Inclusive Futures
Promoting disability inclusion

Disability Inclusion Helpdesk Report

Query	What works on rights and participation for people with mental health conditions and psychosocial disabilities: a rapid review
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Query	What works to ensure people with mental health conditions and psychosocial disabilities enjoy their rights and participate in decision-making? What are examples of effective interventions in this area?

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OVERVIEW

- There is widespread evidence of **human rights abuses** of people with psychosocial disabilities both within and outside of institutions and **exclusion** from development opportunities.
- The UNCRPD is key in the **recognition of human rights** for people with psychosocial disabilities including the right to health.
- **Participation is a core human rights principle** and requisite of a human rights-based approach.

There is a growing, but still limited, **evidence base around what works** to strengthen rights and participation, including:

- Integrating mental health into **laws and policies** related to health, social welfare, employment, education and criminal justice can protect rights and support compliance with the CRPD.
- Developing **national mental health policy and action plans** to protect the rights of people with mental health conditions.
- **Campaigns to tackle stigma** linking mental distress with living conditions may work better than using illness models, along with a recognition of the multifaceted and structural nature of stigma. There is also evidence to show that social contact approaches are effective at tackling discriminatory attitudes and behaviours.
- **Rights-based community services** sensitive to gender and the life course can improve access and outcomes.
- **User-involvement** in service monitoring, planning and research can improve voice and decision making in services and **support for mental health advocacy groups** can help put pressure on national governments to observe rights. However, evaluations of participation are limited, especially from LMICs.

Key enablers include:

- Adequate **resources** for advocacy, support and research led by people with psychosocial disability.
- **Policy and laws** on legal capacity, participation and decision making in line with international conventions.
- The convergence of both human rights and **social determinants**.
- The **WHO's QualityRights** assessment can help drive mental health system reform at the national level.
- **Research** led by or in partnership with people with psychosocial disability, including on participation in decision-making.

1. Rights

Summary[1] of issues and commitments

Widespread evidence exists documenting human rights abuses of people with psychosocial disabilities both within and outside institutions globally (Drew, Funk, Tang, et al., 2011). [2] Furthermore, there is evidence of violations of economic, social and other rights, and the denial of autonomy and legal capacity (Human Rights Council, 2017).

There are complex connections between mental health and human rights and long-standing debates remain, in particular on the use of involuntary psychiatric interventions (Puras and Gooding 2019). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the 2030 Sustainable Development Goals (SDGs), however, have provided the opportunity for all stakeholders to rethink longstanding methods, address power imbalances and implement innovative practices.

The UNCRPD has been key in the recognition of human rights for people with psychosocial disabilities including the right to health[3]. It was developed in collaboration with people with psychosocial disabilities, recognises the equal legal capacity and free and informed consent of persons with disabilities, and equal right to respect for physical and mental integrity, as well as the freedom from torture and cruel, inhuman or degrading treatment or punishment.

The right to health in the UNCRPD contains both freedoms such as the right to be free from non-consensual medical treatment, and entitlements (such as health protection and equality of opportunity). It is regarded as an inclusive right, extending not only to timely and appropriate health care, but also to the pre-conditions which support mental health—social and underlying determinants - such as access to safe and portable water and adequate sanitation, healthy occupational and environmental conditions and opportunities and access to health-related education and information, including on sexual and reproductive health (See Puras and Gooding, 2019; Patel et al., 2018).The right to health may be linked to but is not reducible to a right to treatment or access to services, and should (in line with the UNCRPD) maintain a person's physical and mental integrity (Article 17), and ensure freedom from torture and from cruel, inhuman or degrading treatment or punishment (Article 15). A rights-based approach to mental health offers an alternative to narrow and individualised disease-oriented approaches (Puras and Gooding, 2019).

Persons with mental health conditions and psychosocial disabilities face major challenges in having their rights recognised (Human Rights Council, 2019). A report mandated by the Human Rights Council in resolution 32/18, identifies some of the major challenges faced by users of mental health services including stigma and discrimination, violations of economic, social and other rights and the denial of autonomy and legal capacity (Human Rights Council, 2017). The UN Human Rights Council states that a continued investment in policies and services, with prevailing patterns of coercion, excessive medicalisation and institutionalisation, are also a serious obstacle to the effective realisation of the right to mental health (Human Rights Council, 2019). Research shows many users of mental health services have experienced forms of violence and harm while in institutions (Disability Rights International, UN Human Rights Council, 2019). In addition, research shows that people with lived experience of mental health conditions commonly report feeling devalued, dismissed and dehumanised by health professionals across the board – "the pervasiveness with which negative interactions are reported suggests the

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[1] Please note this short report is based on a light-touch, rapid review of the publicly available evidence, involving 3 person days (2 researcher days, 1 expert day). It is one of four similar reviews examining the evidence on the four outcome areas articulated in DFID's draft theory of change on mental health: leadership and governance, services and community interventions, FCAS and humanitarian contexts. The reviews provide a snapshot of some of the key issues and focus on summarising findings from systematic reviews, evidence syntheses and key global thematic reports, including frameworks and guidance.

[2] There are numerous reports about human rights violations on the Human Rights Watch website: https://www.hrw.org/publications

[3] While widely lauded, the UNCRPD isn't without contention. The main issues within the user/survivor movement have been around whether mental health users find it useful to identify as 'psychosocially disabled'; and about if the social model of disability is useful for understanding mental health problems.

problem is not isolated to a few insensitive providers but is more systemic in nature—that it is a problem with how healthcare culture prioritizes and perceives persons with mental illnesses" (Knaak et al., 2017, p111). Promoting supportive, respectful and non-violent relationships in mental healthcare settings is now considered a priority (UN Human Rights Council, 2019).

What works

Integrating mental health issues into relevant laws and policies, for example, those related to health, social welfare, employment, education, and criminal justice to protect the rights of people with mental and psychosocial disabilities and comply with the CRPD. There is growing recognition of the importance of a comprehensive policy approach to mental health, and addressing the social determinants of mental health through integrating mental health in different policy areas (WHO, 2014). There are examples of high-income countries (HICs) that have successfully adopted such comprehensive approaches. For example, Australia's National Mental Health Strategy includes dedicated mental health policies and action plans as well as integrates mental health across other policy areas such as housing, education, employment and aging (WHO, 2014b). There are fewer cases where LMICs have adopted comprehensive approaches to mental health policy, however there are some examples such as South Africa and Uganda whose mental health policies have been recognised as comprehensive (Zhou et al., 2018).

Developing national mental health policy and action plans to protect the rights of people with mental health conditions. In its technical support to countries to develop mental health policy and action plans, WHO emphasises three areas as crucial: 1) provide evidence based approaches to deinstitutionalise mental health care, 2) integrate mental health into general health care, and 3) develop community mental health services (WHO, 2019). WHO highlights the Gambia as a good example of national mental health policy development. The policy formulation in the Gambia included conducting a situational analysis and numerous consultations with experts in the field of mental health, health professionals and stakeholders from different government sectors (WHO, 2010b).

Understanding the critical role of the social and underlying determinants of health to advance the realisation of the right to mental health and breaking down stigma and discrimination. A recent report by the UN Human Rights Council (2019) argues that "conceptualising the determinants of mental health requires a focus on relationships and social connection, which demands structural interventions in society and outside the health-care sector" (Human Rights Council, 2019, p2). These interventions move away from individualised causal models that tend to focus on immediate factors, including individual behaviour, rather than the structural issues and root causes. The World Health Organisation's (WHO) Comprehensive Mental Health Action Plan 2013–2020 also includes the promotion of mental health through action on social determinants as one of its five key objectives (WHO, 2013). Promising examples to address social determinants around poverty, inequality and gender norms, include, microfinance interventions, peer support networks, school-based interventions with teachers, parents and community members, and family support or parenting programmes (WHO, 2014b).

Tackling stigma and discrimination and human rights violations by using evidence-based strategies. The literature highlights that there are many global campaigns that try to tackle stigma by normalising mental health conditions by educating the public that mental health is similar to physical illness. However, there is growing evidence from research into schizophrenia and stigma (Angermeyer, and Matschinger, 2005; Longdon and Read, 2017; Read et al. 2006;) that illness models may be more stigmatising. This is also supported by a systematic review which shows that large scale initiatives have largely been unsuccessful because they fail to recognise the multifaceted and structural nature of stigmatisation (Kaushik et al., 2016). An evaluation carried out in England on a national anti-stigma campaign called Time to Change, has shed some light on what works in tackling discriminatory arttitudes and behaviours (Henderson, C and Thornicroft, G 2013). Time to Change was aimed both at the general population and at specific target groups (identified by people with experience of mental health and psychosocial disabilities), as well as people with mental health conditions themselves. It involved distributing social marketing campaign materials, collaborating in staging public relations events and holding events to promote social contact. These approaches aimed to tackle different aspects of stigma – for example, the campaign used a conceptual framework that understood stigma as consisting of difficulties of knowledge (ignorance or misinformation), attitudes (prejudice) and behaviour (discrimination) (Henderson, C and Thornicroft, G, 2013). To asses progress, annual surveys of discrimination were carried out over a number of years using the Discrimination and Stigma Scale. Results showed a positive impact for five of the six phases or bursts of the campaign, and suggests a "positive relationship between social contact and a reduction in prejudice, both of improved attitudes and great confidence to tackle stigma" (Henderson, C and Thornicroft, G, 2013, p46). However, the evaluation found that it was harder to address negative attitudes of health professionals through such approaches – "this may have been because the campaign lacked market penetration among health professionals or that the 'clinical fallacy' means their attitudes and behaviours are more resistant to change" (Henderson, C and Thronicroft, G, 2013, p 47). The authors suggest that the social contact model is explored further in future work and that focused and longer-term approaches may also be more effective.

Supporting rights-based community and recovery-oriented services[4] that are sensitive to gender, race, disability and the lifecourse (Mental Health Innovation Network, 2018). These services acknowledge that people with lived experience are best placed to determine which outcomes are important to them and how their needs can be met. In LMICs or contexts where specialised care is scarce, cost effective psychosocial interventions can be provided by general care workers, including family doctors, nurses and home visitors. For example, in Uganda, people with mental health conditions receive general health care together with their mental healthcare. Primary healthcare workers are trained to identify any mental health problems, treat those with more minor mental health conditions, manage emergencies and make referrals when needed. The model was found to improve access, produce better outcomes and minimise disruption in people's lives (WHO, 2010). The findings show that a task sharing model at the community level whereby trained healthcare workers are supported to provide care for people with mental health conditions, is an effective approach, espcially in low-resource settings.

2. Participation

Summary of issues and commitments

Participation is a core human rights principle (Human Rights Council, 2016, p. 5), and the active and informed participation of different groups is a requisite of a human rights-based approach (OHCHR, 2002). 'People have a right to participate in decisions that affect their lives, including those concerning their rights' (Human Rights Council, 2016, p. 5). Despite this, there is widespread exclusion of, and lack of participatory opportunities for, people with psychosocial disabilities in low income settings. The Human Rights Council states that 'in practice, persons with disabilities continue to face barriers to their participation as equal members of society, all over the world and they rarely occupy positions in governments, their opinions are seldom considered, and they are usually not consulted in policymaking, including on matters directly affecting them.' (Human Rights Council, 2016, p. 8). For example, people with psychosocial disability have been found to be 'excluded from development opportunities', including exclusion from development initiatives requiring recipients to be 'mentally and physically sound' to qualify for assistance (WHO, 2010a: xxiv, 34, 3).

While there is evidence of lack of participation opportunities for people with psychosocial disabilities, there is less available evidence, particularly within LMICs, showing effective and meaningful participation across multiple spheres of life (see Human Rights Council, 2016). There is a gap in evidence on the effective and meaningful participation of people with psychosocial disabilities in research, design, delivery, monitoring and evaluation of support services, policies, law and strategies, globally and especially in LMICs. Equal participation of people with psychosocial disability in decision-making and knowledge production is rare and largely undocumented. Lack of evidence does not mean that locally meaningful and promising evidence does not exist, it may instead signify lack of investment in organisations run by, or working with, people with psychosocial disabilities.

Evidence highlights the long-standing exclusion of people with psychosocial disabilties from civic space, including some disabled people's organisations and the disability movement more broadly (Mental Health Innovation Network, 2018). Cross-sectional global surveys (Lasalvia et al., 2013; Thornicroft et al., 2009) found

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[4] Emerging from the Recovery Movement, recovery-oriented approaches are strengths-based, do not focus solely on symptoms, see recovery as an ongoing process, and emphasise recovering control over one's life, including the ability to transform living conditions. Recovery means different things to different people, with a focus on having a good quality of life, that is full and meaningful (Mental Health Foundation & NSUN, 2012).

consistently high rates of both anticipated and experienced discrimination of people with diagnoses of depression and schizophrenia, across countries. Thornicroft et al. (2009) find that negative discrimination experienced in many domains of life might be related to prior coercive mental health service intervention. Their findings emphasise the importance of combing stigma reduction and implementation of disability discrimination legislation with interventions to reduce anticipated discrimination and increase self-esteem. The importance of the participation of people with psychosocial disabilities in planning, monitoring and evaluation of services and programming, is now being more widely recognised and enacted (Sweeney and Wallcraft, 2010; Thornicroft and Tansella, 2005; WHO, 2019). Less prominent in the global literature is engagement with knowledge production (i.e. research and literature) by those who identify as service users, psychiatric survivors, or people with psychosocial disability, and with user-run organisations (which exist globally). Where participation does not extend to participation in knowledge production about mental health, there may be a reliance on professional 'expert driven strategies', with little inclusion of experts by experience (Wallcraft et al., 2009; National Survivor User Network; PANUSP, 2014).

What works?

Increasing the effective and meaningful participation of, and user-involvement in, service monitoring, planning and evaluation, and in research, is key in order to improve quality, accessibility and availability of services and mental health system strengthening (Sweeney et al., 2010, Carroll et al., 2016, Wallcraft et al., 2009, Thornicroft and Tansella, 2005). Supporting the meaningful participation of, and user-involvement in system strengthening is emphasised in much of the global literature to address the poor quality of services:

- Promising evidence and guidelines in this area exist within HICs. For example, the National Involvement Partnership (NIP) project, with the National Survivor and User Network (NSUN), co-produced National Standards (2013) and basic principles for effective co-production in order to improve experiences of services and support across the UK (NSUN, 2013). There is little available evidence, however, to show where and how this has been done in LMICs, particularly at the systems or policy level.
- Positive examples include research in four LMICs, by the World Psychiatric Association (WPA), in collaboration with people with psychosocial disabilities, service users and carers (Wallcraft et al, 2013). The recommendations on best practices in working with service users and family carers' include: respecting human rights as the basis of successful partnerships for mental health; developing legislation, policy and clinical practice relevant to the lives and care of people with mental disorders in collaboration with users and carers; promoting and supporting the development of users' organisations and carers' organisations; improving the mental health of all sectors of the community as a fundamental condition for formulating policies to support economic and social development; recognising that the best clinical care of any person in acute or rehabilitation situations is done in collaboration between the user, the carers and the clinicians; and enhancing user and carer empowerment (Wallcraft et al., 2013).
- Other promising approaches include working with health care providers and staff to teach skills that help them know ''what to say'' and ''what to do" by making use of social contact (seeing people with lived experience as educators as well as service users) and supporting more people-centered recovery interventions (Knaak et al., 2017).

Supporting the active participation, empowerment and organisation of persons with psychosocial disabilities. The right to associate is important for people with mental health conditions because membership in advocacy and peer support groups can foster skills development, empowerment, and autonomy. User-driven self-help and support networks improve the mental health of both participants and families, and result in reduced health care utilisation, enhanced self-management, and improved mental health outcomes (WHO, 2010, p. 52). Mental health advocacy groups are also an effective way of pushing the mental health agenda and putting pressure on national governments to observe the right to health. A 2016 sytematic review established that mental health service users were rarely informed of their rights and as a result, hardly ever made complaints (Semrau, 2016). Service user organisations and peer networks can support people with psychosocial disabilities to learn their rights and better advocate for their needs and rights, as well as support recovery. See example of intervention from Users and Survivors of Psychiatry in Kenya (USP-K) in the next section on effective interventions.

3. Examples of effective interventions

International instruments dictate that the rights and participation of people with mental health conditions and psychosocial disabilities must be promoted at various levels of society. The examples below illustrate effective interventions at different levels, from working through community-based approaches in Kenya to working with the national mental health care programme in Lebanon.

Example 1: Increasing legal capacity of people with psychosocial disabilities through peer-support and self care and self help interventions. Users and Survivors of Psychiatry Kenya (USPK) is a national membership organisation which operates completely outside the mental health system in Kenya. It utilises community-based approaches to support people living with psychosocial disabilities. Since 2012, **USKP has established 15 peer-support groups across Kenya and a virtual support group using WhatsApp**. The peer-support groups provide a space, for people with different psychosocial disabilities, to share information and discuss a range of topics, often centring around mental health care and treatment as well as choices that people face in their daily lives. A qualitative study was carried out on the intervention in 2016, which explored the linkages between peer-support and legal capacity, focusing on the autonomy to make decisions that have legal consequences e.g. related to heath care (USP-K, 2016). The study found multilayered linkages between participating in the peer support groups and participants' capacity to exercise legal capacity, boosting their participation in decision-making on mental health treatment. Participants reported using information shared through peer-support meetings to influence decisions around their mental health treatment. For instance, they learn about side effects of different treatments and about what others can or cannot do to them from a rights-based perspective and use this information to express their wishes regarding treatment options (USP-K, 2016, p. 19). Secondly, increases in autonomy and agency were found as a result of the peer-support meetings. Many people with psychosocial disabilities in Kenya live in situations of dependency on their families and are often poor and unemployed. These factors coupled with social stigma surrounding mental health conditions is seen to affect their self-esteem. Being part of the peer-support groups allow people to see that others in similar situations are able to be active decision-makers in their own lives, which boosts people's sense of independence and agency. And thirdly, people's autonomous decision-making was highlighted. Members of the peer-support groups reported that they increasingly make decisions without seeking advice from the group, as some feel confident enough to make decisions independently: – "*after periods of time, members start to claim their voice and to become more assertive…..in part because they see other people, who share similar diagnosis making their own decisions and bring in control of their lives"* (USP-K, 2016, p. 19).

Example 2: Improving quality and ensuring protection of human rights in mental health systems using WHO's QualityRights Toolkit. Recognising that mental health care around the world is struggling to provide quality care and ensure the rights of service users are respected, WHO's Quality Rights initiative aims to provide tools to support countries to assess and improve their mental health care systems from a rights-based perspective using participatory approaches. The toolkit contains a series of modules that can be used by governments and non-governmental organisations (NGOs) to assess the state of the mental health care system and to build the capacity of mental health care workers, NGOs and disabled persons organisations (DPOs), service users and their families. The modules include understanding human-rights based approaches to mental health care, promoting decision-making in treatment planning, and assessing quality of services (WHO, 2019). In Lebanon, the National Mental Health Programme under the Ministry of Public Heath, with the support of WHO, piloted the assessment in two private facilities. The assessment team included professionals in mental health, public health and social work, human rights advocates, as well as people with lived experience of mental health conditions (MHIN, 2019a). The assessment found that facilities provided services generally of good quality and that facility staff were respectful towards service users, however, their knowledge of human-rights in mental health services was limited (MHIN, 2019b). Furthermore, the development of treatment plans was found to be led by medical staff with limited involvement of service users in decision-making. Professionals and service users have since developed improvement plans jointly with the assessed facilities and a second assessment is planned to be conducted to follow up on progress made against the areas of improvement identified. The active participation of service users is described as a key aspect of the assessment (WHO, 2019). Other countries, including India and Ghana, have started to use the approach. For example, DFID is currently supporting the largest national rollout of the WHO QualityRights initiative in Ghana which will also provide important lessons for delivering human rights based approaches at scale.

There is insufficient allocation of resources for mental health advocacy, support and research led by people with psychosocial disabilities. While development assistance towards the global promotion of mental health is on the rise, less than 1% of the budgets of overseas development assistance goes to mental health (Human Rights Council, 2019). This is also the case for most LMICs; the majority of which invest less than 1% of their health budgets in mental health services (WHO, 2015). UN Special Rapporteurs are also concerned that a human rights-based approach is not fully integrated into international projects that assist developing countries in improving their mental health policies and services.

There is a disconnect between international conventions (i.e. the UNCRPD) and laws particularly on legal capacity, participation and decision making. A review of the evidence on supported decision making for persons with mental health conditions, both in legislation and research globally, with a focus on LMICs shows that only a few countries have provisions for supported decision-making (Pathare and Shields, 2012). A shift to a more inclusive and supportive system enabling decision-making by persons with psychosocial disabilities is taking time, leaving room for different interpretations in policy and programming.

Research on decision-making, when carried out, has been largely restricted to the medical domain, focusing primarily on treatment decisions (Pathare and Shields, 2012). There is limited research outside this sphere on the effectiveness of other decision-making interventions for people with psychosocial disabilities, nor of people with psychosocial disability as knowledge producers and researchers.

The right to health is best enabled through the convergence of both human rights and social determinants. Research and action on the structural, political and social determinants of distress, including poverty, inequality, and discrimination, are vital (Puras and Gooding, 2019). This would also enable focus on developing, and identifying existing, upstream protective factors for mental health, such as standard of living and social inclusion (Puras and Gooding, 2019). In order to rebalance development assistance, it is important to engage with diverse leadership and civil society, especially that representative or are led by persons with psychosocial disabilities

The WHO’s QualityRights assessment, training and guidance tools could enable better advocacy to help drive mental health system reform. The QualityRights tools have already had a significant impact in changing attitudes, practices and service delivery — for respect of the right of the individual to make his or her own decisions, to provide people with information and choice about treatment options, and to end forced treatment, seclusion and restraint (Human Rights Council, 2018).

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Helpdesk services are provided by a consortium of leading organisations and individual experts on disability, including Social Development Direct, Sightsavers, Leonard Cheshire Disability, ADD International, Light for the World, BRAC, BBC Media Action, Sense and the Institute of Development Studies (IDS). Expert advice may be sought from this Group, as well as from the wider academic and practitioner community, and those able to provide input within the short timeframe are acknowledged. Any views or opinions expressed do not necessarily reflect those of DFID, the Disability Inclusion Helpdesk or any of the contributing organisations/experts.

For any further request or enquiry, contact enquiries@disabilityinclusion.org.uk

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