Human rights must be the guiding compass shaping community mental health services

“Building back better” after COVID-19 means community mental health services that are rights compliant, available, accessible, affordable and of high quality

KEY TAKEAWAYS

- The right to health and access to healthcare is a basic human right; nevertheless, COVID-19 has laid bare the existing inequalities.
- The outbreak underlines the call for a swift re-evaluation of mental health systems that rely on involuntary placement in psychiatric institutions.
- Mental Health Europe joins others by calling for emergency measures for deinstitutionalisation and to avoid re-institutionalisation, setting the issue high on the political agenda.
- Community support and social networks showed a high level of resilience and rose to the challenge despite ever-changing measures and circumstances. The human rights imperative of participation, often translated to co-production in mental health, evidences the success of tailor-made solutions, thus posing an element of quality support.
- The wide array of practices around Europe and on a global level demonstrate that it is possible to develop person-centred and rights-based community services that respect rights, promote inclusion and that do not resort to exclusion, isolation, or coercion. These initiatives need to be scaled up, making community mental health services the norm and not the exception.
- Post COVID-19 pandemic calls of building back better demonstrate the need to fundamentally shift mental health systems and services towards human rights frameworks and existing guidance for promising practices, policymakers are well equipped to make this shift a reality.
The cards unevenly reshuffled: COVID-19 impacts on inequalities and persons in institutions

Across the world, the COVID-19 pandemic continues to impact all areas of life. Next to emergency measures such as lockdown requirements, uncertainties about the future such as educational and employment opportunities impact persons’ mental health. The virus has disproportionately affected those in already vulnerable situations, including persons with psychosocial disabilities. The right to health and access to healthcare is a basic human right; nevertheless, COVID-19 has laid bare the existing inequalities.

From lack of information to inaccessible standards of mental health support, discrimination is upheld and maintained at a structural level, preventing marginalised groups from receiving adequate care. Ethnic minorities, women and girls, people with disabilities, LGBTI, undocumented people, the homeless and those with difficult socio-economic realities are just a few examples of groups that are more likely to bear unequal burden of morbidity and mortality. Numerous individuals, including older persons, those in poor health, people with disabilities, and others requiring healthcare services during the pandemic lived with the stress of having to use already overburdened healthcare environments, putting them at greater risk of being exposed to the new coronavirus.

Where we are now – deinstitutionalisation as a public health and social emergency

For a long time, deinstitutionalisation has been a key priority in reforming mental health systems. The MHE Mapping Exclusion reports (2012 & 2017) documented the transition from institutional to community settings – with mixed results across Europe. The latest report showed that there is still a substantial number of persons with psychosocial disabilities living in institutions across Europe and lacking community-based services. Despite some reforms, several barriers continue to persist such as the poor cooperation between social and health authorities, lack of human rights compliant and community-based services, trans-institutionalisation, and austerity. Furthermore, until today deinstitutionalisation has been depicted as a largely Central and Eastern European issue. However, in many Western countries, including France, Belgium, Ireland, the Netherlands, Portugal, Spain or Germany, tens of thousands of persons with psychosocial disabilities are still living in institutions¹, with little being done about the situation. In Central and Eastern Europe, the implementation of EU-funded deinstitutionalisation programmes has been slow, and there are limited data about the actual outcomes of these programmes for persons with psychosocial disabilities.

---

¹ For this policy brief, an institution refers to both psychiatric facilities, with the aim of ‘treatment’ of mental health issues, and social care homes for persons with psychosocial disabilities, being long-term living facilities. In both cases the deprivation of legal capacity fuels institutionalization since people are denied the right to decide where to live or a particular medical ‘treatment’.
This mixed picture of deinstitutionalisation processes however becomes dramatic in the light of the past months. The COVID-19 pandemic had particularly harsh impacts on persons with psychosocial disabilities living in institutions. The outbreak underlines the call for a swift re-evaluation of mental health systems that rely on involuntary placement in psychiatric and social care institutions. While institutionalisation in itself constitutes a violation of human rights, recent Disability Rights Monitor report shows that emergency measures due to the COVID-19 pandemic exacerbated conditions of people living in psychiatric and social care institutions. The highest number of testimonies witnessing the denial of healthcare, not allowing visitors and the imposition of forced isolation once a local outbreak was confirmed, came from EU Member States, including Germany, Austria, France or Spain. As pointed out by the UN Special Rapporteur on the rights of persons with disabilities and a recent study by the London School of Economics and Political Science, beyond its human rights implications, COVID-19 laid bare the heightened risk of infections and deaths in institutions, thus posing a fundamental threat to public health and questioning old approaches to social care.

Deinstitutionalisation also needs to be understood in the context of changing climate. Much has been written about the links between the emergence of public health emergencies such as COVID-19 and capitalist systems of exploitation that pose threats to natural environments of animals and entire ecosystems. Article 11 of the UN CRPD emphasizes that countries “shall take, (...) all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters”. Deinstitutionalisation therefore would not only help the states to implement basic rights of persons with psychosocial disabilities, but would also decrease their vulnerability (due to their institutionalisation) at the outset of emergencies. Common consensus lies in the notion that new public health emergencies will emerge in the coming decades, together with natural disasters at increased intervals. The recent floods in Germany and Belgium, again, underlined how persons with disabilities living in institutions are at heightened risk. As the EU launches “Fitfor55”, deinstitutionalization perhaps has become more urgent than ever.

Across Europe preventing and stopping the spread of COVID-19 in institutions has raised fundamental questions of their very existence. In other words, how can their purpose of “care” be understood in the light of heightened risk of infection and death? The ongoing discussion at the UN level through organising global consultations on deinstitutionalisation underline the urgency of the issue. In this Mental Health Europe joins others by calling for emergency deinstitutionalisation – not understood as immediately stopping institutionalised support with the risk of a service gap given the lack of community support, but rather setting the issue high on the political agenda. In the context of mental health, several scholars have recently pointed to a reparations approach to experiences of institutionalisation, outlining the systemic human rights violations within systems of forced psychiatry. Mental Health Europe also calls for an immediate moratorium on involuntary hospitalisation, as long requested by leading human rights experts.
Vital community-based services and COVID-19 – a delicate balancing act

The pandemic had profound impacts on mental health services in the community, especially during emergency measures such as stay-at-home and physical distancing rules. However, community-based support and services have shown great flexibility in adapting to the COVID-19 pandemic by quickly reinventing themselves. In contrast to the catastrophic conditions at long-term institutions at times, these services were able to keep on supporting recovery and maintaining higher levels of both sanitary standards and human dignity. Indeed, community support and social networks showed a high level of resilience and rose to the challenge despite ever-changing measures and circumstances. Such promising realities in juxtaposition with slow deinstitutionalisation processes foster a future that lies in the community. Many times, community-based services were a backbone of rights-based services in the light of an overreliance on biomedical interventions with an over-prescription of medication as a first – and often only response.

Services in the community can address the needs of people through tailored, coproduced interventions and have the capacity to actively reach out to persons in vulnerable situations who otherwise might not find their way to adequate support. Tailor-made, integrated services also have an essential role to play in mitigating risk factors, including social ones, and offering adequate support. The human rights imperative of participation, often translated to co-production in mental health, often make tailor-made solutions a success, thus posing an element of quality support. Barriers that in fact seemed hard to lift before the crisis, such as effective online psychosocial support, have now become part of many more daily realities. Digital innovations and telehealth provisions put forward throughout COVID-19 are, of course, not the same as face-to-face interactions.

Human Rights as the compass to shape community based services

In the rather recent development of introducing human rights obligations and principles into the reflection and evaluation of mental health services, the UN Convention on the Rights Persons with Disabilities (UN CRPD) is the most prominent example translating obligations into practice. Its emergence with the wide ratification of member states across Europe, including the European Union as a regional organization (a rare example of treaty ratification by the EU) lays out all the ingredients to shape community-based mental health services. These include rights of living in the community, to live free from any coercive measures, to access justice and seek legal aid, as well as the importance of consent and participation or the right to make any legal decisions. Where needed, supported decision-making should be in place to accompany persons in deciding on legal matters (this includes a decision to self-admission at hospital-based services).
These human rights obligations enshrined in international law often seem abstract and complex but, at a closer look, have been quite accessible to many and became a central tool advocating for change by many disability rights organisations around the world, including persons with psychosocial disabilities and mental health problems. It thus appears somewhat confusing when mental health professionals, mostly aligned with a purely biomedical model, argue that the UN CRPD is too complex and inapplicable to the field of mental health.

Beyond the UN CRPD obligations, the Covenant on Economic Social and Cultural Rights (CESCR) comes into play. With reference to article 12 on the right to health the UN Committee on Economic Social and Cultural Rights stated that the right to health is “an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health”, which includes housing as well as healthy occupational and environmental conditions. Here too, guidance is there to translate principle into action. Realizing the right to health should take place progressively, that is States Parties deploying their utmost efforts to making mental health services available, accessible, affordable and of high quality.

These elements of the CESCR combined with the UN CRPD show the importance to use human rights as the guiding compass shaping current and future community mental health services, as recently pointed out by the Commissioner for Human Rights at the Council of Europe. The Commissioner continues by stating that “mental health care that truly respects the autonomy, dignity, will and preferences of service users is simply not possible so long as legal systems continue to tolerate substituted decision-making or segregation in institutions”. Indeed, without free and informed consent by the person, enshrined in the upholding of legal capacity, community mental health services will fall short from human rights compliance (as demonstrated through the increasing emergence of Community Treatment Orders).

No more excuses – policymakers at the forefront, scaling up existing initiatives

Exacerbated through the COVID-19 pandemic, the status quo of human rights violations in institutions underlines the urgency of the issue. While the normative imperative of deinstitutionalisation was clear for many years, in particular through the emergence of the UN CRPD, policy makers can now refer to a steadily growing body of guidance embedding existing practices into human rights frameworks. Previous initiatives by Mental Health Europe, for example, its collection of promising practices around Europe on ending coercion or supported decision making are now joined by prominent support. In June 2021, the World Health Organization launched its guidance on community mental health services: Promoting person-centred and rights-based approaches. It aims to provide information and guidance to all stakeholders who wish to develop or transform their mental health system and services. In particular, the guidance provides in-depth information to develop good practice services that meet international human rights standards and obligations and that promote a person-centred, recovery approach.
Initiatives like these show that the international community is moving towards long existing calls by persons with psychosocial disabilities, mental health users and survivors of psychiatry. The wide array of practices around Europe and globally demonstrate that it is possible to develop person-centred and rights-based community services that respect rights, and promote inclusion and that do not use exclude, isolate, or resort to coercion. These should inspire policy makers and service providers alike to develop these services in their countries.

Promising initiatives can only be successful when putting the person at the centre of all decision-making. Access to information comes into play when discussing free and informed consent. Accessible and adequate tools should be established alongside each practice, allowing the individual choice of support on the basis of reliable information together with the possibility to evaluate the quality of support services. Internet-based information can be a facilitator to improving free and informed consent across Europe, if created in a simple language and in line with accessibility standards.

To fill the gaps, promising initiatives need to be scaled up, making community mental health services the norm and not the exception. Some member states have started to embrace this logic as well as a prominent representation of deinstitutionalisation in the EU Disability Rights Strategy 2021-2030, but it requires concerted action across policy and practice coupled with meaningful involvement of persons with psychosocial disabilities. Financing instruments should allow flexibility and even innovative incentives to encourage service providers moving to support in the community. Post COVID-19 pandemic calls of building back better demonstrate the need to fundamentally shift mental health systems and services – with human rights frameworks and existing guidance for promising practices, policymakers are well equipped to make this shift a reality.

Mental Health Europe
www.mhe-sme.org | info@mhe-sme.org