

Reclaiming citizenship through rights-based, person-centred, and recovery-oriented mental health services.

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Introduction

Human rights violations in mental health care across nations have been described as a “global emergency” and an unresolved global crisis. We know that human rights violations can negatively impact mental health (McGovern, 2022; WHO, 2019, 2021). On the contrary, respecting human rights can improve mental health (Mahdanian, Laporta, Bold, Funk & Puras, 2022). Dainius Pūras, the former Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (2014-2020), has stated: «We need little short of a revolution in mental health care to end decades of neglect, abuse, and violence” (UN, 2020, p. 3). Like many others, he has revealed great concern about the human rights violations, stigma, marginalization, and unavailable and inaccessible services that are common in the mental health systems across the globe. Although there have been some improvements with the development of community mental health services, recovery orientation, peer support work, and emphasis on citizenship, there is a need for urgent action on human rights within mental health services as well as in society as a whole. As Mahdanian and colleagues summarise (Mahdanian, Laporta, Bold, Funk & Puras, 2022): “The human rights perspective requires society, particularly policymakers, to actively promote necessary conditions for all individuals to fully realize their rights. We suggest developing a more comprehensive model in mental health that integrates human rights into existing services and approaches. A model that recognizes that all people with mental health conditions and psychosocial disabilities are rights holders”.

In this paper, we will present and discuss The World Health Organization (WHO) QualityRights initiative, particularly related to the recovery and implementation of the UN Convention on the Rights of People with Disabilities (CRPD). We will start with a brief introduction to the Norwegian mental health system, where the authors are based. This is followed by a discussion of how the QualityRights initiative represents an opportunity to operationalise CRPD rights into mental health services and strengthen ongoing initiatives of recovery orientation and citizenship. QualityRights offers practical guidance as to how services can move toward the reduction of coercive practices and supporting the transition toward mental health services that respect human rights standards and promote recovery orientated and community-based practice (WHO, 2019; 2021). The authors hope to make the case that mental health care services have nothing to fear but much to gain from embracing the QualityRights progressive and forward-looking model for mental health services.

The Norwegian context

Norway has a long tradition as a welfare state beginning in the 1930s. Central values and principles are social solidarity, collective and mutual responsibility for all citizens, and an egalitarian view of distributive justice (Karlsson & Borg, 2017). Mental health services as an integral part of the welfare state have for the last decades gone through similar developments as many western countries, with emphasis on decentralization, community developments, and reduction of traditional inpatient treatment. An important policy document in Norway was the National Action Plan for Mental Health (The Norwegian Ministry of Social and Health Affairs, 1997). Major changes were initiated in this plan, like strengthening user involvement,

interdisciplinarity, and community-based services (CMHC), and a goal for a reduction in the dominance of biomedical approaches. We have seen some developments and positive progression. However, the position of inpatient treatment and traditional diagnostic and standard individualized psychiatric practices have continued – both in institutions and in the community-based mental health services. Unfortunately, in the opinion of these authors, a dominant and narrow biomedical approach to mental healthcare still prevails. Furthermore, a rather fragmented system of care has developed, which is difficult to navigate both for citizens in need of help, family members, and professionals. At present, the Norwegian mental health system consists of a specialist mental health level with traditional inpatient units, outpatient clinics, community treatment teams, and day centers. Then there are mental health and substance abuse services at municipality levels, also as community services and teams, home support, and day centers. In addition, we have The Norwegian Labor and Welfare Administration (NAV), where citizens can get help concerning work, occupational assessments, social benefits, social security, etc. Citizens using services describe a system at odds with itself often with an overwhelming focus on assessment and diagnosis, rather than meaningful engagement and support to realize goals and live a good life.

Norway also has high levels of coercion and forced treatment, and even though this has been cited as a government priority over the last 20 years, the high number of incidents still prevails.

CRPDs status in Norway

Norway ratified the CRPD in 2013, with interpretative declarations that stated that the Norwegian understanding of CRPD articles 12, 14, and 25d allowed for deprivation of legal capacity and forced mental health treatment in exceptional cases. This is in direct contrast to the CRPD-committees interpretation of these articles. The discourse around CRPD at a governmental level has been centered around a high-temperature debate on the use of force in exceptional cases. The Conventions' effect on clinical practice within the mental health system has so far been marginal. There has been no central initiative from the government to ensure knowledge and education about the CRPD. The paradigm shift the CRPD represents remains unknown to mental health professionals at all levels.

The consequences of the CRPD for people with psychosocial disabilities are advocated strongly by WSO – We Shall Overcome, a Norwegian organization run by users and survivors of psychiatry, established in 1968. WSO has throughout many years, advocated for the human rights of persons with psychosocial disabilities and people subjected to interventions from the mental health system. It has campaigned for the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) as well as bringing compulsory mental health practices to an end. WSO has been challenging the high incidence of compulsory treatment in mental health services in Norway, human rights violations, and the lack of incorporation of the CRPD into domestic law (WSO, 2019). All of this is a major barrier to the full and effective realization of the rights outlined in the UN Convention.

The current debate about the role of the CRPD within Norwegian mental health services and the creation of a new model that places rights, citizenship, and recovery at their centre, has been undynamic and fragmented. In March 2021, the government voted against the incorporation of the UN CRPD into Norwegian law for the third time (ref). The primary argument against the incorporation was the requirement of mental health services to treat people against their will, a violation of rights as afforded under the CRPD. It is also against the expressed demands of the organisations of persons with disabilities in Norway (CRPD Koalisjonen, 2019). This is a situation of great concern. Recovery research has for decades revealed that the best way to support a person's mental health and wellbeing is through freedom and experiences of choice, partnership with the individual, listening out, making plans, and working together (Borg & Davidson, 2008; Price-Robertson, Obradovic & Morgan, 2017). Central aspects of recovery are connectedness, hope, identity, meaning in life, and empowerment – and risk.

Recovery of citizenship

The Recovery- perspective more widely has moved from primarily being seen as an individual process, to also being considered as a social process, which involves citizenship, living conditions, and human rights (Hamer, Rowe & Seymore, 2019; Eiroa-Orosa & Rowe, 2017; Pelletier, Corbière, Lecomte & et al., 2015).

In the QualityRights Course Guide on “Recovery practices for mental health and wellbeing” (WHO, 2019) the CHIME framework is used as a basis. CHIME emphasizes connectedness, hope, identity, meaning in life, and empowerment as key to recovery. Risk-taking is included in the QR training as an important component of the recovery process.

1. *Connectedness*: People need to be able to access the same opportunities, services, and resources in the community as any other person. The services that promote recovery should be influenced by, and based on, the local context and needs. It is also important to remember that inclusion goes beyond the individual to involve the community and society as a whole. • Relationships are key to all people’s lives.
2. *Hope*: Recovery is about hope and optimism for the future. Hope is key to recovery. Without hope, people can give up their recovery journey. The belief that changes in one’s life or circumstances are possible is central to the recovery approach.
3. *Identity*: Recovery means exploring your identity. Identity can broadly be defined as how one sees oneself as an individual and in relation to other persons and the community that one lives in. The recovery approach supports people to (re)connect, (re)build, or (re)define their identity as well as overcome the “internalized oppression” or “self-stigma” that can put identity at risk.
4. *Meaning in life*: Recovery supports people to (re)build and finds meaning in their lives. Meaning and purpose in life vary for everyone and people find meaning in very different ways. Dreams and aspirations are key for recovery as they can empower and support people to find meaning and fulfillment in their lives.
5. *Empowerment*: Recovery is a positive message that empowers people and gives them control. Control and choice are central to recovery. People are often denied the right to decide about key aspects of their life, including their care and treatment. In contrast, a recovery approach respects a person’s right to exercise their legal capacity, including the person’s right to make their own choices, with or without support from others.
6. *Risk-taking*: Recovery involves taking risks. Risk-taking may be required if people are to embark on a recovery journey. People must be free to take risks and make mistakes as everyone else does in order to have access to opportunities to learn and grow from their experiences (WHO, 2019).

In our view, these aspects of Recovery are closely linked to citizenship, which has gained attention in the mental health field over the past decade. Citizenship is still a relatively new and less widely known concept than recovery. The goal of recovering citizenship is in our opinion central to the recovery process and of course in taking one’s place as a rights bearer. Citizenship can be described as the person’s strong connection to the 5 Rs of the rights, responsibilities, roles, resources, and relationships that a democratic society makes available to its members. This is done through public and social institutions, the “associational life” of voluntary organizations such as churches and neighborhood organizations, and social networks and everyday social interactions (Rowe & Davidson, 2016).

Two main paths to citizenship are available for excluded persons and groups. One involves the person's efforts and supports to gain access to full citizenship. The other involves society's responsibility to open up access to and support citizenship, including but not limited to legal citizenship for previously excluded or marginalized groups. As governments and societies erect barriers to this path to citizenship, social activism of excluded persons and their supporters, and resulting social conflict, are often required to clear the way (Rowe & Davidson, 2016). As a group, people with psychosocial disabilities and mental health conditions face many barriers to accessing the rights, responsibilities, roles, resources, and relationships that should be afforded to them within a democratic society. Through the prism of citizenship, the solution lies not only in the efforts of the service user movement but the onus on wider society to be inclusive for all citizens.

QualityRights

Earlier in this Bulletin, Michelle Funk and her colleagues give a brief outline of why Quality Rights was developed and what it has to offer mental health and mental health services.

QualityRights is the World Health Organization's global initiative to improve the quality of care in mental health and related services and to promote the rights of people with mental health conditions or psychosocial disabilities in line with CRPD. The major areas of work at the core of the QualityRights initiative are:

- Building capacity among all stakeholders to improve attitudes and practices to address stigma and discrimination and promote human rights and recovery
- Supporting countries in the creation of community-based services and supports that respect and promote human rights
- Promoting the participation of persons with lived experience and supporting civil society
- Supporting national policy and law reform in line with the Convention on the Rights of Persons with Disabilities (CRPD) and other international human rights standards

The wide range of training and guidance tools and materials to strengthen knowledge and build capacity on rights, citizenship, and recovery¹, has a lot to offer service transformation through the easy access and concrete approach. One of the key tools developed is the QualityRights e-training on mental health, recovery, and community inclusion. The e-training is currently available free of cost in the following 11 languages. The training programs are developed in partnership with service users, family members, practitioners, managers, and providers. It is as well culturally sensitive through its global approach.

QualityRights emphasizes capacity-building for citizens as well as services and community, lived experience knowledge (WHO, 2019; 2021). National policies are also highlighted as necessary areas of reform in order to promote the transformation of services. There is an urgent need for radical and fundamental changes in the knowledge base, professionals' skills and competencies, and service objectives and framework. The authors will offer some suggestions as to how QualityRights can support the development of human rights practices within mental health.

How QualityRights can support human rights practices within mental health.

Take recovery seriously and back to its roots

Albeit an individual process that is different for everyone, it remains important to clarify what a person or service means by the use of the word "recovery". As we see it, there is a need for services to have a commitment to human rights, freedom of choice, personal control, and citizenship as a basis for recovery as well as the way that they interact with all service users. Judi Chamberlain said more than 40 years ago that the recovery movement can be seen as a liberation process. Or rather, parts of the movement.

1. For an overview of all WHO QualityRights training and guidance materials, please visit: <https://www.who.int/publications/i/item/who-quality-rights-guidance-and-training-tools>

The part that sees its roots in the service users and activist movement protesting against the humiliating and oppressive services and the violation of human and civil rights for people with mental health problems (Chamberlain, 1978). We still need activist movements that remind us that people experiencing mental health problems, no longer want to be seen as second-class citizens and forced into powerless patient and user roles. The QualityRights initiative has the ultimate goal to change mindsets and practices in a suitable way to empower all stakeholders to promote rights and recovery in order to improve the lives of people with mental health issues. Recovery is based on human rights, living a good life, more than relief of symptoms, reciprocal relationships, safe living conditions, and community involvement and participation (Karlsson & Borg, 2017; Price-Robertson et al 2016).

In order to develop recovery further and embed person-centred approaches to mental healthcare, we need to look more toward society and structural issues, and the barriers and limitations associated with recovery developments. Human rights and recovery is related to access to resources like tailored information, a safe home, friends, meaningful occupation, community, hobbies, safety, and money. Some structural issues nurture recovery, others do not. These issues are described in illuminating detail in the QualityRights Course Guides.

The need for a coherent discussion and debate

The authors of this paper believe that there is a need to break what we regard as a deadlock that can be partly based on a lack of knowledge, fundamental misunderstandings, and worries around what implementation of human rights models in mental health care will mean. We believe that the QualityRights Initiative can 'shake up' some of the rigidity and locked positions and discussions by providing workable and inspiring examples as to how mental health services can be provided. Through the concrete exercises and reflections, based on the reality of everyday practice and clinical settings, people with opposing ideas are invited to rethink the preconditions for their ideas, understandings, and convictions. The World Health Organisation's QualityRights initiative represents an opportunity to operationalise CRPD rights into mental health services. QualityRights provides practical guidance and capacity building as to how services can move toward coercive-free practices and support the transition toward mental health services that respect human rights standards and promote recovery orientated and community-based practice (WHO 2019, 2021). The authors hope to make the case that, mental health care services have nothing to fear but much to gain from embracing this progressive and forward-looking model for mental health services.

The adoption of the convention of rights for persons with disability (CRPD) in 2006 was a watershed moment for the disability movement internationally (UN, 2006). People with physical, psychosocial, intellectual, and cognitive disabilities were to be viewed as rights holders, that must be provided with opportunities and services to live life to the fullest potential and on an equal basis with the rest of society. The UN CRPD was widely welcomed as a major step toward ending generations of discrimination and misperceptions around disability. People with psychosocial disabilities and mental health conditions face human rights violations, barriers, and discrimination in everyday life, preventing full participation in society, and are covered by the convention. The WHO's Quality rights initiative aims to put the CRPD- rights into practice within mental health services and provides a model by which mental health services can be transformed to incorporate rights-compliant and Recovery orientated approaches. QualityRights promotes services that work alongside the person rather than coercion, services that are of high quality and based in the community rather than in institutions, and services that place a focus on living a good life rather than merely symptom reduction. The guidance and transformation materials are truly inclusive and collaborative and were developed by people with lived experience, organisations of persons with disability, and experts in the field of mental health and recovery from across the globe.

Since its adoption, there has been considerable debate around the application of key interpretations of provisions within the convention from the UN Committee on the CRPD. This is specifically regarding the right to equal recognition before the law and to legal capacity (article 12), as well as the right to liberty and security of the person (article 14) (Committee on the Rights of Persons with Disabilities (2014). Much to the concern of the authors, the nuanced and complex debate that is needed around articles 12 and 14 appears to have been reduced in Norway to merits or limitations of forced treatment. It is our opinion that although important, this has resulted in a narrow and at times polarised debate on the use of force in extreme scenarios that has diverted attention from the urgent and pressing need for people with mental health conditions and psychosocial disabilities to have access to their rights on an equal basis with everyone else in society. Rather than urgently exploring ways in which legal capacity can be promoted and that the use of coercion can be reduced and eliminated, recovery orientated approaches have been parodied as lacking an evidence base (Nytingnes & Rugkåsa, 2021). With such a polarised debate, the core and radical aspects of the CRPD fail to take hold and current non CRPD compliant clinical practice remains widespread. The CRPD is clear that people have the right to decide for themselves what treatment and support they wish to receive as part of their recovery and have the right to be liberty and security of person (UN, 2006). These rights should be respected, protected, and fulfilled under the national law.

Freedom of choice in treatment and support

QualityRights and the person-centred, recovery orientation it depicts, welcomes all potential forms of support, that a person may wish to use as a tool to promote health and wellbeing, including medications and the support of mental health services. It is by extension an initiative with the hallmarks of citizenship at its core. Within this model is unequivocal however as to whom should decide what supportive interventions and strategies should be deployed – the person themselves. Recovery is a fundamentally unique experience and while medications may be a potentially important tool in a person's recovery, they should not be depicted as the only tools of relevance or import. Nor should they be forced upon people who have been clear in their opposition to their use. The use of medications should be voluntary and given in the context of free and informed consent. It is important to acknowledge that incorrect use of medications overmedication or documented side effects can lead to suffering in themselves (Young, Taylor & Lawrie, 2015), and a person must have all the information in order to make an informed decision about their treatment. This should not be revolutionary, controversial, or an approach confined to just some of our mental health services but a basic tenant of good practice. Nothing in either the CRPD or QualityRights is antipsychiatry or ideologically opposed to the use of medications. There is an acceptance that medications and the wider therapeutic toolkit of psychiatry may play an important part in the recovery of many people (WHO, 2019). The authors see this not as an existential threat to psychiatry but rather as a group of people rightly reclaiming power in their own lives.

QualityRights calls for the creation of non-discriminatory laws that apply to all of society not just one group or based on discriminatory attitudes. QualityRights recognises that rampant discrimination and traumatic practices, carried out under the guise of treatment are in fact a reality for people living with mental health conditions and psychosocial disabilities around the world. Forced sterilisation of women with an intellectual disability or the provision of invasive and potentially irreversible procedures or treatment without free and informed consent (Funk & Drew, 2019), is in fact a daily reality and aspect of mental health services around the world. These injustices are all too often lost in the debate around the impacts of forced treatment on people's lives. If we are to truly strive to build inclusive societies that promote and respect the rights of all members then these violations of rights need to be urgently relegated to the history books of the psychiatric profession.

Legal capacity and the right to make decisions

The central aspect of article 12 of the CRPD is a person's right to legal capacity which can be understood as the right to make their own decisions on an equal basis with others. QualityRights and the CRPD recognise and promote the use of "supported decision making" (see Shula Ramon's paper in this Bulletin). This is a radically different model than guardianship or substitute decision making, which in their essence deny a person the right to make their own decisions. People may require different levels of support based on their needs, but the model represents a paradigm shift from decision-making based on the perceived best interest of the person to decisions based on a person's will and preference (WHO, 2019). To comply with the CRPD, in particular articles 12 and 14, we need to reimagine the way in which we think about and treat people living with mental health conditions, as rights holders who should always retain their legal right to make decisions. The Quality Rights modules detail how supported decision making, alongside advanced planning, de-escalation strategies, and Ulysses clauses in the vast majority of cases can avoid the use of coercion. Many of the core tenants of Quality Rights such as advanced planning and supported decisions making can be integrated as a good clinical practice throughout mental health services even without changes to the law. An advanced plan provides essential information as to the will and preference of a person in a time of crisis and should be a cornerstone of modern mental health practice. There is a pragmatic and realistic acknowledgment that as services and society transform towards CRPD compliance, conflict might occur, and coercive incidents may emerge. QualityRights gives guidance on how to learn from these incidents and ensure they don't occur in the future.

Concluding remarks

This shift to a new model of understanding places the person and citizen in the centre of all decisions about their lives. Furthermore, it empowers the citizen as a person with a right to be included in their community. Mental health services are viewed as an important tool, among many others, in the armoury of a person navigating the complexities of a mental health condition or psychosocial disability as well as an opportunity to recover citizenship. It is for the person themselves to decide which of these tools are helpful for their recovery journey and when they should be deployed. It is imperative that we move away from societies and services that coerce people into complying with treatments or interventions they do not find helpful. Particularly when they may recreate the trauma of violence or control that many of our service users have already been victims of. Freedom, the right to make your own decisions, and taking back control of one's own narrative is therapeutic and should be the cornerstone of all modern and progressive mental health services.

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