commissioned by the Ministry of Health and Family Welfare, Government of India.

Authors' contributions

LS and SP designed and managed the study. SDMZ and SD collected and analysed the data and contributed to writing the results of the manuscript. LS SDMZ and SD were responsible for data analysis. LS was responsible for drafting the manuscript. LS SP JGFB were responsible for conceptualisation of the manuscript. All authors reviewed the manuscript, and all authors have read and agreed on the final manuscript.

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References

[Accessed on 1 April 2013]
Part 4

Chapter 10

What do service users want? A content analysis of what users may write in psychiatric advance directives in India
What do service users want? A content analysis of what users may write in psychiatric advance directives in India

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Abstract

Background
Although psychiatric advance directives give service users control over their care, very few studies exist on the content of PADs. This paper aims to contribute to this evidence base by presenting the content of psychiatric advance directives in India.

Methods
Participants were 75 clients seeking outpatient care at a mental health services organisation in Tamil Nadu, India, who agreed to draft a PAD.
Results
Most clients were comfortable with appointing a representative (usually a family member) to make decisions on their behalf during a period of decisional incapacity or relapse, were willing to accept admission to the hospital/clinic and take medication if required, wanted to have a trusted person to discuss their mental health problems. No client used the opportunity to outright refuse treatment.

Conclusion
This study highlights an important first step in improving the quality of mental health care by documenting user preferences for care in India. More in-depth research is needed to elicit rich descriptions of experiences of care and user-centred understanding of rights.

Keywords:
Psychiatric advance directive, care preferences, India

Introduction
The United Nations Convention on the Rights of Persons with Disabilities (CRPD) has encouraged a shift from dominant models of guardianship to models of supported-decision making in a number of mental health laws worldwide. Central to the notion of supported decision making is Article 12 of the CRPD, which states that all persons with disabilities should be provided support, where needed, to exercise their legal capacity in all domains of civil, political and judicial life. This includes the right to make decisions about health care and treatment processes, and have them respected by professionals.

Psychiatric advance directive (PAD) is one tool to facilitate supported decision-making. PADs are a tool for recording and implementing service user preferences in advance of periods of decisional incapacity throughout the course of mental illness (Campbell and Kisely, 2009; Henderson et al., 2008). PADs can either be instructional (e.g. specify treatment and personal decisions while in a period of decisional incapacity) or elect a nominated representative (proxy decision maker) to take decisions during this period of incapacity. Furthermore, preferences can be expressed and articulated independently or via a facilitator (typically a health worker or peer support worker). PADs can enhance dialogue between health care professionals, family members, and service users, improve treatment adherence & continuity of care, and reduce
the likelihood of hospitalization and coercive care (Elbogen et al., 2007; Jankovic et al., 2010; Srebnik et al., 2005; Swanson et al., 2006).

Globally, although a sizeable evidence base exists on the benefits and barriers to PAD implementation and use (Henderson et al., 2008; Shields et al., 2013a) we know very little about the content of PADs (Srebnik et al., 2005), with only two studies conducted in the US (Amering et al., 2005; Srebnik et al., 2005) one study in India (Kumar et al., 2012) (Kumar et al., 2012) which detail the content of PADs. Understanding the information provided in PADs is important for anticipating future service user needs, as well as for broader service planning. Furthermore, from the service delivery side, instructions articulated in a PAD may shape individual care, and patterns identified across PADs could shape or catalyse the need for adaptations/different services and policies (Srebnik et al., 2005).

India is one example of a LMIC currently undergoing mental health legislation reform. The revised Mental Health Care Bill (Ministry of Health and Family Welfare Government of India, 2013) adopts a more rights-based approach to care and has made an explicit provision for PADs as a way to promote supported decision-making. The draft legislation provides for a PAD where a service user can a) specify the type of treatment a service user may want b) the type of treatment a service user may not want and c) the person the service user wants to make decisions as a nominated representative (proxy decision maker).

However, as the reform is current, research on PAD implementation in scarce in India, given that is it a relatively new concept in both scientific and academic discourses. There have been two studies from the state of Tamil Nadu (Kumar et al., 2012; Shields et al., 2013b), which have documented completion of PADs and unpacking the concept of PADs with service users. However, there has been anxiety amongst mental health professionals about PADs, including how the process of completing and using a PAD will work, whether it will become a barrier to care and treatment (Kala, 2013; Sarin et al., 2012). Doubts have also been expressed whether PADs are appropriate for the Indian service and cultural context.

In order to implement PADs in a contextually relevant way that is feasible for service users to demand and complete, additional evidence is needed to facilitate conceptualization, operationalization and application of PAD in India. It is unclear whether patterns exist in PADs, and if so, what direction these patterns point to. In an effort to build the PAD evidence base in India and within
LMICs and to provide a voice to service users in care planning, the aim of this paper is to present the content of psychiatric advance directives created by outpatients in Tamil Nadu, India.

**Methodology**

**Design**

This paper was part of a larger study assessing the feasibility and utility of PADs in India, including the process (Shields et al., 2013b) and content of PADs. This study presents the analysis of content of PADs documented by clients.

**Sample and Setting**

**Study location**

PADs were completed in outpatient clinics run by The Banyan, a non-profit mental health service organization in Chennai, Tamil Nadu, India. The Banyan runs services throughout the state of Tamil Nadu, largely concentrated in the city of Chennai and provides a full range of services including preventative services, community-based care, tertiary care, rehabilitation and re-integration, community awareness, and policy advocacy.

**Recruitment and sampling**

Clients enrolled in the study were existing outpatients in The Banyan. Clients receive combinations of pharmacotherapy, psychotherapy, and social care at two urban clinic sites, and one rural clinic site. From March 2013 to June 2013 during outpatient clinic times, health workers trained as facilitators screened clients who were 18 years of age or older. Clients who had been diagnosed with a severe or chronic mental illness such as bipolar disorder, recurrent mood disorder, psychosis or schizoaffective disorder and were able to understand speak, and or/write in Tamil or English were included in the study. The clinic does not maintain formal ICD-10 diagnosis but uses working clinical diagnosis made by the treating psychiatrists. Clients having a diagnosis of mental retardation, or organic psychosis, and those having acute form of illness, which made their participation difficult, were excluded during screening. To include clients in the study, the research team consulted with the psychiatrists at the Banyan to assess current symptoms and capacity. Selected clients were then asked if they would be interested in completing a psychiatric advance directive after being briefed by the health worker. The sample was stratified by gender.
and location (i.e. equal numbers of clients living in urban and rural settings). This was done to ensure that clients living in rural areas and women (who are often underrepresented) were offered the opportunity to write a PAD.

**Training and procedure**

Before commencing the study, health workers (case managers, social workers, psychologists, psychiatrists) at the Banyan were trained for facilitating PADs. The training program focused on providing basic information about PAD, its relevance for clients and staff, methods for facilitating the PADs, and how they are used. This training was expected to equip the facilitator (health worker) to introduce the PAD to the client, communicate its potential value to the client, and guide the client through the process of writing a PAD during the outpatient consultation or at an agreed upon time. For facilitating the PAD, we used PAD forms. On request, trained facilitators assisted clients in writing the PAD. Depending upon literacy level, clients either wrote their PAD or dictated their preferences to PAD facilitators.

**Data collection and statistical analysis**

Demographic information (age, sex, rural/urban living situation, marital status) and clinical characteristics of the clients were collected from the carers as well as from the clinical records of the clients. Data was extracted from PAD forms and entered in SPSS. Contents of the PAD forms were analysed by using MaxQDA.

**Ethical Considerations**

We received local ethical approval from the external research review committee for The Banyan. Consent to participate in the interviews and to complete a PAD was obtained and recorded from every participant either through signature on informed consent forms, or by thumbprint. To ensure confidentiality during the data analysis, names were replaced with unique ID codes. Furthermore, identifying factors associated with the clients were omitted from the data analysis and from this paper. Patient records and completed PADs were only accessible for staff working at The Banyan and the core research team.

**Results**

Throughout a 3-month period, 83 clients were approached to complete a PAD, of which 75 clients agreed. The 8 clients who refused or could not complete a PAD were largely from urban areas (n=7), female (n=6), and could not complete
either a PAD due to the severity of their mental illness at the time of request (n=5) or were not interested (n=3). There were no significant differences between service users who completed PAD versus those who did not complete a PAD. The majority of PAD completers were female, with a low educational status and based in a rural living environment.

Table 1. Sample characteristics (n=75)

<table>
<thead>
<tr>
<th>Variable</th>
<th>N(%) or Mean(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years</td>
<td>38.7(10.9)</td>
</tr>
<tr>
<td>Sex (female)</td>
<td>44(58.6)</td>
</tr>
<tr>
<td>Geographical setting (rural)</td>
<td>43 (57.3)</td>
</tr>
<tr>
<td>Education level*</td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>5</td>
</tr>
<tr>
<td>Up to VIIth Standard</td>
<td>22</td>
</tr>
<tr>
<td>Up to Xth Standard</td>
<td>24</td>
</tr>
<tr>
<td>Up to XII Standard</td>
<td>9</td>
</tr>
<tr>
<td>Up to Graduation</td>
<td>6</td>
</tr>
<tr>
<td>Diploma holder</td>
<td>2</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>6</td>
</tr>
<tr>
<td>Bipolar Disorder</td>
<td>4</td>
</tr>
<tr>
<td>Schizophrenia and/or Psychosis</td>
<td>7</td>
</tr>
<tr>
<td>Alcohol Dependence</td>
<td>4</td>
</tr>
<tr>
<td>Social Anxiety Disorder</td>
<td>1</td>
</tr>
<tr>
<td>Personality Disorder</td>
<td>1</td>
</tr>
<tr>
<td>Number of clients currently taking medication regularly</td>
<td>70 (93)</td>
</tr>
</tbody>
</table>

*Indian education system classification
N.B: Missing data; Education n=7

*Discussing their mental health concerns with their social networks*
Clients were asked if they preferred to discuss their problems related to their mental illness with others, or keep it to themselves, of which the majority (n=67) preferred to share their thoughts and problems with their social networks. Most clients wanted to have a discussion on a regular basis (e.g. once a week, or four to five times a month). Examples of people they would like to share their experiences within included their family members, the community mental health workers, their assigned psychiatric social worker, to a counselling psychologist, or with friends.

**Appointing a nominated representative**

Approximately 84% of the sample (n=66) wanted to appoint someone else to make decisions on their behalf during a period of decisional incapacity, compared to 6 clients who preferred to make decisions on their own. Nearly all PAD completers indicated an immediate family member as their nominated representative (n=62, 82.6%).

In addition, all clients were comfortable and did not express hesitation in talking to their nominated representative about their mental health problems and symptoms.

**Who should make the decision to admit to a hospital?**

Of the 75 clients completing a PAD, 70(93.3%) recognised the need to be taken to a clinic or a hospital to see a doctor during a period of decisional incapacity, and the majority (n=29, 38.6%) wanted to have this decision made by a nominated representative.

The content analysis pointed to a number of consistently stated ‘alert signs’ that professionals and social networks should be aware of to prompt urgent care, or to anticipate a period of decisional incapacity, such as: ‘unable to take decisions on my own’ ‘wandering’ ‘hitting my family member or pets’ ‘not interacting with anyone’ ‘if my anger or tremors increase’ ‘if I create problems in my community’ ‘if I talk too much to myself, laugh to myself’ ‘if I’m unable to sleep’

**Following recommendations**

One theme across the PADs was adherence to the health care professionals’ advice on admission to the hospital, and treatment suggestions. This was not exclusively related to the doctor (psychiatrist) but in relation to other health care professionals as well. This willingness to follow recommendations provided by health care professionals was cited most frequently as ‘whatever the doctor
recommends/prescribes, because I want to get better’. The majority of clients stated that during a period of decisional incapacity, they would adhere to their health care professional’s recommendation to be admitted to the hospital, if necessary. This was cited most for decisions concerning medication or hospitalisation preferences. While admitted to the hospital, 72 would agree to counselling and/or medication in the hospital, and an additional two clients recognised the need for inpatient treated but preferred to be taken to a specific clinic based on prior positive experience (i.e. The Banyan’s clinic) or wanted to base the decision on economic conditions at the time of admission, which is related to the financial out-of-pocket payments required for private inpatient care. One client would not agree to treatment in the hospital, preferring outpatient care instead.

**Medication preferences**

At the time of PAD completion, 70 clients were currently taking psychotropic medications. Interestingly, none of the PAD completers refused medication all together. A number of clients expressed preferences for specific medications when hospitalised (n=13), and three clients articulated that they wanted to continue their existing medication regime even while in the hospital. However, the majority of clients (n=37) did not indicate a preference for a particular kind of psychotropic medication once hospitalised, or were comfortable with their doctor’s judgement. As the aim of this question was only to obtain an understanding of comfort with taking psychotropic medication, explanations behind the preference for a particular medication was not elicited. Of the PAD completers who articulated that they preferred a specific medication, they related it primarily to having an ‘allergy’ to another kind of medication (n=6) or to minimising side effects after having a negative prior experience with a particular kind of medication (n=25): ‘I don’t like medicine that makes me very sleeping’ ‘[please don’t prescribe] medicines which cause drowsiness’. That being said, the majority of clients did not have a preference or problem with receiving an injection if hospitalised.

**Table 2. Content of PADs**

<table>
<thead>
<tr>
<th>PAD content</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you like to appoint a nominated representative?</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>66(88)</td>
</tr>
<tr>
<td>No</td>
<td>6(8)</td>
</tr>
<tr>
<td>No response</td>
<td>3(4)</td>
</tr>
<tr>
<td>Question</td>
<td>Yes</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----</td>
</tr>
<tr>
<td>Would you agree to discuss your wishes and preferences for mental health treatment with your nominated representative?</td>
<td>66</td>
</tr>
<tr>
<td>Do you want to be taken to the hospital during a relapse or a period of decisional incapacity?</td>
<td>70</td>
</tr>
<tr>
<td>Would you like to leave this decision up to your family or friends?</td>
<td>29</td>
</tr>
<tr>
<td>Preferred care setting during a crisis/period of decisional incapacity</td>
<td>32</td>
</tr>
<tr>
<td>If your health professional recommends it, would you agree to be admitted to the hospital?</td>
<td>56</td>
</tr>
<tr>
<td>Would you agree to begin treatment or take medication if required, once admitted to the hospital?</td>
<td>72</td>
</tr>
<tr>
<td>Do you have a certain preference for medication if you are admitted to a hospital?</td>
<td>13</td>
</tr>
<tr>
<td>What kind of medications do you prefer or not prefer?</td>
<td></td>
</tr>
</tbody>
</table>
Anything recommended by doctor | 21 (28)
---|---
Tablets/Pills | 31 (41)
Injections | 6 (8)
Syrup | 2 (3)
No medication, prefer counselling | 2 (3)
No specific medication | 6 (8)
No response | 12 (16)

Would you refuse any specific medications, even if the same medication is recommended by a doctor?
Yes | 7 (9)
No | 46 (61)
No response | 22 (29)

Would you be willing to consider electroconvulsive therapy (ECT) as an alternative treatment?
Yes | 30 (40)
No | 39 (52)
Yes, under certain conditions | 3 (4)

Would you consider ECT as a treatment option if your doctor recommended it for you?
Yes | 12 (16)
No | 23 (31)
No response | 40 (53)

**Electroconvulsive therapy (ECT) preference**

There were roughly equal numbers of PAD completers were willing to consider ECT as an alternative treatment (n=30) compared to those who were unwilling to consider ECT as an alternative treatment (n=39) and 3 clients who specified they would agree to ECT only under certain conditions (i.e. only if it was beneficial for their treatment progress at the time ECT is required). This was the only option on the PAD where a larger proportion of PAD completers (n=23) would disagree with their doctor if ECT were recommended compared to 12 who would adhere to their doctor’s recommendation. In the case of ECT, 31 clients preferred to have their nominated representative make the final decision, and 10 wanted to independently make the decision to have ECT. It should be noted that prior ECT experience was unknown and overall awareness of ECT as a form of treatment seemed to be low among this population.
Themes emerging from the content analysis of the PADs stated that ECT would only be considered ‘only when the doctor recommend it based on my condition’ ‘when I am violent’ ‘when I have suicidal thoughts’ ‘when I have severe symptoms like increased aggression’ ‘If there is no other way – medicine and injections don’t work’ ‘if I become harmful to others’ ‘If I completely lose my insight’ ‘if there is an emergency need’.

It should be noted that a number of the topics documented in the PAD had a high non-response rate, meaning that clients did not provide an answer to the question or document it in their PAD.

Discussion

This paper aimed to explore what service users in India may write in psychiatric advance directives. Several findings have important implications for clinical practice and for future research. First, this study corroborates the findings from studies on the content of PADs in India and the United States showing that people with severe and persistent mental illness can articulate their treatment and care preferences in the format of a PAD (Kumar et al., 2012; Srebnik et al., 2005). Second, within the PADs, no client outright refused care, in line with studies conducted in the US (Amering, Denk, Griengl, Sibitz, & Stastny, 1999) and very few disagreed with the idea of being taken to the hospital or take medication if necessary, which is in contrast with Srebnik et al. (Srebnik et al., 2003).

Compared to studies investigating the content of advance statements in mental health care (Farrelly et al., 2014), more people in this study desired to have a nominated representative and to follow recommendations made by their health care professional. This is not a surprising given the existing doctor-patient hierarchy which exists in India as well as the central role of a carer (in the majority of cases a family member) in decision-making (Kala, 2013). Similar to other studies, clients in this study made a distinction between when to prioritise autonomy in decision-making and when to defer the decision to health care professionals. This is shown in the question on the PAD about medication preferences, when the majority of clients were willing to take whatever medication the doctor recommended. However, when it came to deciding on ECT, many clients preferred to take this decision autonomously or with their carers, and not defer this kind of decision to a health care professional. 63% of clients would not refuse a medication if their doctor recommended it, whereas 31% of clients would refuse ECT even if their doctor recommended it.
Thus, the desired autonomy for decision making may vary by type of decision, in line with findings by (Adams et al., 2007). This may represent a more nuanced way of decision-making, in contrast to other contexts where clients prefer to make treatment decisions alone, or collaboratively with the health care professional (Stacey at al., 2008). However, another study (Simon et al., 2007) found that 75% of clients in their sample judged that when symptoms are too great, decision-making should be placed in the hands of professionals. This may explain why, in our sample, decisions regarding medication or hospitalisation are weighted heavily according to the doctor’s recommendation, as a client may feel that he is too ill at that stage to articulate such a decision.

There are several limitations of this study, which require consideration. First, peer facilitators who are trained to elicit client experiences and preferences for care would help offset the burden of health workers, who in a country like India with a paucity of human resources for mental health, is important to ensure use and meaning of a document like the PAD. Second, there was limited information available on prior experiences with mental health services which may have allowed for a more rich description of preferences for care and rationale for articulating certain kinds of preferences. Third, our sample is restricted to one non-profit outpatient services organisation which limits inferences of our results to other contexts; however our sample is indicative of a service user population with a low educational status which complements the sample from Kumar et al’s (2012) study on advance statements in India (Kumar et al., 2012). Fourth, our data collection was limited and a more thorough data collection period on previous care trajectories leading to care preferences is needed.

This study supports the notion that such documents could be feasible even in a resource-scarce setting like India, and are consistent with standards of care and highlights the importance of involving service user’s social network and family in the care planning process. This study serves as an initial glimpse into the voice of the service user in the Indian context. An essential next step, in line with what other authors have recommended (Amering et al., 2005; Kala, 2013; Sarin et al., 2012) is working closely with health care professionals, service users and carers to understand and review past experiences with crises, hospital admissions and medication history in the Indian context and to adapt the PAD to suit local conditions and needs. More research is warranted to obtain a more in-depth understanding of care trajectories and its influence in determining care preferences in the Indian context.

Conflict of interest
SP served as a technical consultant to the Ministry of Health and Family Welfare in drafting the Mental Health Care Bill which is currently in Parliament.

Acknowledgements

We are extremely grateful to the clients, carers and health care workers who participated in this study.

References


directives: a randomized trial of an intervention to foster advance treatment planning among persons with severe mental illness. Am. J. Psychiatry 163, 1943–51.
Part 5

Chapter 11

Epilogue

Contents of the Mental Health Care Bill
Chapter 11
Epilogue: From Science to Law and Policy

Chapter 4 of this thesis reviewed the human rights violations that many people with mental disorders face across the world. It thus set the tone for the rest of this thesis, which focused on addressing the full citizenship rights of persons with mental disorders, and proposed some strategies for promoting these rights. The aim of the chapters presented in this thesis was to help clarify some of the important concepts underlying citizenship, such as legal capacity, and how they are understood in the context of mental disorders. This led to consideration of a number of ways of enabling persons with mental disorders to exercise legal capacity, for example through supported decision making and the use of a supportive tool such as advance directives. The study, in the scientific literature and in experience from other countries, of these mechanisms and tools formed a basis for further consideration as to how they might work in the Indian context. The thesis therefore aims to contribute both to the scientific body of knowledge in this field and to the realization of practical solutions to deal with the problem of discrimination of persons with mental disorders in society. Cumulatively, the ideas and discussions reflected in its various chapters highlight the nexus of the scientific and social relevance of the research. For example, it also provided input into the new Mental Health Care Bill in India. Below, I describe how evidence derived from this research was used in the Bill as well as my own involvement in the writing process of the Bill.

The author of this thesis was appointed as a technical consultant to assist the Ministry of Health & Family Welfare, Government of India in 2010. Initially the Ministry wanted the author to prepare a brief list of essential amendments to the existing Mental Health Act, 1987 to make this existing law compliant with the Convention on the Rights of Persons with Disabilities (CRPD) (India had ratified the CRPD in 2008 and hence the urgency to amend domestic laws to comply). However over a period of 9 months, sustained advocacy by the author, activists from the mental health field and new progressive civil servants taking over key roles in the Ministry, led to the Ministry taking a decision to draft a new Mental Health Care (MHC) Bill.

The MHC Bill went through many successive drafts and underwent a wide and comprehensive consultation amongst various stakeholders in the field of mental health. The author was involved in all the consultation meetings and prepared successive drafts of the Bill based on feedback at these consultation meetings.
Even critics of the MHC Bill accept “It must be said to the credit of the government that the 3 year long process, which involved consultations over several drafts with various stakeholders like carers, users, and activists has been an inclusive and transparent one….“(Kala, 2013).

The MHC Bill has many features which are unique and a first in Indian legislation. The addition of these features has in part stemmed from their adoption and implementation across the world, some of which are highlighted below. For the first time in India, the right to (mental) health care is enshrined in law. It is worth noting that right to physical health care is not yet a legislated right in India. The MHC Bill also has provisions for Nominated Representatives (for the person with mental disorder to appoint a person of her choice to provide support in making decisions and to act as a proxy decision maker during periods of extreme decisional incapacity), provision for making an Advance Directive outlining the treatment she wants for a mental disorder, the treatment she does not want for a mental disorder and to make provisions for a nominated representative. The MHC Bill also has provisions for a quasi-judicial review of all decisions when a person is admitted to a mental health facility by a proxy decision maker in cases of extreme decision incapacity (needing 100% support). This quasi-judicial review is to be done by Board which also includes a user representative (a person with current or past mental disorder) apart from judicial and mental health professionals, care-givers and a government official and all decisions of this Board are by majority voting. The Bill has provisions for decriminalization of attempted suicide, bans seclusion of persons with mental disorder, bans ‘direct’ Electro-Convulsive Therapy (ECT) [direct ECT is ECT given without anaesthesia and muscle relaxants and is still practised in parts of the country] and protection of various rights such as right to information, right to confidentiality, right to legal aid and protection from cruel, inhuman and degrading treatment.

The author was also appointed a member of the Policy Group by the Government of India in 2011. The Policy Group was formed by the Ministry of Health and Family Welfare, Government of India to draft a National Mental Health Policy and Plan. The Policy Group has recently submitted a draft mental health policy to the Government of India. The draft Policy submitted to the Government of India includes the following in the Values & Principles section of the Policy:
Participatory & Rights based Approach

- Service users and care-givers should be involved in the planning, development, delivery, monitoring and evaluation of mental health services.
- Human rights and dignity of persons with mental health problems should be respected, protected and promoted.
- Mental health care should promote and protect the autonomy and liberty of persons with mental health problems.
- The rights of the care giver and service provider should also be respected, by ensuring good working conditions, adequate training and support.

Under the specific measurable objectives section, it states:
To ensure respect for rights and protection from harm of persons with mental health problems

In the section on Recommendations for Actions it specifically states:

Motivate and engage stakeholders from relevant sectors, in particular persons with mental health problems, carers and family members, civil society leaders and those with management and strategic implementation expertise in the development, implementation and evaluation of mental health policies, laws and services, through a formal mechanism.

The author’s work on the Mental Health Care Bill and participation in the deliberations of the Policy Group were significantly informed by the research work for this thesis. This is reflected in the rights based approach of the Mental Health Care Bill, the ‘fusion law’ like provisions for treatment when capacity is severely impaired and supported decision making is not possible and the inclusion of Advance Directives in the Mental Health Care Bill. The draft National Mental Health Policy also emphasizes a participatory and rights based approach to mental health services.

The author is thankful for the opportunity to contribute in some measure to furthering the rights of persons with mental disorders in India.
THE MENTAL HEALTH CARE BILL, 2013

ARRANGEMENT OF CLAUSES

CHAPTER I

PRELIMINARY CLAUSES
1. Short title, extent and commencement.
2. Definitions.

CHAPTER II

MENTAL ILLNESS AND CAPACITY TO MAKE MENTAL HEALTH CARE AND TREATMENT DECISIONS

3. Determination of mental illness.
4. Capacity to make mental health care and treatment decisions.

CHAPTER III

ADVANCE DIRECTIVE

5. Advance directive.
7. Maintenance of online register.
8. Revocation, amendment or cancellation of advance directive.
9. Advance directive not to apply to emergency treatment.
10. Duty to follow advance directive.
11. Power to review, alter, modify or cancel advance directive.

CHAPTER IV

NOMINATED REPRESENTATIVE
15. Nominated representative of minor.
16. Revocation, alteration, etc., of nominated representative by Board.
17. Duties of nominated representative.

CHAPTER V

RIGHTS OF PERSONS WITH MENTAL ILLNESS

18. Right to access mental health care.
19. Right to community living.

20. Right to protection from cruel, inhuman and degrading treatment.
22. Right to information.
23. Right to confidentiality.
24. Restriction on release of information in respect of mental illness.
25. Right to access medical records.
26. Right to personal contacts and communication.
27. Right to legal aid.
28. Right to make complaints about deficiencies in provision of services.

CHAPTER VI

DUTIES OF APPROPRIATE GOVERNMENT

29. Promotion of mental health and preventive programmes.
30. Creating awareness about mental health and illness and reducing stigma associated with mental illness.
31. Appropriate Government to take measures as regard to human resource development and training, etc.
32. Co-ordination within appropriate Government.

CHAPTER VII

CENTRAL MENTAL HEALTH AUTHORITY

33. Establishment of Central Authority.
34. Composition of Central Authority.
35. Term of office, salaries and allowances of chairperson and members.
36. Resignation.
37. Filling of vacancies.
38. Vacancies, etc., not to invalidate proceedings of Central Authority.
39. Member not to participate in meetings in certain cases.
40. Officers and other employees of Central Authority.
41. Functions of chief executive officer of Central Authority.
42. Transfer of assets, liabilities of Central Authority.
43. Functions of Central Authority. 44. Meetings of Central Authority.

CHAPTER VIII

STATE MENTAL HEALTH AUTHORITY

45. Establishment of State Authority.
46. Composition of State Authority.
47. Term of office, salaries and allowances of chairperson and other members.
48. Resignation.
49. Filling of vacancies.
50. Vacancies, etc., not to invalidate proceedings of State Authority.
51. Member not to participate in meetings in certain cases.
52. Officers and other employees of State Authority.
53. Functions of chief executive officer of State Authority.
54. Transfer of assets, liabilities of State Authority.
55. Functions of State Authority.
56. Meetings of State Authority.

CHAPTER IX

FINANCE, ACCOUNTS AND AUDIT

57. Grants by Central Government to Central Authority.
58. Central Mental Health Authority Fund.
59. Accounts and audit of Central Authority.
60. Annual report of Central Authority.
62. State Mental Health Authority Fund.
63. Accounts and audit of State Authority. 64. Annual report of State Authority.

CHAPTER X

MENTAL HEALTH ESTABLISHMENTS

65. Registration of mental health establishment.
66. Procedure for registration, inspection and inquiry of mental health establishments.
67. Audit of mental health establishment.
68. Inspection and inquiry.
69. Appeal to High Court against order of Authority.
70. Certificates, fees and register of mental health establishments.
71. Maintenance of register of mental health establishment in digital format.
72. Duty of mental health establishment to display information.

CHAPTER XI
MENTAL HEALTH REVIEW COMMISSION

75. Qualifications for appointment of president and members of Commission.
76. Selection Committee.
77. Term of office, salaries and allowances of president and other members.
78. Vacancies, etc., not to invalidate proceedings of Commission.
79. Staff of Commission.
81. Composition of Board.
82. Disqualification and removal.
83. Terms and conditions of service of chairperson and members of Board.
84. Decisions of Commission and Board.
85. Applications to Board.
86. Proceedings before Commission and Board to be judicial proceedings.
87. Meetings
88. Proceedings before Board.
89. Powers and functions of Commission.
90. Commission to appoint Expert Committee to prepare guidance document.
91. Powers and functions of Board.
92. Appeal to High Court against order of Commission or Board.
93. Grants by Central Government to Commission.

CHAPTER XII
ADMISSION, TREATMENT AND DISCHARGE

94. Admission of person with mental illness as independent patient in mental health establishment.
96. Admission of minor.
97. Discharge of independent patients.
98. Admission and treatment of persons with mental illness, with high support needs, in mental health establishment, up to thirty days (supported admission).
99. Admission and treatment of persons with mental illness, with high support needs, in mental health establishment, beyond thirty days (supported admission beyond thirty...
days).
100. Leave of absence.
101. Absence without leave or discharge.
102. Transfer of persons with mental illness from one mental health establishment to another mental health establishment.
104. Prohibited procedures.
105. Restriction on psychosurgery for persons with mental illness.
106. Restraints and seclusion.

CHAPTER XIII

Responsibilities of other agencies

109. Duties of Police officers in respect of persons with mental illness.
110. Report to Magistrate of person with mental illness in private residence who is ill-treated or neglected.
111. Conveying or admitting person with mental illness to mental health establishment by Magistrate.
112. Prisoners with mental illness.
113. Persons in custodial institutions.
114. Question of mental illness in judicial process.

CHAPTER XIV

Restriction to discharge functions by professionals not covered by profession

115. Restriction to discharge functions by professionals not covered by profession.
CHAPTER XV

OFFENCES AND PENALTIES

CLAUSES

116. Penalties for establishing or maintaining mental health establishment in contravention of provisions of this Act.
117. Punishment for contravention of provisions of the Act or rules or regulations made thereunder.
118. Offences by companies.

CHAPTER XVI

MISCELLANEOUS

119. Power to call for information.
120. Power of Central Government to issue directions.
121. Power of Central Government to supersede Central Authority.
122. Power of State Government to supersede State Authority.
123. Special provisions for States in north east and hill States.
124. Presumption of mental illness in case of attempt to commit suicide by person.
125. Bar of jurisdiction.
126. Transitory provisions.
127. Chairperson, members and staff of Authority, Commission and Board to be public servants.
128. Protection of action taken in good faith.
129. Act to have overriding effect.
130. Power to make rules.
131. Power of Central Authority to make regulations.
133. Power of State Authority to make regulations.
134. Laying of rules and regulations.
135. Power to remove difficulties.
136. Repeal and saving.
Chapter 12
Discussion & Conclusions

This chapter will conclude this thesis by presenting the main findings of my research and discussing their implications for future work and practice. The discussion is guided by my broad research question:

**What are the barriers to implementing full citizenship rights for persons with mental disorders in India and what strategies and opportunities can be identified to move towards a more rights based system for persons with mental disorders in India?**

The process of answering this question began with an overview of the relationship between mental health and human rights, and a review of human rights violations and discrimination that occur worldwide towards people with mental disorders (Chapter 4). The research then continued with a review of mental health legislation in Commonwealth countries to understand the extent to which the content of mental health laws discriminate against people with mental disorders (Chapter 5) and a study of the practice of marriage law (Hindu Marriage Act) in Indian courts to understand how judicial practices also discriminate against persons with mental disorders (Chapter 6). This subsequently led to the development of several strategies which could be proposed at the legislative level and professional level to prevent discrimination towards people with mental disorders, in particular, acknowledging the legal capacity of persons with mental disorders (Chapter 7-10). The findings from each of these parts of my thesis are described below their respective sub-questions.

1. **Are people with mental disorders treated as persons with rights?**

Part I of this thesis reviews the scenario with respect to the rights of persons with mental disorders in low and middle income countries. It shows that stigma and discrimination lead to pervasive human rights violations against persons with mental disorders and that denial of legal capacity is central to human rights violations across the world.

Marginalisation, exclusion and discrimination against people with mental disorders were identified by respondents as the most common human rights
violation, followed by denial_RESTRICTION of employment rights, physical abuse/violence and inability to access effective mental health services. Respondents also identified settings (environments) where violation of human rights of persons with mental disorders occur. In descending order of frequency, these were identified as general community settings in everyday life followed by home and family settings, workplace settings and psychiatric institutions & mental health services. This highlights that human rights violations happen in everyday life and nearly all settings.

Empowerment of users of mental health services was suggested by respondents as one of the strategies to address discrimination. To promote empowerment at the individual level, efforts need to focus on ensuring that people with mental and psychosocial disabilities are able to exercise their legal capacity in line with article 12 of the CRPD.

The other strategies identified by respondents to address human rights violations of persons with mental disorders included running information, public awareness and anti-stigma campaigns, better training for mental health professionals and increased funding for mental health services, rehabilitation and participation of persons with mental disorders and implementing effective laws to protect and promote the human rights of persons with mental disorders.

2. Do the content of laws discriminate against people with mental disorders and if so, how?

Part II of this thesis reviewed the content of mental health legislation across Commonwealth countries (including India). The review showed that legislation in many Commonwealth member states is not compliant with the Convention on Rights of Persons with Disabilities (CRPD). In particular, the substantive and procedural provisions related to guardianship in mental health laws are problematic and deny legal capacity to persons with mental disorders.

3. Does the practice of law in India discriminate against persons with mental disorders and how?

Part III of this thesis analysed court cases which were filed for divorce or annulment at the Family Court in Pune, India, where one of the parties had pleaded mental disorder in the spouse as grounds for divorce/annulment. A large majority (85%) of these petitions were filed by husbands alleging mental disorder in their wives, suggesting that women with mental disorders are particularly vulnerable to discriminatory practices. Routine practice in granting
divorces at the Family Court level was problematic, as we found even in cases when no medical evidence to substantiate an allegation of mental disorder in the spouse was presented in Court, divorce or nullity was granted in 22% of cases. Even in cases where medical evidence was presented, it was often of poor quality: for instance, the only evidence of mental disorder presented and accepted by the Court consisted of prescriptions of medicines (3 cases), copies of medical records (1 case), and invoices for purchase of medicine (1 case).

This study also reviewed cases of appeal at all the High Courts across India and found that in the majority of these cases, the original petition at the lower court was filed by the husband, confirming what was seen at the Family Court in Pune. The analysis also revealed that High Courts over-turned the decisions of the Family Courts granting divorce or annulment in more than 50% of the cases, especially when the appeals were filed by women. This suggests that the High Courts are more sensitive to the predicament faced, in particular, by women with mental disorders. However only 5-6% of cases go in appeal to the High Court, as women lack the resources to file appeals in the High Court.

The findings of this study suggest the need for uniform guidelines for the lower courts about the need for adequate medical evidence to substantial allegations of mental disorder and also the need to consider review and deletion of sections of the Hindu Marriage Act which allow divorce and/or annulment on the grounds of mental disorder.

4. Strategies to prevent discrimination by providing legal capacity and treating persons with mental illness as ‘subjects with rights’ rather than ‘objects of charity’. What are the strategies at the legislative level and the professional level?

Part IV of the thesis reviewed different models of supported decision making from around the world. This review showed that only a few countries have provisions for supported decision-making for persons with mental disorders, with a particular lack of such provisions in legislation in low and middle income countries. This was followed by a study about Advance Directives, which is one particular type of supported decision making. A review of the literature showed that implementation of Advance Directives has been difficult globally due to barriers which can be clustered into system level barriers, health professional level barriers and service user level barriers. The review also proposed several potential strategies for overcoming these barriers such as providing facilitators to help persons with mental disorders in writing Advance Directives, increasing
awareness and training for mental health professionals on Advance Directives and supported decision making in general and the need for health information systems for storage and retrieval of Advance Directives.

Part IV also reports on one qualitative study and one quantitative study to understand service user perspectives on Advance Directives in Tamil Nadu, India. Most clients and carers were unfamiliar with Psychiatric Advance Directives (PAD), and while some clients felt it is important to have a say in treatment wishes, carers expressed concerns about service user capacity to make decisions. After completing PAD, clients reported an increase in self-efficacy and an increased desire to make decisions.

The quantitative study found that people with severe and persistent mental disorders can clearly specify treatment preferences and care in an Advance Directive and these PAD are feasible, useful and consistent with standards of care. Belying mental health professionals’ fears that AD will be used to refuse treatment, no user in this study outright refused care in a PAD and very few disagreed with the idea of being taken to hospital if necessary or receiving treatment if necessary.

The findings from these research studies raise issues which are discussed below.

**Theoretical Considerations**

The above research findings show that the legal system in India (laws and their practice) systematically discriminates against persons with mental disorders chiefly by denying the legal capacity of persons with mental disorders. Applying a social model of disability to mental disorders requires that we address social structures, including legal structures that lead to discrimination and exclusion of persons with mental disorders. The laws in India therefore need to recognize the legal capacity of persons with mental disorders. Social model theory also requires that society make appropriate accommodation to enable persons with disability to take part in normal life in the community on an equal basis with others. Supported decision making for persons with mental disorders is an accommodation which allows persons with mental disorders to exercise legal capacity on an equal basis with others. Psychiatric Advance Directives (PAD) are one form of supported decision making which can help persons with mental disorders exercise their legal capacity even during periods of illness when decision making may be impaired. Thus, a supported decision making paradigm enshrined in the law recognizes the ‘personhood’ of persons with mental disorders.
disorders. This recognition of personhood is an important and crucial step in reducing discrimination against persons with mental disorders.

What changes are required to India’s mental health law to address the issue of legal capacity?

India is in the process of adopting new mental health legislation (Mental Health Care Bill, 2013). This Bill is currently in the Upper House (Rajya Sabha – Council of States) of the Parliament. The Bill recognizes that India having ratified the Convention on Rights of Persons with Disabilities has a duty ‘to align and harmonize existing laws with the Convention’.

The work in this thesis has shown that the first and foremost consideration in the law is a need for a presumption of capacity of persons with mental disorders. That is, legislation needs to start with the presumption that all persons with mental disorder have capacity. Based on feedback from the Parliamentary Standing Committee, the Government has agreed to re-draft Section 4 of the Mental Health Care Bill so that there is a presumption of capacity of the person with mental disorder and incapacity has to be proved by those alleging incapacity of the person with mental disorder (Department-Related Parliamentary Standing Committee on Health and Family Welfare, 2013).

Another tool to advance legal capacity for persons with mental disorders is the provision for Advance Directives in the Mental Health Care (MHC) Bill. Section 5 of the Bill makes provisions for any person (not just a person with mental disorder) to make an Advance Directive specifying the following:

‘(a) the way the person wishes to be cared for and treated for a mental illness;
(b) the way the person wishes not to be cared for and treated for a mental illness;
(c) the individual or individuals, in order of precedence, he wants to appoint as his nominated representative (proxy decision maker)’

Such an Advance Directive is only applicable when ‘person ceases to have capacity to make mental health care or treatment decisions and shall remain effective until such person regains capacity to make mental health care or treatment decisions’.

The provision for appointing a person (Nominated Representative) to provide support and act as proxy decision maker (in extreme circumstances) in the MHC Bill (either through an Advance Directive or otherwise through Section 14 of the
Bill) addresses two important issues in moving to a supported decision making regime for persons with mental disorders. First, it gives the person with mental disorder a right to choose who she wishes to provide support for decision making. Second, it addressed a frequently raised question by caregivers and professionals - what happens in circumstances where even the minimum of decision making ability is not present? If there is no way of knowing ‘the will and preferences’ of the person even with maximum effort, who should provide the support and how should the person providing support act? (Bach & Kerzner, 2010)

There are many ways of addressing this issue and different countries have chosen different methods. For instance, the Canadian province of British Colombia has provision for *Representation Agreements (RA)*. The RAs involve elements of supported and substituted decision making and presume everyone has capacity until proven otherwise. Scotland on the other hand, makes provisions in its law for appointment of a proxy through a Power of Attorney. Other countries such as the Australian state of Victoria and Germany have provisions for plenary guardianship which are temporary (time limited) and limited to specific areas of life (e.g. financial decisions) (see Chapter 7 for details).

The MHC Bill (The Mental Health Care Bill, 2013) addresses this issue by making provision for the appointment of a Nominated Representative (NR). An NR can be appointed by a person with mental disorder and can be changed at any time by the person who made the appointment. The NR is supposed to provide support to the person with mental disorder. However in extreme circumstances and in the presence of ‘adverse events’ (Bach & Kerzner, 2010) the NR can also act as a proxy decision maker. The NR is thus similar to the RA in the British Colombia law as the NR has elements of supported and substituted decision making. The MHC Bill also outlines the duties of the NR in Section 17 of the MHC Bill. The person with mental disorder making an appointment of an NR has the right to revoke this appointment. The MHC Bill does not require any capacity assessment for appointment of an NR.

**Mental Health Professionals’ attitudes to proposed changes in law**

Psychiatrists in India have been critical of the MHC Bill. Previous research has shown that negative attitudes towards people with mental disorders are frequent among mental health professionals (Kapungwe A et al, 2010, Nordt C et al, 2006). Respondents in our study (Chapter 4) also commented that people
with authority (including health professionals, government ministers, and officials) are the most resistant groups when it comes to improving the human rights of people with mental disorders.

Psychiatrists in India have focussed their criticism primarily on the provisions for Advance Directives and Nominated Representative. Psychiatrists have suggested these provisions are not culturally appropriate and will ‘drive a wedge’ between ‘patients and families’ (Antony, 2014; Kala, 2013). It is also suggested that it would be inappropriate to give the right to write an Advance Directive to persons with mental disorders when persons with physical illness do not have such a right (Antony, 2014). Psychiatrists have relied essentially on one paper (Sarin, Murthy, & Chatterjee, 2012) to show that Advance Directives have been a ‘failure in western countries where it was given a trial run’ (Antony, 2014; Kala, 2013). However the Sarin et al (2012) only quoted a Cochrane review by Campbell & Kisely (2009) which only included two double blind trials to say that there was inadequate evidence to support the use of Advance Directives. The Cochrane review ignored a wealth of research evidence about Advance Directives, including evidence of professionals’ attitudes as a barrier to implementation of Advance Directives (as shown in our paper on review of barriers to implementation of Psychiatric Advance Directives). Cochrane review methodology only includes trials which are ‘double-blind placebo controlled’ with random allocation of subjects to research studies. While this methodology is appropriate for assessing the efficacy of a new drug or treatment, it is plainly inappropriate for social science research and assessing issues which are matter of legal and social policy.

The President of the Indian Psychiatric Society, representing ‘5000 Indian psychiatrists’ in her evidence to the Standing Committee on Health and Family Welfare of the Indian Parliament said that concepts such as Advance Directive and nominated representative and making the willingness of the patient mandatory to availing treatment were ‘alien to Indian culture’. She further said that India should follow a family model of treatment where ‘families would be in a position to give consent on the need for subjecting a patient to psychiatric treatment’ (Department-Related Parliamentary Standing Committee on Health and Family Welfare, 2013).

The President elect of the Indian Psychiatric Society in his evidence to the Standing Committee on Health and Family Welfare of the Indian Parliament raised fears that a nominated representative who may not be a blood relation (sic) could ‘misuse the said provision for usurping the property or deriving other
benefits which would devolve upon the person suffering from mental illness.’ The President elect quite conveniently ignored a clear provision in the MHC Bill that the provision of Advance Directive and Nominated Representative (NR) only applied to health care decisions and was not applicable to financial, property and any other such decisions (which are proposed to be regulated through a different law, Rights of Persons with Disabilities Bill, which in Bill form is currently also in Parliament).

Fears were also raised by the Indian Psychiatric Society in their evidence to the Parliamentary Standing Committee that such provisions of the MHC Bill would lead to an exodus of psychiatrists from the country!

From the above discussion, it is clear that psychiatrists hold beliefs and attitudes which see persons with mental disorders as lacking any capacity to make decisions about their own health and welfare. Unfortunately these attitudes are expressed not only in academic publications and to Members of Parliament, but also to the general public. In the Times of India dated March 24, 2014, there was an article headlined ‘Psychiatrists see no merit in the healthcare bill’ and quoted senior psychiatrists as saying “major grounds of rejection of bill by the psychiatrist include, the right of the patient of mental illness to decide whether he want to take treatment further or not, right of the patient to nominate someone to take decisions for him..”,” “In this bill, patients of mental illness have been given advanced directive to decide whether he wants to be treated or not. How is that justified?” and a senior psychiatrist is quoted in the same article as saying “How can a patient decide about treatment?” [emphasis added]. These comments encapsulate professional attitudes towards the capacity of persons with mental disorders.

**What changes are required in other laws to address the issue of legal capacity?**

This research has identified problems in the substance & content of the Hindu Marriage Act, 1955 (HMA) with respect to mental disorders. We have also shown there are additional problems with the HMA such as the gender biased and discriminatory use of the law and a failure to following appropriate judicial procedures with respect to, for example, evidence of mental disorder which are discussed later. Here I focus the discussion on the content issues of the Hindu Marriage Act.

According to HMA, a marriage may be solemnised on fulfilment of certain conditions specified in Section 5 of the Act. When HMA was enacted in 1955, Section 5(ii) stated a condition “neither party to the marriage should be idiot or
lunatic”. The Marriage Laws (Amendment) Act, 1976 amended the HMA and substituted this clause with the conditions currently stated in Section 5 (ii) of HMA.

Section 5 (ii) (a) says one of the conditions for a valid marriage are “neither party is incapable of giving a valid consent to it in consequence of unsoundness of mind”.

Section 5 (ii) (b) poses a particular challenge. This sub-section says that conditions for a marriage are not satisfied and the marriage may be annulled if: a party, “though capable of giving valid consent, has been suffering from mental disorder of such a kind or to such an extent as to be unfit for marriage...” So even if a person with mental disorder is able to show that they do not have an ‘unsound mind’ the mere fact of the severity of illness (“of such a kind or to such an extent”) makes persons with mental disorders as ‘unfit’ for marriage. Importantly, this severity is not specified in the Act, but is left completely to the Court’s discretion (“of such a kind or to such an extent”). This discretion can be particularly problematic as shown in our research as the Courts were accepting very poor quality medical evidence as proof of mental disorder and, in 22% of the cases in our research, were comfortable in annulling marriages or granting divorce even when no medical evidence of mental disorder is presented.

Furthermore Section 5 (ii) (c) says that another condition to be met for a valid marriage is “neither party has been subject to recurrent attacks of insanity”. The term “insanity” is once again not defined and is left to judicial discretion. Read together, Section 5 (ii) (a), (b) and (c) mean that no person with mental illness will be able to contract a non-voidable marriage. This section of HMA clearly violates the United Nations Convention on Rights of Persons with Disabilities (CRPD), which India ratified in 2007. This section particularly contradicts Article 23 of the CRPD, Respect for Home and the Family as it discriminates against persons with disabilities in matters related to marriage and divorce.

Section 13 of HMA specifies grounds for divorce. Section 13 sub-section (1) (iii) is the particular section of the Act where mental illness is accepted as grounds for divorce under certain circumstances. This sub-section states if someone “has been incurably of unsound mind or has been suffering continuously or intermittently from mental disorder of such a kind and to such an extent that the petitioner cannot reasonably be expected to live with the respondent”. Section 13(1) has an “Explanation” which states as follows “(a) the expression “mental disorder” means mental illness, arrested or incomplete development of the mind,
psychopathic disorder or any other disorder or disability of the mind and includes schizophrenia; (b) the expression “psychopathic disorder” means a persistent disorder or disability of mind (whether or not including sub-normality of intelligence) which results in abnormally aggressive or seriously irresponsible conduct on the part of the other party, and whether or not it requires or is susceptible to medical treatment.”

Once again the terms “of such a kind and to such an extent” are not defined. The definitions of ‘mental illness’ and ‘psychopathic disorder’ as given in the Explanation to this section of the Hindu Marriage Act also do not necessarily correspond well to medical definitions and understanding of these terms. The term ‘psychopathic disorder’ in HMA encompasses intellectual disability. The term ‘psychopathic disorder’ is hardly found in modern medical literature, which tends to use the term ‘personality disorder’. However there are many concerns articulated in medical literature regarding the diagnosis of personality disorder, particularly the validity and reliability of the diagnosis (Clark LA et al 1997, Clark LA 2007, Scott S 2006).

Personality disorders have long been described as deviances from social norms and values. In the Indian context where patriarchal norms prevail, any challenge to male authority has the potential to be labelled as a personality disorder, which may contribute to explaining why there are a disproportionate number of female spouses labelled as having a mental illness in divorce cases.

Unsound Mind: judicial understanding and attitudes

The term ‘unsound mind’ appears not only in the HMA but in more than 150 other Indian laws (Legal Review Team of National Disability Network and Disability Rights Group, 2012). It also finds a place in the Constitution of India – Section 326 of the Constitution of India states that persons with ‘unsoundness of mind’ are disqualified from being registered as a voter and therefore can neither vote or contest elections.

This term has a long and interesting history. It makes its first appearance in the Indian Contract Act, 1872 (this law is still in force). Section 12 of this Act states:

“A person is said to be of sound mind for the purpose of making a contract if, at the time when he makes it, he is capable of understanding it and of forming a rational judgment as to its effect upon his interests.

A person who is usually of unsound mind, but occasionally of sound mind, may make a contract when he is of sound mind.
A person who is usually of sound mind, but occasionally of un-sound mind, may not make a contract when he is of unsound mind.” (The Indian Contract Act, 1872)

Very unusually for Indian legislation, the Indian Contract Act, 1872, Section 12 actually offers illustrations of what is meant by an unsound mind. It says:

“Illustrations

(a) A patient in a lunatic asylum, who is at intervals of sound mind, may contract during those intervals.

(b) A sane man, who is delirious from fever or who is so drunk that he cannot understand the terms of a contract or form a rational judgment as to its effect on his interests, cannot contract whilst such delirium or drunkenness lasts”.

As can be seen in the illustration, the Indian Contract Act, 1872 takes care to NOT equate unsoundness of mind with mental disorder and in fact gives an example of conditions when a person in a lunatic asylum (presumably a person who has mental disorder) can also enter into a valid contract.

Despite this rather progressive provision for its time, it seems to have been forgotten and/or discarded in subsequent legislation and cases. For example, in 2009, in the case of Hari Singh Gond v. State of MP, the Supreme Court of India said “there is no definition of unsoundness of mind in the IPC. Courts have, however, mainly treated this expression as equivalent to insanity. But the term insanity itself has no precise definition. It is a term used to describe varying degrees of mental disorder” (Hari Singh Gond v. State of M. P., 2008). Courts in India have thus treated unsoundness of mind and mental disorder as synonymous, although this is not supposed to be so (see The Indian Contract Act, 1872).

The Supreme Court’s interpretation that the terms ‘unsoundness of mind’ and ‘insanity’ are equivalent to mental disorder creates many problems and leads to denial of legal capacity to persons with mental disorder and discrimination. This interpretation of the Supreme Court effectively disenfranchises all persons with mental disorder because the Constitution of India says that persons with unsoundness of mind do not have a right to vote! In a democracy, the denial of the right to vote is highly discriminatory and leads to the denial, downstream, of a number of civil, political, economic, social and cultural rights and hence prevents persons with mental disorders the right to full participation in community life.
This interpretation of the Supreme Court equating mental disorder and unsound mind has another unintended consequence. Section 375 of the Indian Penal Code says that a man is said to commit “rape” who – “has sexual intercourse with a woman under circumstances” falling under any of six descriptions. The fifth of these six conditions says “With her consent, when, at the time of giving such consent, by reason of unsoundness of mind or intoxication or the administration by him personally or through another of any stupefying or unwholesome substance, she is unable to understand the nature and consequences of that to which she gives consent”.

In light of the Supreme Court equating mental disorder with unsoundness of mind, Sec 375 can be interpreted to mean that a person having sexual intercourse with any woman with a mental disorder is liable to be charged with rape.

Section 90 of the Indian Penal Code regarding Consent (this is limited to consent issues under the Indian Penal Code) also creates a similar problem with the equating of mental disorder with unsound mind. Section 90 says “Consent of insane person - if the consent is given by a person who, from unsoundness of mind, or intoxication, is unable to understand the nature and consequence of that to which he gives his consent”.

A plain reading of Section 90 in light of the Supreme Court order will mean that no person with mental disorder can give consent. Section 90 also reveals the confusion inherent with the terms ‘unsound mind’, ‘insanity’ and ‘mental disorder’ in the Indian legal system. The title of Section 90 refers to an ‘insane person’ while the content of Section 90 refers to “unsoundness of mind” thus conflating insanity and unsoundness of mind.

The Supreme Court’s interpretation of ‘unsound mind’ as being equal to ‘varying degrees of mental disorder’ will thus result in denial of civil and political rights such as the right to vote and also denies the sexuality and right to marry for persons with mental disorders. The Supreme Court’s judgement essentially denies legal capacity for persons with mental disorders.

This judgement of the Supreme Court is not a ‘one-off’ misinterpretation. In another example from the Madras High Court in 2012, while allowing appeal in a matrimonial case dealing with mental illness and annulment A. Abitha v. Eben Jayanth, the Hon. Judge explicitly stated “I would like to point out the sorry state of affairs that is prevailing in some of the Courts below; throwing to winds the rules and laws, the lower Court passed the ex parte judgment and decree, to say
the least, the Judge ought to have been careful and cautious in granting such decree of nullity. The husband cannot blow hot and cold having chosen to describe his wife as a lunatic represented by her father. The question of setting exparte the said wife in that matter, on her alleged non-appearance despite publication, is a well neigh impossibility and judicial conscience is shaken on seeing the horrible and cavalier fashion, the matter was handled by the concerned Judge, while passed the exparte judgment and decree. This sort of grave injustice should not be perpetrated by the lower Courts in future. I would like to reiterate that a cue should be taken by the Subordinate Judiciary that no more such illegal orders be passed in matrimonial matters; if the respondent is described as a mentally challenged person in any matrimonial matters or any matters, the said respondent legally cannot be set exparte at all.” (A. Abitha v Eben Jayanth, 2012)

The key point in this case is that the Hon. Judge of the High Court accepts uncritically the concept that if the woman has a mental disorder (the term used by the Judge is ‘lunatic’) she should be represented by her father. The Hon Judge does not question this basic presumption as to why a person (or woman) with mental disorder cannot represent herself and has to be represented by her father! So although the judgement above appears to protect the woman against ex-parte judgements, it does not challenge the basic premise that a person with mental disorder cannot represent himself or herself and has to be represented by a ‘guardian’. The Hon Justice does not see the need to recognize the legal capacity of the woman with mental disorder. In this particular case, the woman had also pleaded “by contending that on false and mala fide grounds, her husband filed I.D.O.P.No.277 of 2001 and got an exparte judgment illegally and no medical witness or other witness was examined to prove and establish that the petitioner - Abitha was suffering from mental illness or mental derangement;” Unfortunately, the High Court did not comment or pass any order on this point raised by the petitioner (woman). The High Court uncritically appears to accept (a) that the woman has a mental disorder and (b) consequent to the mental disorder, she does not have legal capacity and should be represented by her natural guardian, her father.

This judgement has elements of charity, but no element of recognition of rights of persons with mental disorders.

As stated earlier, legal capacity consists both of legal standing (the capacity to hold rights) as well as legal agency (the capacity to exercise rights). Article 13 of the CRPD (Access to Justice) requires States Parties to “ensure effective access
to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.”

Another piece of evidence from a different section of the Indian Judiciary highlights judicial attitudes towards mental disorders and persons with mental disorders. The Chennai edition of one of the largest circulated English language newspaper in India, The Times of India, carried an article quoting the Hon Principal Judge of the Family Court, Chennai as saying that “40% of the divorce cases involve people with mental health issues”.

We filed a petition under India’s Right to Information Act, 2005 asking the Hon. Judge to give us information on the basis of which the Hon. Principal Judge made this public statement. Specifically we asked for the following information:

1. Time frame taken into consideration
2. The total number of decided divorce cases during this time frame
3. The total number of cases that ‘involve’ people with mental health issues during this time frame
4. The total number of cases that involve persons living with different levels of schizophrenia during this time frame.

In reply to this query the Hon. Principal Judge claimed that he was misquoted with regard to question number 4 above. “The reporter of Times of India in its report....instead of stating that 30-40% of the cases pending in the Family Court relating to Mental Health Issue (sic), stated that 40% of the cases are relating to serious mental illness namely schizophrenia.”

With respect to the other questions the Hon. Justice had this to say:

“1. The time frame taken into consideration is almost more than two years.
2. Regarding the total number of cases decided during the two years I have no specific data
3. Regarding the total number of cases that involve people with mental health issues during this time frame I have no specific data.” [Emphasis added].
In brief, the Hon. Principal Judge admitted that he had made a public statement that 30-40% of pending cases in the Family Court related to Mental Health issues, but when asked to produce the data, admitted that he had no such data to back up his statement!! Persons with mental disorders were being publicly blamed as being the cause of divorce, but this was not based on any data. Is this not just stigma and prejudice?

To summarize, three cases from different levels of the Judiciary starting with the Supreme Court of India, the High Court and the Family Court, raise issues about the Judiciary’s understanding of the concepts of unsoundness of mind as related to mental disorders, capacity of persons with mental disorders to make decisions and the role of mental disorders in matrimonial disputes. My contention is that the Judiciary in India has erred in its application of the concept of unsound mind, failed to recognize the legal capacity of persons with mental disorders and displayed an inherent bias against persons with mental disorders.

I would like to reiterate here what was said by the Committee on Rights of Persons with Disabilities in its General Comment on Article 12 of the CRPD. It said ‘The CRPD (Article 12) now makes it clear that ‘unsoundedness (sic) of mind’ and other discriminatory labels are not legitimate reasons for the denial of legal capacity (legal standing and legal agency).’

It is worth repeating that India has ratified the Convention on Rights of Persons with Disabilities (CRPD) and is bound by it.

The draft Mental Health Care Bill (2013) referred to above and currently in the Indian Parliament, attempts to partially address this issue of unsound mind and undo the effect of the Supreme Court judgement equating unsound mind with mental disorders. Section 3 sub-section 5 of the Mental Health Care Bill states “The determination of a person’s mental illness shall alone not imply or be taken to mean that the person is of unsound mind unless he has been declared as such by a competent court.”

The research at the Family Court also highlighted the failure to follow appropriate procedures in matrimonial matters related to persons with mental disorders. These include for example, accepting questionable evidence of mental disorder as being sufficient to fulfil grounds for granting divorce under the Hindu Marriage Act and granting ex parte orders, and thus fails to meet Article 13 (Access to Justice) of the Convention on Rights of Persons with Disabilities (CRPD).
How can we address Judicial Officers and Mental Health Professionals understanding and recognition of legal capacity of persons with mental disorders?

As is evident from the above discussion, changes to the law need to be accompanied by changes in understanding of legal capacity by judicial officers and mental health professionals. The author has been part of two separate training efforts to address this issue.

**Example 1: International Diploma in Mental Health Law and Human Rights**

In 2008, the Indian Law Society (ILS), Pune, India in collaboration with the WHO, set up the International Diploma in Mental Health Law and Human Rights. The Diploma aims to build capacity in countries to promote the rights of persons with mental disorders in line with the CRPD and other international human rights standards. The Diploma aims to equip national actors with the skills needed to be able to advocate for human rights and influence national reform efforts.

The author is the Co-ordinator for this Diploma and helped conceptualize the Diploma with colleagues from the World Health Organization and the ILS. The author is actively involved in all aspects of the Diploma including selection of the faculty, supervision of students and the teaching. Over the past 6 years, the course has had 95 students from 45 different countries. The professional backgrounds of the students is given below:

<table>
<thead>
<tr>
<th>Professional background</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrists</td>
<td>35</td>
</tr>
<tr>
<td>Psychologists</td>
<td>14</td>
</tr>
<tr>
<td>Law professionals</td>
<td>15</td>
</tr>
<tr>
<td>Psychiatric nurses</td>
<td>7</td>
</tr>
<tr>
<td>Users</td>
<td>6</td>
</tr>
<tr>
<td>Care-givers</td>
<td>4</td>
</tr>
<tr>
<td>Others (NGO activists, Govt. officials etc.)</td>
<td>14</td>
</tr>
</tbody>
</table>

A large proportion of the Diploma students are mental health professionals as is evident from the table above. This is an encouraging sign as it shows there is demand for more knowledge and awareness on mental health legislation from mental health professionals.
Example 2: Training for Judicial Officers

The author and a colleague from the Indian Law Society (ILS) have run training programmes for Judicial Officers for the past 2 years in collaboration with the Maharashtra Judicial Academy, the Karnataka Judicial Academy and the Punjab and Haryana Judicial Academy. These state judicial academies are tasked with continuing judicial education for judicial officers in their state.

Four such programmes have been conducted for judicial officers in these states. Each programme is 2 day long programme and covers the Mental Health Act, 1987, Hindu Marriage Act, 1955 Convention on Rights of Persons with Disabilities and Legal Capacity issues. Through these programmes, nearly 150 Judicial Officers have received training on this issue.

Judicial Officers have generally commented favourably on this training programme. Some of the typical comments are:

“The programme has made me aware about the rights, provisions and conventions on differently abled people and has broadened the outlook”

“The provisions of Mental Health Act are discussed in detail, which would help in deciding such cases if received and in divorce cases and children's custody cases”

Two Judicial Academies permitted us to collect formal feedback from the participants of these workshops. The pooled results showed of the total 101 participants at these two training programs, 25 participants rated the program overall as “Excellent – exceeded my expectations” and 74 participants rated the programme as “Good – met my expectations”, 2 participants left this question unanswered and no participant rated the program as “Fair” or “Poor”.

There is a need to conduct such training programs for Judicial Officers in other states in India to sensitize them to issues faced by persons with mental disorders and to enhance their understanding of legal capacity for persons with mental disorders.

To summarize the findings of the research in this thesis and the above discussion:

1. Persons with mental disorders face discrimination around the world.
2. Denial of legal capacity is fundamental aspect of this discrimination; mental health laws in many countries deny legal capacity and basic principles of justice and due process to persons with mental disorders.
3. Denial of legal capacity leads to denial of a number of civil & political rights (such as the right to vote) as well as economic, social and cultural rights (such as the right to marry and the right to sexuality).
4. Promoting and protecting legal capacity requires that laws in general and mental health laws in particular, recognize the legal capacity of persons with mental disorders and move to a supported decision making paradigm.
5. Persons with mental disorders, even those with severe and chronic mental disorders are able to write psychiatric advance directives expressing their wishes regarding mental health treatment.
6. The concept of ‘unsound mind’ as stated in Indian Laws and interpreted by the Indian Judiciary as equal to mental disorders, leads to denial of legal capacity and hence denial of multiple rights for persons with mental disorders.
7. Mental health professionals and legal professionals either lack an understanding of legal capacity issues with respect to mental disorders or hold negative attitudes towards capacity of persons with mental disorders to make decisions.
8. Training mental health professionals and legal professionals is a way of changing knowledge and attitude barriers.

Validity of the findings

External Validity

The applicability of the findings to the broader Indian context and also to other low and middle income countries is a question that needs to be addressed.

The paper which reviewed Commonwealth mental health legislation is generalizable to other Commonwealth countries, as all Commonwealth countries have a shared law tradition arising from their colonial experience. Like India, many of the Commonwealth countries are low and middle-income countries. The results were stratified by the income level of the Commonwealth countries. All Commonwealth countries have a shared law tradition (common law) due to their colonial experience.
The findings presented in the supported decision-making paper and the paper reviewing barriers to implementing advance directives were both globally oriented, which, although they lack country-specific information, are relevant and generalizable to other countries. Both papers addressed specific issues that low and middle-income countries may face to see how these countries could learn from the findings in these reviews.

In Chapter 6, the paper on divorce and the Hindu Marriage Act is based on data collected from only one Family Court in India, which limits generalizability. However, all family courts use the same law and there is no reason to believe that the Family Court in Pune (from where the data was collected) is non-representative of Family courts across the country. This paper also reviewed the judgements from High Courts across the country (High Courts are the appellate courts for cases from the Family Courts) and this provides further validation of the findings.

The primary research papers on Advance Directives are based on data collected from only one particular NGO in one state of the country and therefore there is a risk that these findings may only have been observed in this particular case. To minimize these risks we tried to ensure adequate representation of sub-populations (e.g. Women, rural population) to ensure that all ‘voices’ were heard. There is another study from the same city in a different clinical setting which had very similar findings (Kumar et al, 2013).

*Internal Validity*

For the quantitative data we piloted our questionnaire prior to commencing the study and ensured adequate training for the researchers who collected the data. There is an element of selection bias as convenience sampling was used for this study (Chapter 10). However this data was collected from busy out-patients clinics with substantial clinical load, so a more structured sampling method would have not been feasible. We decided a priori the exclusion and inclusion criteria and only a small number of people who were approached refused participation in the study. The ‘refusers’ were not significantly different from those that did participate in their demographic and clinical characteristics. We decided a priori the exclusion and inclusion criteria and only a small number of people who were approached to participate, actually refused to participate. The ‘refusers’ were also not different from those that did participate in their demographic and clinical characteristics.
A check to reduce researcher bias and maintain objectively was to have the qualitative data analysed by multiple researchers. This was done in Chapter 9. When there were any disagreements regarding the qualitative data coding strategy, there were discussed openly among the researchers, and when consensus was still not possible, the author involved a third researcher. Methodological and investigator triangulation also helped to ensure that the bias in the qualitative studies was minimized.

**Future Research Agenda**

*Addressing legal issues in recognition of legal capacity*

The first point of attention for future research is to further explore how different laws (e.g., contract laws, employment laws) impact the legal capacity of persons with mental disorders. In particular, there is a need to further explore the concept of “unsound mind” in Indian legislation and its impact on persons with mental disorders. Research is also needed to better understand the intersection of gender and mental disorder. Research in this thesis (Chapter 6) suggests that women with mental disorder face a ‘double whammy’ of discrimination and denial of legal capacity as commented on by several other authors (Dhanda, 2000; Addlakha, 2007).

*Addressing implementation issues*

The new Mental Health Care Bill is likely to become law in India very soon. A major criticism of the existing law (Mental Health Act, 1987) has been its poor implementation, in particular the lack of regulatory regime as included in the Act. The MHC Bill has many provisions which have the potential to improve the recognition of legal capacity for persons with mental disorders, if fully implemented. There is a need to identify potential barriers to implementation and identify strategies to address these barriers. A code of practice, for example, could help implementation. Raising awareness about the new law amongst professionals, users and care-givers and training of users, care-givers and professionals on the provisions of the new law are some other strategies to support implementation. Research needs to look at how well these provisions get implemented once the law comes into force. In particular, research is needed to identify barriers to implementation of the provision of Advance Directives and strategies devised to overcome these barriers.
SUMMARY

Discrimination is an everyday occurrence for many people with mental disorders in all spheres of life. Discrimination leads to denial of opportunities to live a normal social life, exclusion from the community and abuse. Stigma and discrimination are inter-related and represent two facets of the same underlying phenomena. Stigma represents the negative attitudinal aspects associated with mental disorders, while discrimination represents its behaviour component. Discrimination can be addressed directly by legislative efforts (e.g. laws to prevent discrimination) and policy efforts (e.g. affirmative action).

Self-determination is fundamental to enable people to achieve their full potential. However legal systems across the world presume that persons with mental disorders are unable to act and manage their lives independently. The presumption of lack of capacity for self-determination and the consequent denial of legal capacity to persons with mental disorders is the fundamental discrimination which then leads to discrimination in other spheres of life. This thesis hopes to shed light on this important issue and suggest possible solutions for addressing discrimination faced by persons with mental disorders.

It is hypothesized that, Indian laws and their judicial interpretation systematically discriminate against persons with mental disorders through the denial of legal capacity and thus prevent their full and effective participation in society. These legal barriers go hand in hand with attitudinal barriers of mental health professionals towards persons with mental disorders.

Based on this hypothesis the overall research question guiding this thesis is as follows:

*What are the legal barriers to implementing full citizenship rights for persons with mental disorders in India and what strategies and opportunities can be identified to move towards a more rights based system for persons with mental disorders in India?*

Using a mixed methods design, this thesis attempts to answer the overall research question by breaking it down into the following sub-questions:

1. *To what extent are persons with mental disorders treated as persons with rights in low and middle income countries?*

Part I of the thesis brought together different sources of evidence from reports and publications in addition to experiences of 51 people with mental disorders.
from across low and middle income countries to provide a comprehensive picture of the human rights violations experienced by persons with mental disorders. The key finding from this study was discrimination led to pervasive human rights violations. Empowerment of users of mental health services was suggested by respondents as one of the strategies to address discrimination.

In many countries people with mental or psychosocial disabilities are deprived of their legal right to make decisions and the authority is handed to a third person, a guardian. Decisions concerning health care are also made by guardians, which can result in people being detained in mental health facilities and treated against their will. Despite the far-reaching powers that can be exercised by guardians, there are very often few or no judicial mechanisms to enable people to appeal their involuntary admission and treatment or protect their right to exercise their legal capacity more generally.

The denial of legal capacity can also mean that a person is excluded from participation in social and political life, such as the right to vote or be elected, and to participate in the development and implementation of laws and policies that concern them.

To promote empowerment at the individual level, efforts need to focus on ensuring that people with mental and psychosocial disabilities are able to exercise their legal capacity in line with article 12 of the CRPD. Law and policy reform was identified by respondents in the study as a key strategy to promote human rights.

2. Does the content of mental health laws discriminate against people with mental disorders and if so, how?

Part II of this thesis reviewed the content of mental health legislation across Commonwealth countries (including India). The review showed that substantive and procedural provisions related to guardianship in mental health laws are problematic and deny legal capacity to persons with mental disorders.

Mental health legislation in only four Commonwealth member states had provisions for supported decision making including the provision of Advance Directives in their mental health legislation. 24 (53 per cent) Commonwealth countries had provisions for guardianship in their mental health laws. 7 countries only allowed limited guardianship usually restricted to property matters, while the majority (58 per cent) of mental health laws had provisions for both limited and plenary guardianship. This provision of plenary guardianship is almost certainly in conflict with the countries’ obligations under
Article 12 of the CRPD.

There were also procedural issues with guardianship in Commonwealth countries. Only 3 country laws required that the person who is the subject of guardianship should be present at or represented at the guardianship hearing. Majority of the country laws (66%) had no provision for appeal against the guardianship ruling and 79% of the laws did not have any provisions for regular time bound review of the guardianship decisions. The lack of these procedural protections is contrary to the requirements of Article 13(1) of the CRPD.

3. Does the practice of law in India discriminate against people with mental disorders and if so, how?

Part III of this thesis analysed court cases which were filed for divorce or annulment at the Family Court in Pune, India, where one of the parties had pleaded mental disorder in the spouse as grounds for divorce/annulment. A large majority of these petitions were filed by husbands alleging mental disorder in their wives, suggesting that women with mental disorders are particularly vulnerable to discriminatory practices. In nearly a quarter of the cases, divorce or nullity was granted even when no medical evidence to substantiate an allegation of mental disorder in the spouse was presented in Court. Even in cases where medical evidence was presented, it was often of poor quality.

At the Family Court level, 85% of cases filed were by husbands alleging mental illness in their wives. Similarly, of the cases that reached the High Court level, male petitions had filed 95% of the petitions originally at the Family Court. This suggest that men rather than women are using mental illness in their spouse as a grounds for divorce or nullity. This is possibly reflective of the differential social positions of men and women in Indian society.

We also found that medical evidence for mental illness was presented in only a third of the cases despite the fact that mental illness was pleaded as the basis for nullity or divorce. When no medical evidence was presented, divorce or nullity was still granted in 22% of instances, compared to (only) a 35% success rate of petitions when medical evidence of mental illness is presented. Even when medical evidence is presented, the results show that it was often of poor quality to be considered as robust proof of a mental illness.

4. What strategies can be employed at the legislative level and at the professional (judicial professionals and mental health professionals) level to
prevent discrimination by recognizing legal capacity of persons with mental disorders?

Part IV of the thesis reviewed different models of supported decision making from around the world. Our findings indicated dis-connect between international conventions (CRPD) and domestic legislation. We found very limited evidence on supported decision-making, and even less evidence on interventions assessing autonomy and decision-making outside treatment decisions.

This review showed that only a few countries have provisions for supported decision-making for persons with mental disorders, with a particular lack of such provisions in legislation in low and middle income countries (LMICs). We found no evidence of programs in LMICs to train health professionals in supported decision making. The question remains as to how supported decision-making models can be feasible for clinicians and clients, and adapted to suit the legal and medical context in LMICs.

Psychiatric Advance Directives (PAD) are one form of supported decision making which allows the person with mental disorder to retain control over her treatment even during periods of illness when there may be severe impairment of decisional capacity. A review of the literature showed that implementation of Advance Directives has been difficult globally due to barriers which can be clustered into system level barriers, health professional level barriers and service user level barriers. Potential strategies for overcoming these barriers include providing facilitators to help persons with mental disorders in writing Advance Directives, increasing awareness and training for mental health professionals on Advance Directives and supported decision making in general and the need for health information systems for storage and retrieval of Advance Directives.

Part IV of the thesis also included one qualitative study and one quantitative study to understand service user perspectives on Advance Directives in Tamil Nadu, India. Most clients and carers were unfamiliar with Psychiatric Advance Directives (PAD), and while some clients felt it is important to have a say in treatment wishes, carers expressed concerns about service user capacity to make decisions. After completing PAD, clients reported an increase in self-efficacy and an increased desire to make decisions. The quantitative study found that people with severe and persistent mental disorders can clearly specify treatment preferences and care in an Advance Directive and these PAD are
feasible, useful and consistent with standards of care. Belying mental health professionals’ fears that AD will be used to refuse treatment, no user in this study outright refused care in a PAD and very few disagreed with the idea of being taken to hospital if necessary or receiving treatment if necessary.

5. How can lessons learnt from the above inquiries be applied in practice?

The author was a technical consultant to the Ministry of Health and Family Welfare for drafting the new mental health law (MHC Bill) for India. The epilogue represents a reflection of the author’s application of research findings in mental health and human rights to the MHC Bill as well as work as a member of the Policy Group.

The research findings presented in this thesis show that the legal system in India (laws and their practice) systematically discriminates against persons with mental disorders chiefly by denying the legal capacity of persons with mental disorders. As a first step, laws in India need to recognize the legal capacity of persons with mental disorders. Social model theory also requires that society make appropriate accommodation to enable persons with disability to take part in normal life in the community on an equal basis with others. Supported decision making for persons with mental disorders is an accommodation which allows persons with mental disorders to exercise legal capacity on an equal basis with others. Psychiatric Advance Directives (PAD) are one form of supported decision making which can help persons with mental disorders exercise their legal capacity even during periods of illness when decision making may be impaired. Thus, a supported decision making paradigm enshrined in the law recognizes the ‘personhood’ of persons with mental disorders. This recognition of personhood is an important and crucial step in reducing discrimination against persons with mental disorders.

Along with changes to legislation there is also a need to address mental health professionals and legal professionals lack an understanding of legal capacity issues with respect to mental disorders and negative attitudes towards capacity of persons with mental disorders to make decisions. Training programmes for mental health professionals and legal professionals hold promise of bring about changes in knowledge and reducing negative attitudes.
SAMENVATTING

Veel mensen met een psychische aandoening worden dagelijks geconfronteerd met discriminatie in alle facetten van het leven. Discriminatie resulteert in beperkingen in het leiden van een normaal leven, exclusie uit de samenleving en misbruik. Stigma en discriminatie zijn met elkaar verweven en vertegenwoordigen twee aspecten van hetzelfde onderliggende fenomeen. Stigma vertegenwoordigt de negatieve houding ten aanzien van psychische aandoeningen, terwijl discriminatie de gedragscomponent hiervan representeert. Discriminatie kan worden aangepakt door middel van juridische maatregelen, zoals anti-discriminatie wetten en beleidsinspanningen, zoals het gebruik van een voorkeursbeleid.

Zelfbeschikking is van fundamenteel belang om mensen in staat te stellen zich volledig te kunnen ontplooien. Rechtssystemen wereldwijd nemen echter aan dat mensen met een psychische aandoening niet in staat zijn om hun eigen keuzes te maken en hun eigen leven te leiden. Deze aanname van een verminderd vermogen tot zelfbeschikking en de gerelateerde ontzegging van het zelfbeschikkingsrecht van mensen met een psychische stoornis leidt tot discriminatie in verschillende facetten van het leven. Dit proefschrift draagt hopelijk bij aan het inzichtelijk maken van dit probleem en bespreekt mogelijke oplossingen die kunnen leiden tot een vermindering van discriminatie ervaren door mensen met een psychische aandoening.

Dit proefschrift is gebaseerd op de hypothese dat Indiase wetten en hun juridische interpretatie mensen met een psychische aandoening systematisch discrimineren door ontzegging van het zelfbeschikkingsrecht en daardoor volledige participatie van mensen met een psychische aandoening in de samenleving belemmerd. Deze wettelijke barrières vallen vaak samen met een negatieve houding van geestelijke gezondheidsmedewerkers tegenover mensen met een psychische aandoening.

Gebaseerd op deze hypothese is de centrale onderzoeksvraag van dit proefschrift als volgt geformuleerd:
Wat zijn de wettelijke barrières in het implementeren van volledige mensenrechten voor mensen met een psychische aandoening in India en welke strategieën en mogelijkheden kunnen worden geïdentificeerd om een meer rechten gebaseerd systeem voor mensen met een mentale aandoening in India te bewerkstelligen?

Gebruik makend van een studieontwerp dat meerdere onderzoeksmethodes combineert wordt getracht de hoofd onderzoeksvraag van dit proefschrift te beantwoorden door deze te verdelen in de volgende vragen:

1. *In welke mate worden mensen met een psychische aandoening behandeld als personen met rechten in landen met een laag- en middeninkomen?*

Het eerste deel van dit proefschrift beschrijft de schending van de mensenrechten van mensen met een psychische aandoening aan de hand van informatie uit rapporten, publicaties en verslagen van de ervaringen van 51 mensen met een psychische aandoening uit landen met een laag- en middeninkomen. De hoofd bevinding van dit onderzoek was dat discriminatie leidt tot schending van de mensenrechten. ‘Empowerment’ van mensen met een psychische aandoening werd geopperd door de deelnemers aan deze studie als een van de strategieën om discriminatie te verminderen.

Het wettelijke recht op het maken van beslissingen wordt mensen met een psychische aandoening in vele landen ontnomen, waarbij dit recht over wordt gedragen aan een derde, een zogenaamde voogd. Beslissingen aangaande de gezondheidszorg worden ook gemaakt door de voogd, wat kan resulteren in het tegen hun wil behandelen en opnemen van deze mensen in geestelijke gezondheidsinstellingen. Ondanks de verreikende macht die kan worden uitgeoefend door de voogd, zijn er doorgaans slechts enkele of helemaal geen rechtelijke instrumenten die mensen met een psychische aandoening in staat stellen hun onvrijwillige opname en behandeling aan te vechten of om hun recht op zelfbeschikking in zijn algemeenheid te verdedigen.
Het ontzeggen van het zelfbeschikkingsrecht kan ook tot gevolg hebben dat een persoon geweerd wordt van deelname aan sociale of politieke activiteiten, zoals stemmen, de mogelijkheid om gekozen te worden als volksvertegenwoordiger en medewerking in de ontwikkeling en implementatie van wetten en beleidsmaatregelen die hun zelf betreffen.

Om de ‘empowerment’ op individueel niveau te verbeteren, moeten maatregelen genomen worden die mensen met een psychische aandoeningen de mogelijkheid biedt om hun zelfbeschikkingsrecht uit te oefenen zoals beschreven in Artikel 12 van het CRPD. Wettelijke- en beleidsaanpassingen werden door de participanten in de studie aangedragen als de belangrijkste strategie om dit zelfbeschikkingsrecht te verbeteren.

2. **Discrimineert de inhoud van geestelijke gezondheidszorg wetten mensen met een psychische aandoening en zo ja, op welke manier?**

Het tweede deel van dit proefschrift belicht de inhoud van geestelijke gezondheidswetgeving in de Gemenebest, waaronder India. Hieruit blijkt dat inhoudelijke en procedurele bepalingen gerelateerd aan voogdijschap in de geestelijke gezondheidswetten problematisch zijn en het zelfbeschikkingrecht van mensen met een psychische aandoening beperken.

De geestelijke gezondheidswetgeving van slechts vier Gemenebest landen omvatte voorzieningen die ‘supportive decision making’ mogelijk maken, waaronder het opstellen van wilsverklaringen. Vierentwintig Gemenebest landen, wat overeenkomt met 53 procent, hadden de mogelijkheid tot voogdijschap opgenomen in hun geestelijke gezondheidswetgeving. Zeven landen lieten een beperkte mate van voogdijschap toe, meestal gelimiteerd tot eigendomskwesties, terwijl de overgrote meerderheid van de aan de geestelijke gezondheidszorg gerelateerde wetten in deze landen, 58 procent, beperkte en volledige voogdijschap toestonden. Het verstrekken van volledig voogdijschap is vrijwel zeker in tegenstrijd met de verplichtingen van de landen ten opzichte van Artikel 12 van de CRPD.

Er waren ook enkele procedurele factoren van belang bij voogdijschap in de Gemenebest landen. De wetgeving in slechts drie landen verplichte de
aanwezigheid van de persoon die onderworpen wordt aan het voogdijschap, of een vertegenwoordiger van deze persoon, ten tijde van de hoorzitting. De meerderheid van de landelijke wetten, 66 procent, bood geen mogelijkheid tot het in beroep gaan tegen de uitkomst van de voogdijzitting en 79 procent van de wetten voorzagen niet de mogelijkheid tot een regelmatige, tijdgebonden beoordeling van het voogdijschap. De afwezigheid van deze procedurele beschermingsmaatregelen zijn in tegenstrijd met de verplichtingen verbonden aan Artikel 13(1) van de CRPD.

3. Discrimineert de juridische praktijk in India mensen met een psychische aandoening en zo ja, op welke manier?

Het derde deel van dit proefschrift beschrijft scheidingsrechtszaken die voorgekomen zijn in de ‘Family Court’ in Pune, India, waarbij een psychische aandoening als oorzaak voor de scheidingsaanvraag was opgegeven door een van de partijen. Het merendeel van deze aanvragen werd ingestuurd door mannen die hun vrouw ervan beschuldigden dat ze leed aan een psychische aandoening, wat aangeeft dat vooral vrouwen getroffen worden door dit type discriminatie. De scheiding werd toegewezen in bijna een vierde van de gevallen, zelfs zonder medisch bewijs van een psychische aandoening om de aanklacht te onderbouwen. In het geval dat er wel medisch bewijs werd geleverd was dit over het algemeen van slechte kwaliteit.

Vijfentachtig procent van de scheidingszaken bij de ‘Family Court’ waren ingediend door mannen die hun vrouw beschuldigden van het hebben van een psychische aandoening. Vijfennegentig procent van de zaken die het ‘High Court’ bereikten, waren aangevraagd door iemand van het mannelijke geslacht. Deze argumenten suggereren dat mannen eerder dan vrouwen psychische aandoeningen bij hun partner aangrijpen als reden voor een scheiding. Dit geeft mogelijk het verschil weer in sociale posities van mannen en vrouwen in de Indiase samenleving.

Uit onze studie komt ook naar voren dat slechts in een derde van de scheidingszaken medisch bewijs werd geleverd voor het bestaan van een psychische aandoening, ondanks het feit dat deze aandoening de reden was
voor de scheidingsaanvraag. In 22 procent van deze gevallen werd de scheiding alsnog toegewezen, indien er wel medisch bewijs was geleverd voor de aanwezigheid van een psychische aandoening was er sprake van 35 procent toewijzingen. Alhoewel de resultaten ook laten zien dat zelfs indien er medisch bewijs werd geleverd, dit vaak van te slechte kwaliteit was om hier een gefundeerde beslissing op te baseren.

4. Welke strategieën kunnen worden gebruikt op wetgevend en professioneel (juridische en geestelijke gezondheidszorg professionals) niveau om discriminatie te voorkomen?

Het vierde deel van dit proefschrift beschrijft verschillende ‘supported decision making’ modellen die wereldwijd worden gebruikt. Onze resultaten suggereren dat er een discrepancy bestaat tussen de internationale conventies (CRPD) en de nationale wetgeving. In onze studie hebben wij weinig bewijs gevonden dat er gebruik wordt gemaakt van ‘supported decision making’ en nog minder bewijs voor het gebruik van interventies die de autonomie en besluitvorming buiten de behandelingkeuzes onderzoeken.

Dit onderzoek toont aan dat slechts enkele landen het gebruik van ‘supported decision making’ faciliteren voor mensen met psychische aandoeningen, waarbij het faciliteren hiervan vooral tekort schiet in landen met een laag- en middeninkomen. In deze landen werden gezondheidsmedewerkers ook niet getraind op het gebied van ‘supported decision’. Het blijft de vraag hoe de ‘supported decision making’ modellen gebruikt kunnen worden door artsen en patiënten en hoe deze aangepast kunnen worden aan de medische en juridische context in de landen met een laag-en middeninkomen.

‘Psychiatric Advance Directives’ (PADs) is een vorm van ‘supported decision making’ die mensen met een psychische aandoening de mogelijkheid biedt de controle over hun behandeling terug in eigen handen te nemen, zelfs ten tijde van ziekte wanneer hun besluitvorming ernstig gestoord kan zijn. Uit literatuur onderzoek blijkt dat de implementatie van PADs verschillende problemen met zich meebrengt op het niveau van systemen, op het niveau van de gezondheidsmedewerkers en op het niveau van de gebruikers van de zorg. Deze
problemen kunnen opgelost worden door het gebruik van verschillende strategieën: er kan een bemiddelaar worden ingeschakeld die mensen met een psychische aandoening kan helpen bij het aanvragen van PADs, er moet meer aandacht en training worden gegeven over PADs en ‘Supported decision making’ aan gezondheidsmedewerkers en er moet een mogelijkheid worden gecreëerd voor het opslaan en opvragen van PADs in informatie systemen van gezondheidsinstellingen.

Ook bevat het vierde deel van dit proefschrift een gecombineerd kwalitatieve en kwantitatieve studie die inzicht geeft in de visies van de ‘Advance Directive’ gebruikers in Tamil Nadu, India. De meeste cliënten en zorgverleners waren niet op de hoogte van het bestaan van de PADs. Slechts enkele cliënten benadrukten het belang van inspraak in hun behandeling, terwijl zorgverleners zorgen uitte over het besluitvormingsvermogen van hun cliënten. Na het afvullen van de PADs rapporteerden cliënten een verhoogd niveau van zelfredzaamheid en een verhoogde behoefte om eigen beslissingen te maken. De kwantitatieve studie toonde aan dat mensen met een ernstige psychische aandoening duidelijk hun behandelingswensen konden formuleren in een PAD en dat deze PADs haalbaar, bruikbaar en in overeenstemming met de zorgstandaarden zijn. Ondanks de zorgen van de zorgverleners dat de PAD zal worden gebruikt als middel om behandeling te weigeren, werd dit door geen van de cliënten aangedragen in hun PAD en slechts enkelen waren het oneens met gedwongen opname en behandeling.

5. *Hoe kunnen de bovenbeschreven inzichten in de praktijk worden toegepast?*

De auteur van dit proefschrift heeft als consulent bij het Ministerie van Volksgezondheid en Welzijn bijgedragen aan het tot stand komen van de nieuwe geestelijke gezondheidszorg wet (MHC wetsvoorstel) in India. Het laatste deel van dit proefschrift geeft de bijdrage weer van de auteur aan het tot stand komen van het MHC wetsvoorstel en als lid van de beleidsgroep op basis van de toepasbare bevindingen uit dit proefschrift.

De bevindingen van dit onderzoek geven weer dat het rechtssysteem in India, de wetten en het in praktijk brengen van deze wetten, systematisch mensen
met een psychische aandoening discrimineert door deze mensen het zelfbeschikkingsrecht te ontzeggen. Als eerste zouden wetten in India het zelfbeschikkingsrecht van mensen met een psychische aandoening moeten erkennen. Tevens is het vereist dat mensen met een beperking kunnen deelnemen aan de samenleving en gelijkwaardig zijn aan anderen, zoals beschreven in de ‘social model theory’. ‘Supported decision making’ stelt mensen met een psychische aandoening in staat tot gebruik te maken van hun rechten zoals ieder ander. PADs zijn een vorm van ‘supported decision making’ die mensen met een psychische aandoening in staat stelt om van hun zelfbeschikkingsrecht gebruik te maken, zelfs ten tijde van ziekte wanneer hun besluitvormingsvermogen mogelijk gestoord is. Het opnemen van ‘supported decision making’ in de wet, erkent het bestaansrecht van mensen met een psychische aandoening en is van cruciaal belang om discriminatie te verminderen.

Naast het veranderen van de wetgeving is het ook noodzakelijk juridische en geestelijke gezondheidszorg professionals inzicht te verschaffen in de mogelijkheden tot zelfbeschikking voor mensen met een psychische aandoening en hun eigen negatieve houding hiertegenover. Het trainen van deze professionals biedt de mogelijkheid om ze meer kennis op dit gebied te laten vergaren en hun negatieve houding te reduceren.
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