Global Mental Health 6

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

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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.

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

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

Search strategy and selection criteria

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 (eg, “mental health problems”, “mental illness”, “mental disorder”, and “mental health services”) and restrict the focus to low-income and middle-income countries where possible (eg, “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 (eg, “violations”, “abuse”, “discrimination”, “stigma”, “exclusion”, “financial”, and “employment”); and identify strategies (eg, “mental health literacy”, “empowerment”, “service user organisations”, “complaints mechanisms”, “rehabilitation”, and “advocacy”).
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.

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 (see webappendix). 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.

Respondents were contacted by use of a convenience sampling method. The authors identified organisations representing people with mental and psychosocial disabilities and other relevant entities (eg, 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—ie, the thematic codes were generated directly

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

See Online for webappendix
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%), and the median age was 41.0 years.

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 (eg, health, food, education, and employment) and guaranteeing basic freedoms (eg 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. 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. This tends to perpetuate patterns of unemployment and dependence.

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. Poverty-related constraints mean they are usually the first to be deprived of the possibility of going to school. 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 education. 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. 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. 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. 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. Deficiencies in the built environment of mental health facilities can impede effective treatment and recovery, which can result in worsened mental and physical health of service users. 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 psychosocial 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.22,25,28

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.22,29 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.30–32 Seclusion, isolation, and restraint—used as punishment or coercion—are another feature of many institutions.1,33,34 In many low-income and middle-income countries, there is an absence of recovery-oriented treatment,35 with people with mental and psychosocial disabilities chained to beds or posts and made immobile for long periods of time.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.27,36 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.11,32,34

**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.36,37 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.2,17

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.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.39 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.30–42

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.39 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 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.44 However, there are few examples of such campaigns in low-income and middle-income countries, and fewer assessments of their effectiveness.43 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.44–46

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.51 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.47 Finally, information campaigns should be conducted on a long-term, routine basis.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.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.6,7,52,53

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,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.1,7,32

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.1,7

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.1,16–18 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.1,19

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.20,21 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.22 Types of support might include advocates, a
personal ombudsperson, community services, personal assistants, peer supports, and advance planning.63

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 psychosocial 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.64 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.65–67 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.68–70 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.18–20 Participation also leads to assessments that are more likely to address people’s requirements and concerns.21–22 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.71 Despite these benefits there is little evidence of countries involving people with mental and psychosocial disabilities in service assessment.72

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.15–27 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.15–29,40 In reference to legislation specifically, one respondent from Nepal said that “[our] laws are discriminatory. They encourage the authorit[i]es 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

### 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
- 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

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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.17,81–83

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 (ie, 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.84

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 Rights46 and the Inter-American Court on Human Rights85 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,29,85 and the European Committee on Social Rights has decided on two collective complaints concerning the education of children with intellectual disabilities.86,87 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.88

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 Shukataurov 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. 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.

Acknowledgments
We thank all the people with mental and psychosocial disabilities and their organisations who provided their expertise and opinion on issues related to mental health and human rights. We also acknowledge a number of people for their help and support in the development of this article: Albert Maramis, Anita Marini, BasicNeeds Sri Lanka, Charlene Sunkel, Dan Taylor, Daniel Rivera, George Tudor Florea, Jan-Paul Kwaski, Manana Sharashidze, Moody Zaki, Patricia Robertson, Sarah Skeen, and Shadi Jaber.

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