

Mental Health, Psychosocial Disability and the Right to live in the Community:

Deinstitutionalisation and Advocacy for Change



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INTRODUCTION

For many decades, mental health and well-being not only have been misunderstood and misrepresented in the public discourse and most political agendas, but also have been presented mostly from the bio-medical perspective¹. During more recent decades, the evidence base has expanded to include the human rights based approach to mental health and disability. In addition, the bio-psycho-social paradigm has evolved, to supplement the predominant bio-medical interventions.

The UN Convention on the Rights of Persons with Disabilities has promoted the human rights based approach² across the world ever since its adoption in 2006. Additionally, more and more scientific research findings have emerged about the public health side of the mental health field, recovery, and social determinants of mental health³⁴. This has naturally expanded the view, in which we see and promote mental health, as well as prevent and respond to mental health conditions and related disabilities.

Mental health and psychosocial disability are no longer a matter for only the field of psychiatry: they include and concern biological, psychological, social, environmental and other factors too. Addressing them properly requires a multi-disciplinary and inter-sectoral approach; simply responding to mental health problems in a bio-medical way is no longer enough. Prevention of mental health problems, as well as promotion of mental health and well-being is of paramount importance. As is the human rights based approach, which should be the foundation for all new developments in this field.⁵

The main purpose of this publication is to serve as a training module, to aid practical training delivery to various target audiences. It may also serve as a tool for designing and implementing other types of educational and awareness raising activities on topics outlined in this publication.

¹ Caldas de Almeida, J. M., Aguilar-Gaxiola, S. 2013. The burden of mental disorders: implications for policy. In J. Alonso, S. Chatterji, and Y. He (Eds.), *The Burdens of Mental Disorders: Global Perspectives from the WHO World Mental Health Surveys* (pp. 230–243). Cambridge, United Kingdom: Cambridge University Press.

² UN Convention on the Rights of Persons with Disabilities:

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

³ UN Human Rights Council 2017. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Dainius Pūras. A/HR/C/35/21.

⁴ UN Committee on Economic, Social and Cultural Rights 2000. General Comment No. 14. E/C.12/2000/4.

⁵ UN Human Rights Council 2017. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Dainius Pūras. A/HR/C/35/21.

Human Rights

The idea for a universal human rights bill emerged following the horrors of World War II. The extermination of over six million Jews, Sinti and Romani, LGBT persons, and persons with disabilities horrified the world. Trials were held in Nuremberg and Tokyo after the World War II, naming those 'crimes against peace' and 'crimes against humanity'.⁶

The international community vowed never to allow such atrocities to happen again and committed themselves to establishing the global organization called United Nations (UN), with the primary goal of upholding international peace and striving for a better world for all. The Charter of the United Nations was signed on 26th June 1945 in San Francisco, at the conclusion of the United Nations Conference on International Organization, and came into force on 24th October 1945. The Preamble of the Charter⁷ sets its purpose and goals, as follows:

„We the peoples of United Nations determined:

- to save succeeding generations from the scourge of war, which twice in our lifetime has brought untold sorrow to mankind, and*
- to reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small, and*
- to establish conditions under which justice and respect for the obligations arising from treaties and other sources of international law can be maintained, and*
- to promote social progress and better standards of life in larger freedom.”*

One of the first tasks of the UN body was to draft a document – a road map to guarantee the rights of every human being in the world. The document, which would later become the Universal Declaration of Human Rights, was taken up at the first session of the General Assembly in 1946⁸. Governments of the world promised that they would protect, respect and fulfil the rights contained in the UN Universal Declaration of Human Rights (UDHR) by ratifying the Declaration, adopted by the UN General Assembly meeting in Paris on 10th December 1948. The entire text of the UDHR was composed in less than two years. At the time, when the world was divided into Eastern and Western blocks, finding a common ground was a tremendous task.

The United Nations emphasize, that human rights are rights inherent to all human beings, regardless of race, sex, nationality, ethnicity, language, religion, or any other status. Human rights include the right to life and liberty, freedom from slavery and torture,

⁶ 31 Colum. J. Transnat'l L. 457 (1993-1994). Crimes Against Humanity: The Need for a Specialized Convention: <https://heinonline.org/HOL/LandingPage?handle=hein.journals/cjtl31&div=23&id=&page=>

⁷ The Charter of the United Nations: <https://www.un.org/en/charter-united-nations/>

⁸ History of the Document. Universal Declaration of Human Rights. United Nations, available at: <https://www.un.org/en/sections/universal-declaration/history-document/index.html>

freedom of opinion and expression, the right to health, work and education, and many more. Everyone is entitled to these rights, without discrimination⁹.

See the WHO QualityRights training module *Human Rights*.¹⁰

What is the UN Universal Declaration of Human Rights?

The UDHR was adopted by the 56 member states of the United Nations on 10th December 1948. The vote was unanimous, although eight nations abstained from it. Until nowadays, it guides us as a common standard of achievements for all people and all nations. It sets out, for the first time, fundamental human rights to be universally protected and it has been [translated into over 500 languages](#)¹¹. UDHR includes civil and political rights, like the right to life, liberty, free speech and privacy. It also includes economic, social and cultural rights, like the right to social security, health and education.

The UDHR claims that all rights are [interdependent](#) and [indivisible](#). Its Preamble asserts that:

“Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice, and peace in the world“

It has to be noted, that UDHR was drafted by representatives with different legal and cultural backgrounds from all regions of the world and endorsed by high, middle and low income countries across the world. Thus, it is universal and international from its core, not denying any cultural norms, nor has it been set against any specific income level. Although UDHR is not a legally binding document, it has had a profound influence and effect on the development of international human rights law and national legal systems.

The UN Human Rights Commission set the task to create a body of international human rights law based on the Declaration, and to establish the mechanisms needed to enforce its implementation and use. Thus, the International Covenant on Civil and Political Rights¹² (ICCPR) and the International Covenant on Economic, Social and Cultural Rights¹³ (ICESCR) were adopted in 1966 and both entered into force in 1976. These Covenants have been ratified by the vast majority of countries around the world, thus, undertaking

⁹ Human Rights. United Nations, available at: <https://www.un.org/en/sections/issues-depth/human-rights/>

¹⁰ <https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools>

¹¹ Universal Declaration of Human Rights. United Nations, available at: <https://www.un.org/en/universal-declaration-human-rights/>

¹² International Covenant on Civil and Political Rights, 16 December 1966, available at: <https://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx>

¹³ International Covenant on Economic, Social and Cultural Rights, 16 December 1966, available at: <https://www.ohchr.org/EN/ProfessionalInterest/Pages/ICESCR.aspx>

obligations to protect human rights of their citizens. Among them, Ukraine ratified ICCPR and ICESCR on 12th November 1973.¹⁴

What is the UN Convention on the Rights of Persons with Disabilities?

The UN Convention on the Rights of Persons with Disabilities¹⁵ (CRPD) and its Optional Protocol¹⁶ were adopted on 13th December 2006 at the United Nations Headquarters in New York, and was opened for signatures on 30th March 2007. There were immediately 82 signatories to the Convention, 44 signatories to the Optional Protocol, and 1 ratification of the Convention: the highest number of signatories in history of any UN Conventions on its opening day. It is the first comprehensive human rights treaty of the 21st century and the first human rights convention having been opened for signatures by regional and international organizations. The Convention entered into force on 3rd May 2008.¹⁷

United Nations claim, that 177 countries have ratified the CRPD to date, and 92 of them have ratified the Optional Protocol. Ukraine ratified the CRPD and its Optional Protocol on 4th February 2010.

The CRPD is the first binding international human rights instrument to specifically address disability and sets its purpose in Article 1:

„The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.“

The Convention is a powerful tool to help people with disabilities, local communities and governments explore ways of fulfilling the rights of all persons with disabilities by developing and implementing legal, policy and practical measures.¹⁸ The CRPD emphasizes the movement from viewing persons with disabilities as ‘objects’ of social and medical care towards ‘subjects’ with rights, who are capable of claiming those rights and

¹⁴ Chapter 4. Human Rights. Multilateral Treaties Deposited with the Secretary-General. United Nations Treaty Collection, available at: <https://treaties.un.org/Pages/Treaties.aspx?id=4&subid=A&clang=en>

¹⁵ The Convention on the Rights of Persons with Disabilities, 13 December 2006, available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>

¹⁶ Optional Protocol to the Convention on the Rights of Persons with Disabilities, 13 December 2006, available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/optional-protocol-to-the-convention-on-the-rights-of-persons-with-disabilities.html>

¹⁷ Convention on the Rights of Persons with Disabilities (CRPD). Department of Economic and Social Affairs Disability. United Nations, available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

¹⁸ EU Framework for the UN Convention on the Rights of Persons with Disabilities. European Union Agency for Fundamental Rights, available at: <https://fra.europa.eu/en/theme/people-disabilities/eu-crp-d-framework>

making decisions for their lives based on their free and informed will and consent, as well as being active citizens and members of society. There are eight guiding principles that underlie the Convention and each one of its specific Articles¹⁹:

- a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and the independence of every person
- b) Non-discrimination
- c) Full and effective participation and inclusion in society
- d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- e) Equality of opportunity
- f) Accessibility
- g) Equality between men and women
- h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

The CRPD mainstreams full participation of persons with disabilities in all fields of life, challenging stereotypes and harmful practices, as well as stigma. It does not create new rights, which were not referred to in previous treaties, but it specifies them from the point of view of persons with disabilities.

The Committee on the Rights of Persons with Disabilities is the body of independent experts, which monitors implementation of the CRPD in countries, which have ratified it²⁰. The Committee undertakes such reviews regularly and issues recommendations on how human rights violations can be tackled and rights of persons with disabilities upheld.

See the WHO QualityRights training module *Mental Health, Disability and Human Rights*.²¹

What is the right to live in the community?

Thomas Hammarberg, the former Commissioner for Human Rights at the Council of Europe, has described the right to live in the community as a foundational platform for all

¹⁹ Guiding Principles of the Convention. [Convention on the Rights of Persons with Disabilities \(CRPD\)](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/guiding-principles-of-the-convention.html). Department of Economic and Social Affairs Disability, available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/guiding-principles-of-the-convention.html>

²⁰ The UN Committee on the Rights of Persons with Disabilities, UN [Convention on the Rights of Persons with Disabilities \(CRPD\)](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/committee-on-the-rights-of-persons-with-disabilities-3.html). Department of Economic and Social Affairs Disability, available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/committee-on-the-rights-of-persons-with-disabilities-3.html>

²¹ <https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools>

other rights: the precondition for anyone to enjoy all their human rights is that they are first of all within and among the community²².

The right to live independently is closely linked with fundamental rights such as personal liberty, private and family life and freedom from ill-treatment or punishment, equal recognition before the law. It stems from some of the most fundamental human rights standards, both within the United Nations legal framework, e.g. the ICCPR, ICESCR, and UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment²³ or UN Convention on the Rights of the Child.²⁴ These standards have been captured in an overarching objective of Article 19 of the CRPD as 'full inclusion, independent living and participation in the community'.

The three key elements of Article 19 of the CRPD are as follows:

- a) Being able to choose how, with whom and where to live;
- b) Availability of individualized support and services preventing isolation or segregation from the community;
- c) Making services for the general public accessible to people with disabilities. For full implementation of the right to live independently and being included in the community all elements have to be implemented, as well as other rights²⁵ enshrined in the CRPD.

Thus, Article 19 is very broad in scope and covers various interrelated issues, which influence social and health care infrastructure and reflect on society. The UN Committee on the Rights of Persons with Disabilities has provided a number of Concluding Observations on Article 19²⁶, in which they repeatedly highlight the choice of residence for persons with disabilities as limited by the unavailability of various necessary individualised services. Those living in segregated residential institutions are reported to often have no alternative to institutionalisation. The focus on deinstitutionalisation is especially relevant in

²² Hammarberg, T. The right of people with disabilities to live independently and be included in the community, CommDH/Issue Paper 2012, Strasbourg: Council of Europe, Commissioner for Human Rights

²³ Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 10 December 1984, available at: <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CAT.aspx>

²⁴ Convention on the Rights of the Child, 20 November, 1989, available at: <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>

²⁵ Article 12 of CRPD (the right to equal recognition before the law)

Article 13 of CRPD (right to access to justice);

Article 14 of CRPD (the right to liberty and security of the person);

Article 15 – (the right to freedom from torture or cruel, inhuman or degrading treatment or punishment);

Article 23 of CRPD (the right to home and the family);

Article 24 of CRPD (the right to education);

Article 27 of CRPD (the right to work and employment);

Article 28 of CRPD (the right to adequate standard of living and social protection);

Article 29 of CRPD (the right to participation in political and public life);

Article 30 of CRPD (the right to participation in cultural life, recreation, leisure and sport).

²⁶ International Disability Alliance's Compilation of the CRPD Committee's Concluding Observations and List of Issues Article 19, 2013, available at: <http://www.internationaldisabilityalliance.org/resources/compilation-crpd-committee%E2%80%99s-concluding-observations>

the Post-Soviet context, where 'traditionally' people with disabilities continue to be institutionalised in large segregated institutions, be it social care homes or psychiatric hospitals, and individuals are often put under guardianship.

Considering the above, the focus on deinstitutionalisation and development of community-based services is the key process to be facilitated by decision makers for independent living and inclusion in the community of persons, who have mental health problems, intellectual and/or psychosocial disabilities.

Social Model of Disability

The social model of disability proposes that what makes someone 'disabled' is not their medical condition or individual traits, but instead the attitudes and structures of society that they face²⁷. The social model of disability, as presented by Mental Health Foundation²⁸:

"It is a civil rights approach to disability. If modern life was set up in a way that was accessible for people with disabilities then they would not be excluded or restricted. The distinction is made between 'impairments', which are the individual problems which may prevent people from doing something, and 'disability', which is the additional disadvantage bestowed by a society, which treats these 'impairments' as abnormal, thus, unnecessarily excluding these people from full participation in society. The social model of disability says that it is society, which disables impaired people."

Some of the key ways people are disabled by society might be as follows:

- Prejudice and labelling;
- Ignorance;
- Discrimination;
- Lack of financial independence;
- Lack of physical accessibility;
- Lack of information in formats, which are accessible;
- Families/ carers/ service providers being over-protective or patronizing.

The social model of disability was developed by people with disabilities in the 1970's and 1980's. It came around as a reaction to the medical (or individual) model of disability, which had been widely agreed with at that time by various stakeholders. The medical model states that disability is caused by the health or physical condition a person has and the nature of this condition will determine what they can and cannot do. The medical model would say that in order for everyone to participate fully in society, everyone would need a 'non-disabled' body and mind. This makes 'disability' the result of the person being 'different' and thus supposedly stems from such an 'individual problem' not from society and societal barriers.

On the contrary, an illustration of the social model of disability in practice would be a town designed with wheelchairs in mind, with no stairs or escalators. If we designed our environment this way, people who use wheelchairs would be able to be as independent as everyone else. It is society, which puts these barriers on people by having certain disabling attitudes, as well as by not making our environments and information accessible to everyone. Therefore, the focus is not on 'fixing' the person's impairment, but on

²⁷ Social model of Disability. Foundation for People with Learning Disabilities:

<https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/s/social-model-disability>

²⁸ Social Model of Disability. Mental health Foundation, available at: <https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/s/social-model-disability>

accepting it as a part of human diversity and working on ways to accommodate the individual's requirements, putting them at the centre of such decision making.²⁹ Moreover, since the UN CRPD was adopted, the social model of disability was expanded and grounded firmly in the human rights based approach, which acknowledges people with disabilities as subjects of human rights, equally to all other people.

What is a psychosocial disability?

The perception and understanding of disability has changed dramatically in the last century. Traditionally, the focus of any disability had been on the individual, i.e. on the impairment that a person had, which needed to be 'fixed' or 'cured'. In the context of mental health, the impairment would be identified as a 'mental disorder' of some kind – not limited to the common diagnoses that are known, but also anything which falls into the definition of what a 'mental disorder' could be – a definition, which is by no means, completely defined.

For example, take the definition in the Diagnostic and Statistical Manual's 5th Edition as follows:

"A mental disorder is a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behaviour (for example, political, religious, or sexual) and conflicts that are primarily between the individual and society are not mental disorders, unless the deviance or conflict results from a dysfunction in the individual, as described above."

If we accept this as a definition of impairment or 'mental disorder', this, in itself, is not a disability. A disability is not an inherent condition, but instead it is a result of the interaction of two things: the impairment itself, and the barriers that exist around it. What are these barriers? Clearly, every person faces various barriers in their everyday life; it is rare to find an individual with enough privileges to claim otherwise. Is every person, therefore, a person with a disability?

The barriers that are relevant here are those that, first of all, interact with the person's impairment. What barriers could a person with a mental health condition face? Access to appropriate and effective support may be one of them. Societal stigma and a lack of

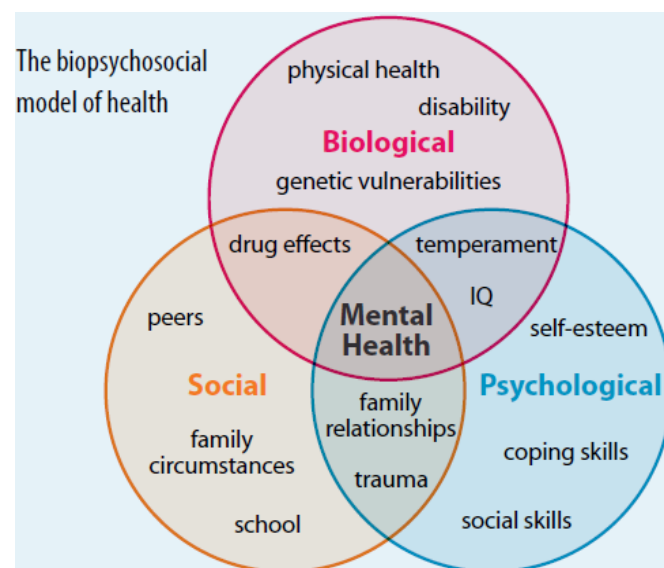
²⁹ Amba Salelkar, What is a psychosocial disability? The White Swan Foundation, available at: <https://www.whiteswanfoundation.org/article/what-is-a-psychosocial-disability/>

understanding by family members, carers, support providers or employers may be another example. Crowded or inaccessible public transport may be yet another one. These examples relate directly to the impairment that a person may have.

Secondly, these barriers must result in a situation, where the person is unable to enjoy full and effective participation in society on an equal basis with others. For example, a lack of access to their own needed level of support means that a person is unable to fully manage their own condition, in order to function at their own highest level of satisfaction. A lack of understanding by others means that a person is not given the needed accommodations and the space that they may need in order to function at par with their family members, peers and colleagues. Crowded and inaccessible public transport means that they might have to encounter additional costs to use private transport, unlike everyone else.

The term 'psychosocial disability' acknowledges and encompasses the fact that the medical definition of a 'mental disorder' or 'mental disability' is not broad enough to describe the diversity of both the determinants of mental health conditions and also the barriers that exist in society and disable people. There are both psychological and social aspects that surround the concept of disability in this case, and both of these aspects need to be acknowledged and addressed in order for the person, who has a 'psychosocial disability' to recover and have the best possible quality of life.

What is the biopsychosocial model?



The biopsychosocial model of health³⁰

³⁰ https://www.physio-pedia.com/Biopsychosocial_Model

In 1977, an American pathologist and psychiatrist George Engel (1913-1999) published his paper “The need for a new medical model: A challenge for biomedicine” in the journal *Science* introducing the term Biopsychosocial Model for the first time.³¹ While traditional biomedical models of clinical medicine focus on pathophysiology and other biological approaches to diseases, the biopsychosocial approach in our training programs emphasises the importance of a broader view of understanding human well-being, health and illness in their fullest contexts.³² The biopsychosocial approach systematically considers biological, psychological, and social factors and their complex interactions, in understanding health, illness, and services’ delivery.

³¹ [Papadimitriou G](#). The "Biopsychosocial Model": 40 years of application in Psychiatry. [Psychiatriki](#). 2017 Apr-Jun;28(2):107-110.

³² Engel GL: The clinical application of the biopsychosocial model. *Am J Psychiatry* 1980;137:535-544.

Deinstitutionalisation

Segregation of people with disabilities is a human rights violation. The CRPD requires states to develop “a range of in-home, and other community support services, including personal assistance to support living and inclusion in the community, and to prevent isolation or segregation from the community.” Thus, countries have to facilitate the political and social process, called deinstitutionalisation, which means a shift and transition from segregated institutional care to independent living, supported by community-based services. The provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support are all essential here.

Moreover, deinstitutionalisation is also about preventing institutionalisation in the future in any special and segregated services, such as residential institutions, special schools, group living homes, long-term hospitals for healthcare, and similar. Thus, various programmes supporting children and adults with disabilities, as well as their families and significant others in community settings have to be delivered.

Open Society Foundations define deinstitutionalisation as a gradual relocation of residents to regular, community-based housing. It is accompanied by the development of services that support inclusion and participation in the community, and that offer flexible and personal assistance, support, and coordination so people can live the lives they want. In some cases institutions are enabled to transform themselves into community based service providers, redeploying staff and providing supported housing and personal assistance³³.

The UN Office of the High Commissioner for Human Rights³⁴ describes deinstitutionalisation as:

“A process that provides for a shift in living arrangements for persons with disabilities, from institutional and other segregating settings to a system enabling social participation where services are provided in the community according to individual will and preference.”

Deinstitutionalisation is a complex, systemic and multi-layered process. All of the main areas of people’s lives must be taken into account and addressed during the development of community-based services and the related transition. For the housing part, flexible and individualised ‘supported living’ models have so far been assessed as effective: “once in

³³ What Is Deinstitutionalization? Open Society Foundations, available at: <https://www.opensocietyfoundations.org/explainers/what-deinstitutionalization>

³⁴ Thematic study on the right of persons with disabilities to live independently and be included in the community,), From institutions to community living- Part II: funding and budgeting UN General Assembly 12 December, Luxembourg.

supported housing, the majority stay in housing and are less likely to become hospitalised".³⁵

Additionally, education and employment are of paramount importance and can support positive effects on mental health. The most promising vocational rehabilitation model today is believed to be 'supported employment'.³⁶ Also, social skills training is an essential part of psychosocial rehabilitation and deinstitutionalisation: "social and community functioning improve, when the trained skills are relevant to the individual's daily life, and the perception of the environment reinforces the changed behaviour".³⁷ Professionals of various fields, including psychiatry, psychology and social work, need to be integrated in community teams. Such a multidisciplinary, complex and consistent support is crucial, especially to individuals with persistent, long-term mental health problems and conditions.³⁸

What is 'an institution'?

The concept of 'total institutions'³⁹ proposed by a sociologist E. Goffman (1961) refers to the way of residence and day-to-day living common for various establishments like social care homes, prisons, psychiatric hospitals, military encampments and convents, bearing the common feature of institutional culture, which could be defined by five main features as follows:

- 1) Depersonalisation;
- 2) Rigidity of routine;
- 3) Block treatment;
- 4) Social distance;
- 5) Paternalism.⁴⁰

The European Expert Group on the Transition from Institutional to Community-based Care⁴¹ define an Institution as follows:

³⁵ Rossler, W. (2006) Psychiatric Rehabilitation Today: an Overview. World Psychiatry. Oct; 5 (3): 151–157.

³⁶ Grigaitė, U. (2017) The Deinstitutionalization of Lithuanian Mental Health Services in Light of the Evidence-based Practice and Principles of Global Mental Health, *Socialinė teorija, empirija, politika ir praktika*, 15, p. 7-26. doi: 10.15388/STEPP.2017.15.10806.

³⁷ Rossler, W. (2006) Psychiatric Rehabilitation Today: an Overview. World Psychiatry. Oct; 5 (3): 151–157.

³⁸ Grigaitė, U. (2017) The Deinstitutionalization of Lithuanian Mental Health Services in Light of the Evidence-based Practice and Principles of Global Mental Health, *Socialinė teorija, empirija, politika ir praktika*, 15, p. 7-26. doi: 10.15388/STEPP.2017.15.10806.

³⁹ Goffman, E. [*Asylums: essays on the social situation of mental patients and other inmates*](#), 1961:

Total institution is place of residence and work where a large number of like situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life. (p.17)

⁴⁰ Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care, European Commission, 2009.

“...any residential care, where residents are isolated from the broader community and/or compelled to live together; residents do not have sufficient control over their lives and over decisions which affect them; the requirements of the organisation itself tend to take precedence over the residents individualised needs.”

Also the Expert Group emphasizes, that a small size of accommodation does not in itself guarantee elimination of institutional culture within the setting. The World Health Organization⁴² defines an institution as:

“...any place, in which persons with disabilities, older people, or children live together away from their families. Implicitly, a place, in which people do not exercise full control over their lives and their day-to-day activities. An institution is not defined merely by its size.”

The Regional Office for Europe of the United Nations Office of the High Commissioner for Human Rights defines Institutional care⁴³ by emphasizing that the size of a building is only one of a number of factors that create a culture of institutionalisation, while others include rigidity of routine, such as fixed timetables for waking up, eating and other activities, irrespective of individuals’ personal preferences, needs or choices.

The European Union Agency for Fundamental Rights⁴⁴ (FRA) defines an institution as social care services functioning in an overly restrictive manner. This means that even small scaled social care services can function as institutions, even if they are physically located closer to the community. This highlights an issue of both physical and social/cultural aspects, which were discussed at the meeting of experts held at FRA in November 2015:

“There was a broad agreement among the experts present that physical features of institutions include isolated locations; segregation and compulsion; impossibility to live with families; and long length of admission. Social/cultural features include de-personalised services; lack of choice and control; lack of privacy and intimacy; lack of liberty and free expression of wishes; lack of accountability; strict schedules and regimes; requirements of the institution taking precedence over the needs of residents; residents

⁴¹ Common European Guidelines on the Transition from Institutional to Community-based Care, European Expert Group on the Transition from Institutional to Community-based Care, 2012, updated version 2014, available at: <https://deinstitutionalisation.com/eeg-publications/>

⁴² World Health Organization (WHO) and World Bank (2011), World report on disability, Geneva, World Health Organization. p. 305

⁴³ Parker, C., The Human Rights of Persons Placed in Institutions, Forgotten Europeans – Forgotten Rights, Regional Office for Europe of the United Nations Office of the High Commissioner for Human Rights, 2011, available at: http://www.europe.ohchr.org/Documents/Publications/Forgotten_Europeans.pdf

⁴⁴ Summary overview of types and characteristics of institutional and community-based services for persons with disabilities available across the EU. European Union Agency for Fundamental Rights. Luxembourg: Publications Office of the European Union, November 2017.

are viewed as disabled; strict separation between staff and users; and the place of residence is contingent on the provision of care.”

This means that what defines an institution is not only the building, but rather is the institutional culture.

FRA research⁴⁵ elaborates on the physical and cultural characteristics of institutional settings:

“Physical characteristics of institutions:	“Cultural characteristics of institutions:
<ul style="list-style-type: none">• large buildings;• isolated / remote locations;• segregation - only people with disabilities;• large groups of non-family members living together;• long length of admission / residence;• compelled to live together;• sharing room and personal space.”	<ul style="list-style-type: none">• lack of privacy and intimacy;• lack of liberty and expression of wishes;• lack of accountability;• strict schedule / regime and predefined procedures and activities;• block treatment defined by one size fits all; individual's lack control over daily activities;• rules and interest of the institution take precedence over the will and preference of the client;• division between staff and users - medical model of care reducing individuals to their diagnoses/impairment;• no choice of support personnel• place of residence contingent on care provision.”

For example, development of new smaller ‘group homes’ may be “...commonly presented as a ‘stepping stone’ to real life in the community, but remain a permanent ‘home’ for people leaving institutions. In the context of poorly developed support options, their existence encourages the ‘placement’ of disabled people and prevents real inclusion ... Many countries are showing worrying trends of grouping apartments into residential compounds, comprised of dozens of units targeted exclusively at people with

⁴⁵ From institutions to community living for persons with disabilities: perspectives from the ground European Union Agency for Fundamental Rights. Luxembourg: Publications Office of the European Union, 2018

disabilities”⁴⁶⁴⁷. Thus, in such cases, even though large institutions get dismantled, the institutional culture simply gets transferred into smaller facilities closer to the community.⁴⁸

What are ‘community-based services’?

In the process of deinstitutionalisation, accessibility of community-based services, such as (supported) housing, personal assistance, personal budgets, crisis support teams, and so on, should eliminate the existing segregated residential institutional care services. Considering issues related to the definition of an institution, it is important to understand, whether newly developed services in the community comply with human rights standards. In addition, mainstream community services and facilities for the general population must be available and accessible on an equal basis to persons with disabilities and should be responsive to their needs.⁴⁹

The Common European Guidelines on the Transition from Institutional to Community-based Care²⁶ define community-based services for persons with disabilities as follows:

“...a spectrum of services that enable individuals to live in the community and, in the case of children, to grow up in a family environment as opposed to an institution”.

The European Coalition for Community Living defines not only community-based services, but also good practice community-based services, which are organised on the basis of the following key principles; emphasising client-centred and user-led approaches, family participation, the social model of disability, seeking good quality of life and ensuring that these principles are expressed in the day-to-day assistance:⁵⁰

- “ - They are person-centered, which means that they are tailored to the individual’s needs, wishes and aspirations, and can change as required over time;*
- They support family and community life, ensuring that additional help is given to the person, their family and friends, to enable them to live and participate in the community;*
- They adopt a social model of disability (this identifies the failure of society to accommodate disabled people, such as the inaccessibility of buildings and discriminatory*

⁴⁶ Angelova-Mladenova, L. (2017) The Right to Live Independently and be Included in the Community: Addressing Barriers to Independent Living across the Globe. European Network on Independent Living.

⁴⁷ Mulheir, G. (2015) Ending institutionalisation: An Analysis of the Financing of the Deinstitutionalization Process in Bulgaria. Lumos: https://wearelumos.org/sites/default/files/Finance_BG_online_final_2.pdf

⁴⁸ Grigaite, U. (2017) Human Rights Conditions and Quality of Care in ‘Independent Living Homes’ for Adults, who have Intellectual and/or Psychosocial Disabilities, in Vilnius: Analysis of Good Practice Examples, Systemic Challenges and Recommendations for the Future. WHO Quality Rights Assessment: http://www.who.int/mental_health/policy/quality_rights/QRs_Lithuania.pdf?ua=1

⁴⁹ Angelova-Mladenova, L. (2017) The Right to Live Independently and be Included in the Community: Addressing Barriers to Independent Living across the Globe. European Network on Independent Living.

⁵⁰ Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities, European Coalition for Community Living, Focus Report 2009, available at: <http://community-living.info/wp-content/uploads/2014/02/ECCL-Focus-Report-2009-final-WEB.pdf>

attitudes, as the barrier to their inclusion in society rather than their particular impairment);

- They are user-led, which means that people with disabilities are closely consulted with and actively involved in the design, delivery and evaluation of services;*
- They address all of people's lives, ensuring that they provide whatever help is needed to enable the person to have a good quality of life, regardless of the effects of their impairment and disability.*
- They ensure that these principles are expressed in the day-to-day assistance provided to the individuals they support."*

Independent Living

Living independently does not mean living alone, doing everything by yourself or not having support. Independent living is about having choice and control over your life and having the same range of opportunities as people with no disabilities.⁵¹

What independent living looks like in reality very much depends on the needs of every individual person. For example, one person may need someone to come in once a week to help with budgeting or with shopping. Another person might need personal assistance 24 hours per day. Someone else may just need temporary support to access employment. The main principle lays in the *individual approach* and living *in the community*, not in a segregated institution.

In 2016, European Disability Forum adopted the following definition of Independent Living⁵²:

"Independent Living is the daily demonstration of human rights-based disability policies. Independent living is possible through the combination of various environmental and individual factors that allow persons with disabilities to have control over their own lives. This includes the opportunity to make real choices and decisions regarding where to live, with whom to live and how to live. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing persons with disabilities flexibility in their daily life. Independent living requires that the built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that Independent living is for all persons with disabilities, regardless of the gender, age and the level of their support needs."

What is 'personal assistance'?

According to European Network on Independent Living⁵³ (ENIL), personal assistance is a tool which allows to facilitate independent living. Personal assistance is delivered to an extent, which satisfies the individual needs of persons with disabilities to live independently and with dignity. Personal assistance should be provided on the basis of an

⁵¹ Fact Sheet: Independent Living for People with Intellectual Disabilities. Inclusion Europe, European Network on Independent Living, available at: <https://enil.eu/wp-content/uploads/2018/07/Fact-sheet-on-people-with-ID.pdf>

⁵² Independent living and social services. European Disability Forum, available at: <http://www.edf-feph.org/independent-living-social-services>

⁵³ Definitions. European Network on Independent Living, available at: <https://enil.eu/independent-living/definitions/>

individual needs assessment and depending on the specific life situation of each individual.

The Committee on the Rights of Persons with Disabilities has issued a General Comment on Article 19: Living independently and being included in the community⁵⁴, which stipulates a definition and elements of personal assistance as follows:

“Personal assistance refers to person-directed/“user”-led human support available to a person with disability and it is a tool for independent living. Although modes of personal assistance may vary, there are certain elements, which distinguish it from other types of personal assistance, namely:

(i) Funding for personal assistance must be provided on the basis of personalized criteria and take into account human rights standards for decent employment. The funding is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required. It is based on an individual needs assessment and upon the individual life circumstances. Individualised services must not result in reduced budget and/or higher personal payment;

(ii) The service is controlled by the person with disability, meaning that he or she can either contract the service from a variety of providers or act as an employer. Persons with disabilities have the option to custom-design his or her own service, i.e. design the service and decide by whom, how, when, where and in what way the service is delivered and to instruct and direct service providers;

(iii) Personal assistance is a one-to-one relationship. Personal assistants must be recruited, trained and supervised by the person granted personal assistance. Personal assistants should not be “shared” without full and free consent by the person granted personal assistance. Sharing of personal assistants will potentially limit and hinder their self-determined and spontaneous participation in the community; and

(iv) Self-management of service delivery. Persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to their life circumstances and preferences. Even if the responsibilities of “the employer” are contracted out, the person with disability always remains at the centre of the decisions concerning the assistance, who must be enquired about and respected, upon individual preferences. The control of personal assistance can be through supported decision-making.”

⁵⁴ General comment on article 19: Living independently and being included in the community . Committee on the Rights of Persons with Disabilities. Eighteenth session. 14-31 August 2017, available at: <http://www.ohchr.org/Documents/HRBodies/CRPD/CRPD.C.18.R.1-ENG.docx>

Psychiatric Diagnosis

The psychiatric diagnosis is generally defined by a mental health professional (usually a psychiatrist) according to the set of reported symptoms and corresponding diagnostic categories listed in a diagnostic manual. Diagnostic manuals such as the DSM or ICD were created to provide a common diagnostic language for mental health professionals, attempting to provide a definitive list of mental health problems, including their symptoms. Still extremely prevalent, the biomedical model of disability emphasises a person's mental health problems according to the psychiatric diagnoses.

The social model of disability and modern mental health discourse brings a different view on psychiatric diagnosis.

According to Mental Health Europe⁵⁵:

“...medical diagnosis is the process of determining which disease or condition explains a person's symptoms and signs. The information required for a medical diagnosis is typically collected from a history and physical examination of the person seeking medical care. A psychiatric diagnosis is different – there are often no physical symptoms, nor are there any biological tests conclusive to follow up mental distress. Although tests can be important to rule out underlying physical causes, a health professional making a psychiatric diagnosis has to rely on a person's own description of their thoughts and feelings, alongside observations of their behaviour. In this sense, it is often said that those best placed to make a diagnosis are the people themselves, supported by information and empowered discussion with health care professionals.”

What is ‘mental distress’?

Mental or emotional distress is something that everyone experiences at some point in their life. The [Health and Wellbeing Changes Organization](#) defines mental distress as follows:

“A disturbing or unpleasant mental or emotional state, such as fear, anxiety, depression, confusion, mood swings ... often impairing your ability to cope with day-to-day living.”

Mental distress is a term used to describe a range of symptoms and experiences of a person's internal life that are commonly held to be troubling, confusing or out of the

⁵⁵ A Short Guide to Psychiatric Diagnosis. 2018. Mental Health Europe, available at: <https://mhe-sme.org/transshort-guide-psychiatric-diagnosis-2-2/>

ordinary. It is understood as a disturbing or unpleasant mental or emotional state, such as fear, anxiety, depression, confusion, mood-swings, unusual ideas, one's senses 'playing tricks', etc. (often also producing physical symptoms or behaviours) and often impairing the person's ability to cope with day-to-day living.⁵⁶

Mental distress has a wider scope than the related term 'mental disorder'. The medical term 'mental illness' often refers to a specific set of medically defined conditions. However, life situations such as bereavement, stress, lack of sleep, use of drugs or alcohol, experiences of assault, abuse or accidents can induce mental distress. This may be something which resolves without further medical or other types of interventions, though people who endure such symptoms on a longer term are more likely to be diagnosed with mental health problems⁵⁷.

What is the purpose of a psychiatric diagnosis?

A diagnostic classification is used in many countries for people coming in contact with a health-care system: facilitating the identification of those who need mental health services and help to direct them to the necessary and appropriate care.

Mental Health Europe³⁷ explains as follows:

"The main purposes of current psychiatric diagnoses are to help health professionals communicate with each other, and to determine which forms of treatment would potentially be best to prescribe. Some people find receiving a diagnosis helpful and reassuring, while others find it stigmatizing. A diagnosis can be a way of recognising and recording a person's distress and open doors to obtaining help, but it can also lead us to think that our distress comes about as a result of an illness. For some people this might be a helpful way of seeing things, but it is not the only way to make sense of psychological distress.

In the field of mental health, both medical diagnosis and medical treatment are particularly contentious, and can have negative consequences. Psychiatric diagnosis frequently leads to the prescription of medication. Psychiatric medication can bring temporary relief, but it can also have unpleasant or debilitating effects. If these occur, it is very important to discuss them with a doctor. Psychiatric medications can also be addictive; coming off them quickly can either be very unpleasant as the effects of the medication wear off, or can result in a return of the original distressing thoughts and feelings in a worse form.

⁵⁶ "Mental Distress Changes". *Changes.org.uk*.

⁵⁷ Horwitz AV. Distinguishing distress from disorder as psychological outcomes of stressful social arrangements. *Health* (London, England : 1997). 11: 273-89

Anyone experiencing mental distress has the right to be, and needs to be, meaningfully involved at every stage of a medical assessment and potential treatment. You should participate throughout the decision-making processes, discussing and agreeing on the best course of action for you."

Where do psychiatric diagnoses come from?

According to Mental Health Europe³⁷:

"There are two main sources for the current diagnostic model– the International Classification of Diseases and Related Health Problems (ICD) produced by the World Health Organization and the Diagnostic and Statistical Manual of Mental Disorders (DSM) produced by the American Psychiatric Association. Both have a long history and are constantly being revised. The most recent edition of the ICD is now version 11 which was released in June 2018 and the most recent version of the DSM is version 5 published in 2013."

The development of the ICD was a core function of the World Health Organization, spelt out in its Constitution: "to standardize diagnostic procedures as necessary". The ICD was initiated in Paris in 1900 and became WHO's responsibility when it was founded in 1948 as an agency of the United Nations. The gap between ICD-10 and ICD-11 is likely to be 24 years, the longest between successive revisions since 1900. The section concerned with psychiatric diagnoses is called 'Mental and Behavioural Disorders'.

The DSM-I was published in the USA in 1952 by the American Psychiatric Association, after the US military decided they needed to have a useful classification of mental health problems. The DSM is the official classification used in the USA for clinical diagnoses, although its influence now covers the globe, particularly because of its apparent advantages for research and the general belief and assumption that it is in some way 'more accurate' than the ICD. The DSM has been revised more frequently, with successive revisions in 1987, 1994, 2000 and, more recently, in May 2013 ([American Psychiatric Association 1987, 1994, 2000, 2013](#))⁵⁸.

How are diagnostic manuals compiled?

Mental Health Europe³⁷ explain as follows:

⁵⁸ <https://www.cambridge.org/core/journals/advances-in-psychiatric-treatment/article/comparison-of-dsm-and-icd-classifications-of-mental-disorder/625C40990677716E8C92AF0A6374F896/core-reader#>

“Because there are no defining physical or biological markers or tests for mental health difficulties, the manuals rely on the collective opinions of panels of experts who decide how to describe different forms of distress. They compile lists of thoughts, feelings and behaviours which fit the illness they have named and described. These lists in medical terminology are described as symptoms. In reality, all of the symptoms are also experienced by people who are not described as mentally ill and for whom the impact on their lives may be temporary or unproblematic.”

There is a tendency observed, that diagnostic manuals tend to create more diagnoses rather than fewer with new revisions, and also to create pathology out of normal variation. Allen Frances (2013), the former chair of the DSM-IV Task Force, has written about the dangers. He argues that DSM 5 offers a radical and reckless set of proposals that will overnight turn 'normal' people into 'mental patients'. Everyday aches, pains, disappointments, stresses, and existential sufferings are being reframed as mental illnesses with such exuberance that it is getting hard for anyone to get through life without a psychiatric diagnosis. Is grief a useful, inevitable and poignant sign of a broken heart or is it Major Depressive Disorder? Are temper tantrums a normal part of childhood or a sign of mental illness? Are you nervous about an upcoming presentation or job interview or do you have Mixed Anxiety Depression? If you don't remember a face or a fact once in a while, do you have Dementia?⁵⁹ These questions raises reasonable doubt of use of the classification nowadays.

What is the criticism of the ICD and DSM manuals?

A recent scientific study, led by researchers from the University of Liverpool, involved a detailed analysis of five key chapters of the latest edition of the widely used Diagnostic and Statistical Manual (DSM), on 'schizophrenia', 'bipolar disorder', 'depressive disorders', 'anxiety disorders' and 'trauma-related disorders'.⁶⁰

The main findings of the research study were as follows:

- Psychiatric diagnoses all use different decision-making rules
- There is a huge amount of overlap in symptoms between diagnoses
- Almost all diagnoses overlook the role of trauma and adverse life events
- Diagnoses tell us little about the individual person and what support or treatment they need

⁵⁹ Frances, A (2013) Saving Normal: An Insider's Revolt Against Out-of-Control Psychiatric Diagnosis, DSM-5, Big Pharma, and the Medicalization of Ordinary Life. William Morrow. [Google Scholar](#)

⁶⁰ Kate Allsopp, John Read, Rhiannon Corcoran, Peter Kinderman. Heterogeneity in psychiatric diagnostic classification. *Psychiatry Research*, 2019; 279: 15 DOI: [10.1016/j.psychres.2019.07.005](#)

The lead researcher Dr. Kate Allsopp, University of Liverpool, said: "Although diagnostic labels create the illusion of an explanation they are scientifically meaningless and can create stigma and prejudice. I hope these findings will encourage mental health professionals to think beyond diagnoses and consider other explanations of mental distress, such as trauma and other adverse life experiences."⁶¹

Professor Peter Kinderman, University of Liverpool, said: "This study provides yet more evidence that the biomedical diagnostic approach in psychiatry is not fit for purpose. Diagnoses frequently and uncritically reported as 'real illnesses' are in fact made on the basis of internally inconsistent, confused and contradictory patterns of largely arbitrary criteria. The diagnostic system wrongly assumes that all distress results from disorder, and relies heavily on subjective judgments about what is normal."

Professor John Read, University of East London, said: "Perhaps it is time we stopped pretending that medical-sounding labels contribute anything to our understanding of the complex causes of human distress or of what kind of help we need when distressed."

Mental Health Europe³⁷ also contributes with a similar view as follows:

"Critics of the diagnostic approach to mental health problems point to several issues:

- *The constant debate about what to include as diagnostic criteria indicates the difficulty in deciding what is a normal human reaction to distressing circumstances or experiences and what is abnormal or a sign of illness,*
- *"Symptoms" are often overlapping between diagnoses and therefore distinctions between different conditions are unreliable. This can lead to a person receiving a number of different diagnoses which can be confusing and unsettling,*
- *The combination of opinion with science in psychiatry gives an artificial authority to the medical profession and to medical treatment which their results do not merit,*
- *Focusing too much on illness and a medical perspective can act as a distraction from other important factors responsible for mental distress such as social and cultural issues. "*

⁶¹ University of Liverpool. "Psychiatric diagnosis 'scientifically meaningless'." ScienceDaily. ScienceDaily, 8 July 2019. <www.sciencedaily.com/releases/2019/07/190708131152.htm>.

What are ‘coercive measures’ in the field of mental health?

According to Mental Health Europe, coercion or coercive measures refer to involuntary, forced or non-consensual practices used in mental health and social care services against people with mental health problems.⁶²

Involuntary, forced or non-consensual placement/commitment or treatment can be defined as any treatment or placement to a hospital or other institution administered against someone’s expressed wishes – expressed verbally or by any other means (body language, advance directive, etc.) Please note that the legal definitions of involuntary placement and treatment vary from country to country. It is also important to note that in many countries, laws and regulations that apply to the health care sector (covering involuntary psychiatric hospitalisation and related practices) do not cover the social sector (institutions for persons with disabilities or the elderly) where there is still little control or even awareness of the fact that these practices exist.

There are different types of restraint used in mental health and social care services:

- Physical restraint: manually holding a person to prevent or restrict the movement of their body or parts of the body.
- Mechanical restraint: the use of devices (e.g. straps, belts, cage beds, etc.) to prevent or subdue the movement of one’s body or parts of the body.
- Chemical or pharmacological restraint: the use of medication to control or subdue behaviour (e.g. rapid tranquillisation).
- Seclusion: confinement in a room or secluded area from which a person cannot freely exit.

See WHO QualityRights training modules *Freedom from coercion, violence and abuse* and *Strategies to end seclusion and restraint*.⁶³

Also see the publication *Monitoring Places of Detention to Prevent Torture and other Cruel, Inhuman and Degrading Treatment or Punishment: Practical Guide*.⁶⁴

⁶² Promising practices in prevention, reduction and elimination of coercion across Europe. Mental Health Europe. 2017. <https://www.mhe-sme.org/coercionreport/>

⁶³ <https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools>

⁶⁴ <http://hrmi.lt/wp-content/uploads/2019/10/2019-10-09-Guide-to-monitoring-places-of-detention-brochure-A5-ENG.pdf>

Are there other ways of thinking and talking about mental distress?

According to Mental Health Europe³⁷:

“Many people, including psychologists and some doctors are questioning the value of the medical model. This is not in any way to minimise the pain or disruption to peoples' lives but rather to take a less narrow and one size fits all view of mental distress. Instead of deciding on a medical diagnosis, alternatives can be discussed between persons experiencing distress and their health professionals.

Rather than asking; “What is wrong with this person?”, clinicians are increasingly giving voice to the question, “What has happened to this individual that they have been unable to cope with?”

This kind of approach, they argue, leads to more personalised help, and means that people are more involved and in charge of their own care - the solutions are more individualised and should be based on the persons will and preferences, as well as their informed consent. They may include short courses of medication to bring relief, but the objective is always about finding what works for this person to recover and rebuild the life that they want to lead. They also take into account the fact that we are social beings and that our mental health relies on the relationships and the communities in which we live.”

*“**Mental health** is a dynamic state of internal equilibrium, which enables individuals to use their abilities in harmony with universal values of society. Basic cognitive and social skills; ability to recognize, express and modulate one's own emotions, as well as empathize with others; flexibility and ability to cope with adverse life events and function in social roles; and harmonious relationship between body and mind represent important components of mental health, which contribute, to varying degrees, to the state of internal equilibrium”.⁶⁵*

⁶⁵ DOI: [10.1002/wps.20231](https://doi.org/10.1002/wps.20231), [World Psychiatry](https://doi.org/10.1002/wps.20231). 2015 Jun; 14(2): 231–233.

What is Recovery Approach?

Recovery is the realisation of a meaningful and fulfilling life in the presence or absence of any mental health problems. This is the essence of the social model of disability, as well as the human rights model, instead of biomedical model.

World Health Organisation describes the recovery approach as follows:⁶⁶

“The meaning of recovery can be different for each person. For many people recovery is about regaining control of their identity and life, having hope for their life and living a life that has meaning for them whether that be through work, relationships, community engagement or some or all of these.

By framing it in this way, recovery no longer means ‘being cured’ or ‘being normal again’. Instead, it is about gaining new meaning and purpose in life, being empowered to live a self-directed/determined and autonomous life, despite any emotional distress that a person may have lived through or is currently experiencing.

To gain a better understanding of what recovery means, it is important look at the flipside, that is, what recovery is not.

- 1. Recovery is NOT necessarily a cure or the absence of a condition, diagnosis or symptoms as people with psychosocial, intellectual and cognitive disabilities can still recover and lead a fulfilling life in the presence of any one of these. In other words, for some people, being free from what they perceive and interpret as symptoms is a key feature of their recovery. But in other cases, people may continue to have these but still experience recovery.*
 - *Recovery is happening when people can live well in the presence or absence of a condition, diagnosis or symptoms.*
 - *Recovery involves dealing with and returning from the many losses that a person may experience, such as isolation, poverty, unemployment, and discrimination. Mental Health affects all aspects of our lives so “getting better” means that these aspects of our lives are “recovering” as well.*
 - *The person may not recover all of their losses such as their old job or previous relationships, but they can still live fulfilling lives – for example, getting a new job and starting new relationships.*
- 2. Recovery is NOT something that practitioners, families or care partners “do” to people. Recovery is led by the individual concerned. Those involved in the life of people with psychosocial, intellectual, or cognitive disabilities can be coaches or support persons that can assist a person on their journey of recovery.*

⁶⁶ WHO QualityRights guidance and training tools, available at:

https://www.who.int/mental_health/policy/quality_rights/guidance_training_tools/en/

3. *Recovery is NOT a new word for rehabilitation. Rehabilitation is still often practiced within the framework of the medical model and in many cases rehabilitation practices do not put the individual and the life they want to lead at the centre.*
4. *The recovery approach is NOT a theoretical model. The recovery approach is very practical and can be readily applied in mental health and related services. It is not something confined to paper.*
5. *Recovery is NOT something that has been widely practiced despite the common usage of the term in some contexts. Recovery involves rethinking the way mental health and related services and supports are designed and provided.*
6. *The recovery approach is NOT a reason for closing down services. Some people fear that the recovery approach will be used as a justification for closing down formal mental health and related services and reducing spending on mental health. This should never be the case.*
7. *The recovery approach is NOT 'blaming' the individual for their situation and recognizes the social inequalities, discrimination and violations of rights at community and societal levels that lead people to situations of emotional distress and act as important barriers to the recovery process. It recognizes that policy, legislative reform and social justice at a much larger scale are required to truly promote recovery.*

The meaning of recovery can be different for each person. For many people recovery is about regaining control over their identity and life, regardless of having a disability or mental health problems. It might be about having hope for their life and living a life that has meaning for them, whether that be through work, relationships, community engagement, some or all of these factors.

See WHO QualityRights training modules *Recovery and the Right to Health* and *Recovery Practices for Mental Health and Well-being*.⁶⁷

⁶⁷ <https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools>

Peer Support

According to the World Health Organisation:

“Many people who have received a diagnosis find it helpful to consult others with similar experiences. There are many organisations, led by people with lived experience of mental distress, which offer support, advice and who campaign for better policies in the healthcare and legal systems. Some are mainly concerned with particular forms of distress, such as the Hearing Voices Network, while others represent persons with lived experience who want to improve the way people in mental distress are treated, for example the European Network of (Ex-)Users and Survivors of Psychiatry (ENUSP).”

What is individualised peer support?

Individualised peer support is one-to-one support provided by a peer with a lived experience of mental health problems, psychosocial, intellectual or cognitive disability and experience of the recovery process, to another peer who would like to benefit from this experience and support. The aim is to support people on the issues they see as important for their own recovery, in a way that is free from assumptions and judgment, and in doing so serve as a compassionate listener, educator, coach, advocate, and partner. Peer supporters, who are experts by experience, are able to relate to, connect with and support individuals going through challenges in a unique way because of their own experience.

Peer support can be provided in a variety of settings, for example, in people's homes, and in a full range of mental health, social care, and other services. Peer support can be provided by volunteers or paid workers. Depending on the organisation or group, peer supporters may be referred to as peer specialists, peer leaders, or recovery coaches, among other titles.

Peer support is central to the recovery approach. Through sharing experiences, listening emphatically, and providing encouragement, peer supporters can support people with mental health problems, psychosocial, intellectual or cognitive disabilities to find their own meaning of recovery in order to live fulfilling and satisfying lives.

See the WHO QualityRights training module *One-to-one peer support by and for people with lived experience*.⁶⁸

Examples of peer support actions and practices include the following:

- Sharing experiences and stories of hope and recovery

⁶⁸ <https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools>

- Encouraging people to take responsibility for their own life and recovery
- Encouraging people without doing things for them
- Providing people with relevant information
- Helping people to build social networks in the community
- Respecting rights, dignity, privacy and confidentiality

What are 'peer support groups'?

According to the World Health Organisation:

“Peer support groups are a valuable service and resource that brings together people affected by a similar concern so they can explore solutions to overcome shared challenges and feel supported by others who have had similar experiences and who may better understand each other’s situation. Peer support groups are run by members for members so the priorities are directly based on their needs. Peer support groups also allow members to benefit from natural occurring social support in the community in order to form unique relationships that may not otherwise have been possible. Peer support groups can be provided on a formal basis with paid ‘specialist’ trained peer group facilitators or on a more informal basis with volunteer peer facilitators.”

See the WHO QualityRights training module *Peer support groups by and for people with lived experience*.⁶⁹

What are the benefits of support groups?

According to the World Health Organisation:

“The benefits of group peer support are wide-ranging and can include the provision of a safe environment to freely express and share emotions and thoughts about one’s current situation and challenges; sharing of information and experiences and learning from others in similar situations that can help provide ideas and solutions to overcome challenges that group members are facing; the opportunity to build new relationships and strengthen social support networks which helps to reduce isolation and feelings of loneliness; sharing of knowledge about available community resources and practical support to help group members access resources and support, for example, helping others complete administrative procedures to access social and disability benefits, employment programs and so on.”

⁶⁹ [Ibid.](#)

Advocacy for Mental Health and Human Rights

The concept of mental health advocacy has been developed to promote the human rights of persons with mental health problems, psychosocial and intellectual disabilities, and to reduce related stigma and discrimination. Also to promote accessible and client-centred mental health and social care services. Advocacy consists of various actions aimed at changing the major structural and attitudinal barriers to achieving positive mental health outcomes in populations, e.g. awareness raising, trainings, policy dialogue and policy change, legal and strategic litigation, human rights protection and defence, etc.

Advocacy in this field began when the families of people with mental health problems and related disabilities first made their voices heard. People with mental health problems and disabilities also contributed to this process themselves. Gradually, these individual people and their families were joined and supported by a range of organizations, a large number of mental health and social care workers and their associations, as well as some governments. More recently, the concept of advocacy has been broadened to include the general population, as everybody in society has mental health needs.⁷⁰

See WHO QualityRights training modules *Advocacy for mental health, disability and human rights* and *Civil society organizations to promote human rights in mental health and related areas*.⁷¹

⁷⁰ Advocacy for mental health. Geneva, World Health Organization, 2003

⁷¹ <https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools>

Good Practice Examples

Community Mental Health Centres in Trieste, Italy⁷²

Back in 1971, a major reform of mental health services started in Trieste, Italy. With the great leadership of a psychiatrist called Franco Basaglia, a moratorium was achieved on the national level in 1978, which meant that no more persons were allowed to be admitted in psychiatric hospitals – i.e. large segregated asylums – across Italy.



“Liberty is Therapeutic” – a building on the grounds of the former San Giovanni psychiatric hospital and the blue horse Marco Cavallo, the symbol of freedom in Trieste.

© Ugnė Grigaitė

⁷² Muusse, C. and van Rooijen, S. (2015) Freedom First: A study of the experiences with community-based mental health care in Trieste, Italy, and its significance for the Netherlands. Trimbo instituut, Utrecht.

The San Giovanni psychiatric hospital in Trieste city was closed in 1980. Instead, a new system of ambulatory and community-based services was created, focusing on the inter-sectoral work of social care and health care services, based on principles of respect for autonomy, liberty and dignity of all persons, as well as their fully-fledged human rights. For example, doctors, nurses, social workers, psychologists and volunteers were given new opportunities to undertake extensive on-site training and start working in new ways in the community.

Methods that are used in these community-based services include outreach and home visits, crisis support, open dialogue, group support, psychosocial rehabilitation, psychotherapy, peer support, supported housing, a 24/7 helpline, and 24/7 open-door low-threshold Community Mental Health Centres, with only 6 inpatient/temporary accommodation beds in each of the 4 Centres in Trieste. The doors in these Centres are never locked, including the inpatient treatment options. The families of persons with mental health problems or psychosocial disabilities are closely involved in support provision and recovery processes of individual clients at these Centres. The whole ethos of these services in Trieste is enshrined in principles of *inclusion* instead of *exclusion*, and *liberty* instead of *confinement and isolation*.

When compared with the mental health care sector in the Netherlands, Trieste demonstrated the following outcomes in 2015⁷³:

- 20% of the number of Dutch admission beds;
- 23% of the budget per capita;
- Much shorter admissions;
- No long-stay admission facilities;
- A similar suicide rate;
- Only open doors. In the Netherlands, 25% of the admission capacity is located on closed wards.

Open Dialogue in Western Lapland, Finland

The Open Dialogue Approach is both a philosophical/theoretical approach to people experiencing a mental health crisis and their families/networks, as well as a system of care, developed in Western Lapland in Finland over the last 30 years.

The Open Dialogue Approach focuses on care decisions, which are made with the personal input of the individual concerned, together with wider networks of their choice. The Open Dialogue Model was initially designed as a treatment alternative to avoid

⁷³ Muusse, C. and van Rooijen, S. (2015) Freedom First: A study of the experiences with community-based mental health care in Trieste, Italy, and its significance for the Netherlands. Trimbo instituut, Utrecht.

hospitalisation. As such, there is less likelihood of coercion being used, including seclusion and restraint. Open Dialogue is based on support in people's homes and communities.

Open Dialogue based practices help persons and their families feel heard, respected, and validated.⁷⁴ Service providers aim to facilitate regular 'network meetings' between the person and his/her choice of an immediate network of friends, carers or family, and several consistently attending members of the health and social care team. A strong emphasis is placed on an equal hearing of all voices and perspectives as both a means and an objective of treatment. The emphasis is on transparency with the person, empathy, and positive regard.

There has not yet been a major evaluation on the direct impact of Open Dialogue on the use of coercive measures. However, in Lapland, Open Dialogue has entirely replaced the emergency, medicalised treatment. Overall, the benefits of a two-year follow-up were as follows: less hospitalisation, more family meetings, less medication, fewer relapses and better employment status.⁷⁵

[Open Dialogue: an alternative Finnish approach to healing psychosis](#) (Full Documentary Film).

Drug Free Unit at Åsgård Psychiatric Hospital, Tromsø, Norway

In 2009, Grete Johnsen, a long-time mental health activist, joined other activists to write a manifesto for change titled Cooperation for Freedom, Safety and Hope: "We wanted to create an alternative to psychiatry. We wanted to create something of our own. Our goal was to create a place, or a center, with freedom and without forced treatment, and without medication being the center of care."⁷⁶

The Drug Free Unit at Åsgård psychiatric hospital in Tromsø was established on 1st January 2017. It is a six-bed unit situated in a large hospital. It offers a possibility for persons with serious mental health problems to choose treatment that does not include neuroleptics. 22 specialists work here including one psychiatrist and one psychologist. The unit is managed by a nurse.

The approaches of Open Dialogue (by Jaakko Seikkula) and Reflective Process (by Tom Andersen) are the core foundation for the methods used at the Drug Free Unit. Also art therapy and physical exercise take important place during the recovery process on the ward.

Criteria for admitting patients to the Drug Free Unit:

⁷⁴ Olson, M, Seikkula, J. & Ziedonis, D. (2014). The key elements of dialogic practice in Open Dialogue. The University of Massachusetts Medical School. Worcester, MA. September 2, 2014

⁷⁵ Open Dialogue: and Internatipnal Community: <http://open-dialogue.net/>

⁷⁶ <https://www.madinamerica.com/2017/03/the-door-to-a-revolution-in-psychiatry-cracks-open/>

- No coercion;
- Only patients who are motivated;
- Priority given to patients with psychosis or bipolar conditions;
- Referrals only from other specialised services;
- No acute admissions;
- No patients with major problems of substance use;
- Only 'safe' and non-violent therapeutic methods and procedures;
- Tapering of psychotropic drugs prior to admission.

People who get admitted to the ward undergo assessment of their mental capacity. Treatment at the Drug Free Unit is available to those, who are assessed as capable of understanding their actions and making decisions prior to their admission.



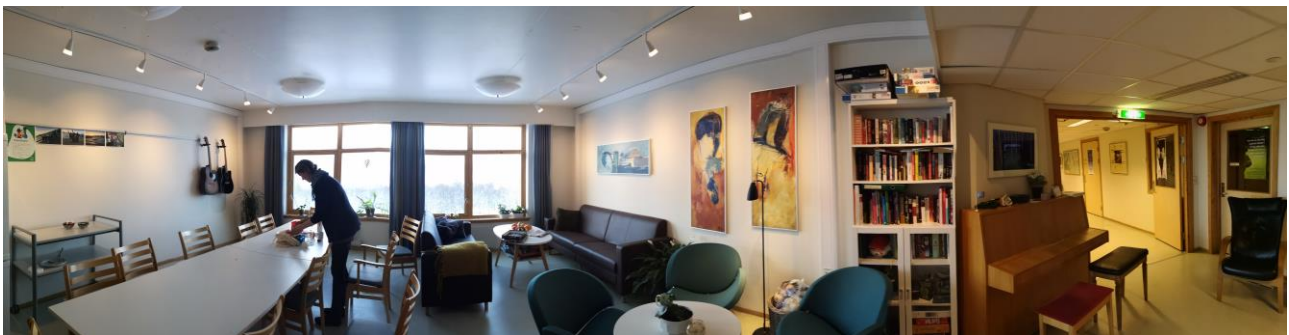
Åsgård psychiatric hospital in Tromsø, Norway. © Ugnė Grigaitė

When people start their treatment, they are approached by staff members with the questions "What's difficult or hard for you?" instead of "What's wrong with you?". Employees do not use any constraints, there is no pressure in making personal decisions.

People spend a lot of time talking, communicating, listening, reflecting on despair, loneliness, traumatic experiences, etc.

The drug-free treatment is provided under the protocol which stipulates:

- Secure choice / options for patients;
- Is a part of a major effort to reduce the use of psychotropic drugs;
- Is based on patients' choice;
- Should focus on cooperation with local treatment programs;
- Should include a recovery perspective;
- Should be network oriented;
- Should engage families and other people important to individual patients;
- Focus on activity / work / studies / network;
- Help patients to be independent and autonomous;
- Employ people with lived experience of mental health problems, i.e. Experts by Experience;
- Patients and employees must develop a program that they all believe in together;
- Follow national treatment guidelines.



Drug Free Treatment Unit at Åsgård psychiatric hospital in Tromsø, Norway.

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Penumbra, Scotland

Penumbra is one of Scotland's largest mental health charities, which supports around 1800 adults and young people every week and employ 400 staff across Scotland. Penumbra was founded in 1985 and works to promote mental health and wellbeing for all, prevent mental ill health for people who are 'at risk', and to support people with mental health problems.⁷⁷

⁷⁷ <http://www.penumbra.org.uk/>

Penumbra envisages a society where people with mental health problems expect recovery and are accepted, supported and have the resources to fulfil their potential. Five key strategic aims are:

Recovery: to ensure that all mental health services and activities are hopeful, personalised and recovery focused.

People: to ensure a highly valued, skilled and involved workforce.

Innovation: to develop, support and provide innovative responses that; promote recovery, social inclusion and citizenship for people with mental health problems.

Influence: to promote mental health and wellbeing in communities by influencing; policy makers, funders and others.

Improvement: to ensure quality and continuous improvement in all business processes to achieve our mission.



Penumbra offers a range of services to improve health and wellbeing that provide practical, emotional and social support. All services are recovery focussed and offer personalised support. Some services require a referral from a mental health practitioner but many accept self-referrals and self-directed support requests.

Supported Living Services

Penumbra's Supported Living Services offer personal support to meet people's needs in their own home and in the community. Penumbra offers tailored practical and emotional support to help individuals lead an ordinary and fulfilling life in the community. The time, length and areas of activity covered are different for everyone, but can include help with budgeting, life skills, confidence building and social inclusion.

Supported Accommodation Services

Penumbra's Supported Accommodation projects operate as small homes in three local authority areas. They provide accommodation, care and support in both shared houses and self-contained flats. Supported accommodation offers an important opportunity for people with long-term mental health problems to live independently and access daily support, both practical and emotional.

Crisis and Short Term Support

The Edinburgh Crisis Centre is unique in Scotland. It is open 24 hours a day 365 days of the year and provides community based, emotional and practical support at times of crisis.

⁷⁸ It is a service for people who are aged 16 and over who are using or have used mental health services and are resident in the City of Edinburgh when they are facing a crisis. This includes people who have seen their GP, used voluntary services and people who identify themselves as having a mental health issue. Over 1300 people contact the Centre each year, over half have made contact for the first time. Penumbra also runs a number of 1st Response services for people who need short term support or information about local services.

Nova (Social Inclusion) Services

Penumbra's award winning Nova Projects seek to integrate people experiencing mental health problems, including those who self-harm and/or who are at risk of suicide, more fully into their community by helping them to access mainstream activities and groups such as further education, sports, clubs and work, whether voluntary or paid. Support is provided on a one to one basis for a fixed period of time, looking at an individual's hopes and aspirations in moving out of social isolation towards meaningful opportunities, relationships and community engagement.

Self-Directed Support (SDS)

Whether it's learning a new skill, becoming more involved in the local community, reducing stress, getting fit or getting connected with local activities, Penumbra can help people achieve outcomes through SDS. SDS is a system which allows people to choose how their support is provided, and gives them as much control as they want of their individual budget.

Peer Work

Many of Penumbra's services employ people with personal experience of mental health problems. Peer Support Workers act as 'recovery guides', promoting the recovery of people engaging with services. Peer work also promotes the recovery and inclusion of the Peer Support Workers who, like the majority of people who experience long-term mental health problems, may find it difficult to secure employment.

Homelessness Services

Penumbra's Homelessness Services engage with homeless people who have mental health problems or chaotic lifestyles. The Services provide person-centred support designed to meet each individual's needs and goals. The service in Glasgow has staff available 24 hours a day for practical and emotional support.

Alcohol Related Brain Damage

⁷⁸ www.edinburghcrisiscentre.org.uk

Penumbra supports individuals with Alcohol Related Brain Damage with daily living skills, health issues, social activities, education and employment. Support is individually based, flexible and tailored to individual needs.

Self-Harm Services

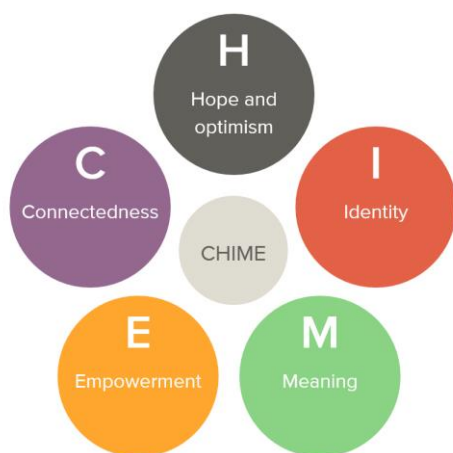
Self-Harm Projects are community-based services that work with people who self-harm and who might be at risk of suicide. Projects provides a safe, non-judgemental, person centred environment in which people can explore their self-harm issues and look at ways to manage and identify coping strategies. Penumbra provides informal emotional support for people who self-harm as well as their families and carers.

Scottish Recovery Network

Scottish Recovery Network⁷⁹ is hosted by Penumbra on behalf of an alliance of organisations. It undertakes a wide programme of activities that promote recovery and recovery based practice. It is funded by [the Scottish Government](#).

The Network's strategic aims are:

1. To work with others to support communities and the people within them, to achieve their recovery potential.
2. To place lived experience at the centre of health and social policy in Scotland.
3. To support and share recovery learning and approaches via:
 - Sharing evidence from robust research;
 - Raising awareness of and supporting best practice happening at a local, national and international level;
 - Encouraging and facilitating conversations about recovery.



The Network suggests, that [recovery can be very personal and mean different things to different people](#). To bridge the gap between the general (what applies to everyone) and the personal experience they underpin the work with the [CHIME framework](#).

'Hand in Hand' – Supported Living Services in Georgia

An activist Maia Shishniashvili has been fighting for the rights of former residents of social-care and psychiatric institutions for over a decade. In 2010, she established a supported living service 'Hand in Hand' for persons with mental health problems, intellectual and psychosocial disabilities, and assists in their adaptation to living in the community, after they leave large segregated institutions. The service is based on the supported living model⁸⁰⁸¹; similar services also exist in Croatia, as well as in the UK.



Maia Shishniashvili and 'Hand in Hand' – a supported living service in Georgia. © Ugnė Grigaitė

Essentially, houses or flats are rented out in the community, in mainstream neighbourhoods, towns and cities, where up to a maximum of 5-6 persons with disabilities live. They have support staff available 24/7, according to each residents' individual needs. Residents are supported to have a home of their own, with rules which they create

⁸⁰ Grigaitė, U. (2017) The Deinstitutionalization of Lithuanian Mental Health Services in Light of the Evidence-based Practice and Principles of Global Mental Health, *Socialinė teorija, empirija, politika ir praktika*, 15, p. 7-26. doi: 10.15388/STEPP.2017.15.10806.

⁸¹ Rossler, W. (2006) Psychiatric Rehabilitation Today: an Overview. *World Psychiatry*. Oct; 5 (3): 151–157.

themselves; they are supported to make all decisions and choices which affect their own lives, in order to lead as fulfilling a life as possible. They have support available from staff for; developing their daily living skills, to find and keep employment, develop relationships and to be a part of society and their local community in every way possible, just as everyone else.

