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February 2016

Mental Health Europe contribution to the call for submissions from the Committee on the Rights of Persons with Disabilities on the General Day of Discussion Art. 19 on the right to live independently and be included in the community

Executive Summary

Mental Health Europe (MHE) is a leading European mental health NGO whose work is underlined by the social model of disability in the UN CRPD and who represents associations, organisations and individuals active in the field of mental health and well-being in Europe, including (ex)users of mental health services, service providers, volunteers and professionals.[1] MHE is a member of the European Expert Group on the transition from institutional to community-based care (EEG) and has been advocating for community-based services for persons with psychosocial disabilities as well as their full inclusion in society for many years. MHE has carried out research to map institutional and community-based services in the mental health field in Europe and published our finding in our Mapping Exclusion Report in 2012.[2] With these experiences in mind, MHE would like to provide our views on the meaning of and barriers to independent living and community participation for persons with psychosocial disabilities including institutionalisation, the State and non-State actor obligations which derive from Art. 19 as well as request clarification from the Committee on certain issues including re-institutionalisation, community treatment orders and the nature of some of the obligations owed by State Parties in respect of Art. 19.

[1] For more information on Mental Health Europe please see our website at: http://www.mhe-sme.org/about-mhe/. MHE's work is funded through financial support received from the European Union Programme for Rights, Equality and Citizenship. The views expressed herein should not be taken to reflect the official opinion of the European Commission.

[2] (Mapping Exclusion Report) Mapping Exclusion: Institutional and Community-based Services in the Mental Health Field in Europe, MHE, 2012, available at: http://tasz.hu/files/tasz/imce/mapping_exclusion_-_final_report_with_cover.pdf.

Introduction

Art. 19 appears to be rooted in two pre-existing rights: the right to choose one's place of residence and to participate in the community[3]. Art. 19 therefore does not create any new rights but provides a novel formulation of how these rights can be realised by persons with disabilities in light of the societal barriers they face. Art. 19 recognises the interdependency between independent community living and inclusion and participation in the community. Without Art. 19 fully inclusive societies will never become a reality and in this respect it should be seen as a cornerstone of the Convention as it is underlined by all the General Principles in Art. 3 including independence, autonomy, inclusion, participation and equality and non-discrimination. It is a clear panacea to the historic and continuing tendency to create separate and segregated communities, services and residential institutions for persons with disabilities including persons with psychosocial disabilities. The detrimental effects of long-term institutionalisation for persons with psychosocial disabilities are well-known[4], and various reports suggest that poor quality care and violations of human rights are endemic in institutions across Europe.[5] As a result of this, a process of de-institutionalisation (DI) has been ongoing in Europe for many years, with varying degrees of success. However, it is important to remember that in many cases DI has failed to achieve the full inclusion of persons with psychosocial and other disabilities. Without independent living as well as community participation and inclusion, persons with psychosocial disabilities will remain invisible and voiceless in society.

Normative content

What independent living means

According to subparagraph a) the core of independent living is the ability of persons with disabilities to make real choices about their living arrangements on an equal basis with others. It includes a recognition of the need to provide persons with disabilities with the opportunity to choose where and with whom they live but also includes the need to assure that persons with disabilities are not obligated to live in a particular arrangement. We know that the choices of persons with psychosocial disabilities are limited in a number of ways including through legal restrictions provided for in mental health laws but also by a lack of available and appropriate alternatives to institutions. In many respects the obligations outlined in subparagraphs b) and c) make it clear that independent living in the community is contingent on access to community-based services which enable meaningful choices.

[3] Elements of the right to choose ones place of residence appear in the following Articles of various international human rights treaties: Art. 13 (1), Art. 29, Universal Declaration on Human Rights (UDHR); Art. 12 (1), International Covenant on Civil and Political Rights (ICCPR); Art. 11, International Covenant on Economic, Social and Cultural Rights (ICESCR); Art. 5, International Convention on the Elimination of All Forms of Racial Discrimination; Art. 26, Convention Relating to the Status of Refugees; Art. 39, International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families. Elements of the right to participate in the community appear in many of the participative rights articulated in the following Art.s: Art. 25 a) ICCPR and Art. 15 b) Art. 13of ICESCR as well as, ICESCR. The right to live in the Community also appears in other regional human rights treaties including in Art. 15, the European Social Charter and Art. 26, the Charter of Fundamental Rights of the European Union and Art 4 Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities.

[4] Barton, R. (1959). Institutional neurosis. Bristol: Wright. Goffman, E. (1961); Asylums : Essays on the social situation of mental patients and other inmates. London: Penguin Books and Deinstitutionalisation and Community Living: Position Statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. Journal of Intellectual Disability Research Volume 54, Issue 2, pp. 104–112, February 2010.

[5] The archipielago of the forgotten: social care homes for people with mental disorders in Bulgaria. Bulgarian Helsinki Committee Freyhoff et al. 2004; Cage Beds: Inhuman and Degrading Treatment or Punishment in Four EU Accession Countries. Mental Disability Advocacy Center, Budapest; South Gloucestershire Safeguarding Adults Board, 2012, Winterbourne View Hospital, A Serious Case Review. Available at: http://hosted.southglos.gov.uk/wv/summary.pdf) 32 http://espresso.repubblica.it/dettaglio/cosi-hanno-ucciso-mastrogiovanni/2191955/

In some States, the right of persons with psychosocial disabilities to live in the community can be conditional upon complying with a treatment regime or community treatment orders as they are sometimes known.[6] MHE believes, in line with Art. 25, that consent to treatment should be free and informed but we would like to seek clarification from the Committee on whether community treatment orders would be viewed as a violation of Art. 19.

Access to services

Subparagraph b) and c) outline the services needed to foster independent living and inclusive communities. MHE takes subparagraph b) to mean that a variety of affordable specialised services including in-home, residential and other community services should be made available. In our Mapping Exclusion Report, MHE noted that there is a distinction between short-term psychiatric treatment and long-term social care of people with mental health problems. Long-term institutionalisation is often caused by a lack of adequate residential and social support in the community. Institutionalisation happens in a variety of services and settings (such as psychiatric hospitals, psychiatric departments of general hospitals, social care institutions, residential care homes, group homes, rehabilitation centres, and secure psychiatric facilities). There is evidence that psychiatric hospitals or institutions increase stigmatisation and can further deteriorate mental health.[7]

Although residential services are mentioned in subparagraph b), the General Comment should ensure that this should not be seen as an endorsement of 'institutional' residential services as institutions contribute to isolation or segregation from the community.[8] MHE hopes that the Committee will build on the work already done by the OHCHR's Thematic Study on the right of persons with disabilities to live independently and to be included in the community[9] and provide clarification in the General Comment on what types of residential services would comply with the UN CRPD.

It is important to recall that the needs of persons with disabilities vary between different groups and from person to person. For services to truly support independent living and inclusion, they should be individualised and respond to the needs of each person.[10] When thinking about numbers and types of service provision it is also essential to remember that institutions are not just buildings, they can be a culture. Block-treatment in residential care and compulsory treatment orders in the community can also create institutional cultures. Personal budgets and peer support are two important ways of ensuring that living in the community does not carry on the institutional culture by providing autonomy and in the case of peer support combating the 'us versus them' model prevalent in service delivery. Meaningful participation and inclusion can be achieved through training (ex) service users to provide individual or group peer support to other people with psychosocial disabilities and by valuing peer support as an equal and essential part of services.

Subparagraph c) should be taken to mean that mainstream services including housing, employment, healthcare, legal, social protection and welfare services should be accessible and take into account and cater for the needs of persons with disabilities. MHE believes that for mainstream services to be fully responsive to the needs of persons with psychosocial disabilities, they should be created in full and meaningful consultation with them and their representative organisations.[11] Training of staff is essential to this process

[6] Mapping Exclusion Report at pg 24.
[7] Mental health: Facing the challenges, building solutions. World Health Organisation , 2005, Geneva
[8] For more information on how the EEG defines an institution, please see pg 10 of the Common European Guidelines on the Transition for Institutional to Community-based Care (Common European Guidelines) available at the following: http://deinstitutionalisationguide.eu/wp-content/uploads/Common-European-Guidelines-on-the-Transition-from-Institutional-to-Community-based-Care-English.pdf.
[9] Thematic study on the right of persons with disabilities to live independently and be included in the community, Report of the Office of the United Nations High Commissioner for Human Rights, 2014, A/HRC/28/37.
[10] For more information about individual plans and assessments which support the creation of individual care/support plans, please see pg 115 of the Common European Guidelines.
[11] The concept of co-production of services can serve as a good example of best practice of meaningful consultation with persons with disabilities which leads to better individualised and person-centred services. MHE defines co-production as: Co-production is an inclusive working practice between service users and organisations, where all stakeholders are continuously involved in the design, development and delivery of the service, policy or activity.

and collaborative, creative thinking is often required to address the sometimes complex needs of persons with psychosocial disabilities.[12]

State Obligations

Obligations with immediate effect

States parties have an obligation to respect, protect and fulfill the right of all persons with disabilities to live independently and be included in the community. In this regard, States parties should refrain (negative obligations) from any action that deprives persons with disabilities of the right to independent living and are obliged to protect persons with disabilities from being deprived of this right as well as take efforts to fulfill it (positive obligations). Some obligations under Art. 19 are of immediate effect whereas some elements which relate to the provision of services will be subject to the standard of progressive realisation as outlined in Art. 4 (2). Negative obligations have immediate effect as they are not restricted by budgetary or resource concerns and go to the heart of the meaningful content of the right.

Art. 19 states that State Parties 'shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right'. But what are 'effective and appropriate measures' and which elements are of immediate effect? An indispensable measure in terms of the realisation of Art. 19 a) will be the amendment or enactment of laws which empower persons with psychosocial disabilities to make decisions for themselves. The Committee discussed some of the barriers to persons with psychosocial disabilities making choices for themselves in its General Comment on Art. 12 as well as the recent Guidelines on Art. 14. MHE requests that the relationship between these Articles and the obligations derived from this relationship are fully examined in the drafting of the General Comment on Art. 19. National policies and strategies on DI as well as community participation and inclusion should also form part of 'effective and appropriate measures' and should implement and reflect the need to provide a range of specialised community-based services as outlined in Art. 19 b) and underline the respect for autonomy and the empowerment of person with psychosocial disabilities. Of course, in keeping with the principle of participation which runs throughout the UN CRPD, these policies and legal frameworks should be drafted in meaningful collaboration with persons with disabilities in order to understand their needs.

Other clearly defined obligations include the need to provide support and access to a range of services which facilitate independent living in the community as well as the need to ensure that mainstream services are responsive to the needs of persons with disabilities. Elements of this obligation would be subject to the progressive realisation standard whereas some obligations would have immediate effect. Obligations in terms of services with immediate effect include the need to take measures to prohibit discrimination, including through the denial of reasonable accommodation, within the services mentioned by Art. 19. In addition, minimum core obligations have immediate effect and the minimum level of community-based services which would satisfy Art. 19 including housing, employment, healthcare, legal, social protection and welfare services should be defined in the General Comment. MHE would like to stress that in many countries mental healthcare is seen as a luxury when it is actually an essential part of basic healthcare. MHE hopes that any core obligation which relates to basic healthcare is understood to include basic mental healthcare which is particularly important for persons with psychosocial disabilities. MHE requests that the Committee define the core minimum obligations which derive from Art. 19 in its General Comment. Using the General Comments of the Committee on Economic, Social and Cultural Rights and the Human Rights Committee,

[12] MHE promotes a number of best practices for providing support which enables independent and community living and participation including specialised systems such as the personal ombudsman system as well as mainstream solutions such as training programmes for housing services to be more responsive to the complex housing needs of persons with psychosocial disabilities (ELOSH Project) and the Individual and Placement Support Method which supports persons with psychosocial disabilities to find quality employment (tried and trusted).

MHE has put together a list of the following obligations which we believe must have immediate effect in order to ensure the core meaningful content of the right:

- To refrain from supporting institutions which segregate persons with disabilities from the community and perpetuate their exclusion including through legislative or financial measures;
- To reform laws which obligate persons with disabilities to live in a particular setting;
- To ensure access to a social security scheme that provides a minimum essential level of benefits that cover at least essential inclusive health care which includes mental health care, and a range of basic shelter and housing which is accessible and community-based.
- To eliminate any barriers or obstacles that inhibit or restrict persons with disabilities from accessing services which are available to the general population including housing, employment, healthcare, legal, social protection and welfare services;
- To take legislative and any other necessary steps including policy measures to guarantee non-discrimination in the enjoyment of the right to live independently and be included in the community;
- To facilitate the right to live independently and be included in the community by according it sufficient recognition within the national political and legal systems, preferably by way of legislative implementation; adopting a national DI strategy and plan of action to realize the right to independent living in the community which are monitored in consultation with civil society;
- To promote the right to live independently and be included in the community through education and awareness raising;

Progressive realisation

As regards the progressively realisation of the right to access services which support independent living and community inclusion and participation, the State should take appropriate measures which are deliberate, concrete and targeted within a reasonable time, keeping in mind the maximum available resources, provide access to a range of affordable in-home, residential and other community support services which are developed in consultation with persons with disabilities, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community. MHE would like to seek clarification from the Committee on whether the obligation to make services and facilities which are available to the general public responsive to the needs of persons with disabilities is considered to have immediate effect.

Retrogressive actions

Retrogressive measures which deny economic, social and cultural rights are prohibited according to General Comment 3 of the Committee on Economic, Social and Cultural Rights (CESCR). MHE as well as other European NGOs have expressed concern [13]in recent years that austerity measures introduced as a result of the financial crisis have not only slowed the process of DI in Europe but has led to re-institutionalisation and homelessness due to cuts to disability benefits, to personal budgets and assistant schemes and healthcare. The Committee should address whether re-institutionalisation as a result of austerity measures is a violation of the States duties under Art 19.

Relationship to other Articles

Art.5: Equality & non-discrimination –The reference in Art 19 to 'on an equal basis with others' points to the already existing discriminatory status quo where mainstream society has been supported to live in community settings whereas separate segregated communities have been setup and maintained for people with disabilities. Persons with psychosocial disabilities face the added stigma and discrimination of being wrongly perceived as either dangers to themselves or society which has served as an additional barrier to DI

[13] ENIL Press Release: EU Alliance against Disability Cuts News, December 2015, available at: http://www.enil.eu/news/enil-press-release-eu-alliance-against-disability-cuts-news/

for persons with psychosocial disabilities.[14] The General Comment could benefit from an elaboration of what reasonable accommodation means in terms of independent living and community participation.

Art. 7 – Many long-term residents enter institutions as children and are denied the opportunity to live in a family setting as well as denied of their right to live independently and be included in the community from an early age. Upon reaching majority their ability to make choices are limited either officially through legislation or they remain in institutions in unregulated arrangements because they have become institutionalised.

Art.8: Awareness raising - The medical model of disability is still prevalent in Europe where MHE operates. Living independently in the community is a concept which remains alien to many and is often misunderstood and viewed with . This is why Art 8 is key to the realisation of Art 19 - more awareness of the social model of disability and psychiatry needs to be raised in order to combat negative stereotypes and misconceptions that persist in society. These misconceptions and stereotypes are often the root justifications for the harmful practices to which persons with psychosocial disabilities are subject. Models of good practices of community-based care need to be spread widely and more awareness of the benefits of such services should be raised.

Art.9: Accessibility - Without accessible communities, buildings, services etc independent community living and participation are practically impossible.

Art.12: Equal recognition before the law - In order for people to enjoy their right the right to live independently and be included in the community, their freedom of choice must first be respected. Therefore, **Art. 12** on legal capacity plays a central role in whether or not persons with psychosocial disabilities can legally exercise their right to make the choices outlined in Art 19. As Art. 12 implies, persons with disabilities must be supported as far as possible when exercising their legal capacity.

Art.14: Liberty and security of the person- there is clear link between institutionalisation and forced placement which has been recognised by Committee in its jurisprudence and Guidelines on Art 14.

Art. 22 – Respect for privacy – this Article has clear implications for how services are delivered and States as well as other actors should ensure that the privacy of persons with disabilities is not unlawfully interfered with in the provision of any services including housing.

Art. 24 – Education - persons with disability who drop-out of school can easily get entangled in a range of issues that may lead to institutionalisation so awareness-raising in schools is important.

Art. 28 - Adequate standard of living and social protection – this is a pivotal Article in terms of support for persons with psychosocial disabilities to live independently. Without proper social protection and a guaranteed standard of living many individuals might choose to remain outside the community because they might lose vital support if they leave. This is why when giving training on DI processes the EEG always stresses that the process is not just about closing facilities but creating viable and affordable services and support. Social protection is one of the most important factors in relation to independent living.

Art. 25 on the right to health**, Art. 27** on work and employment - Community-based treatments and care are associated with improved outcomes in social functioning, employment and independent living. Shorter hospital stays have been found to be as effective as longer stays and community-based programmes are more effective, or at least as effective. [15]

Other non-State actors

[14] Please see MHE's Mythbuster on Compulsory psychiatric treatment (2014) at: http://www.mhe-sme.org/fileadmin/Position_papers/MHE_Myth_Buster_on_forced_treatment_2014_01.pdf

[15] WHO (2003). Organization of services for mental health. (Mental health policy and service guidance package). World Health Organisation, Geneva

According to the UN Guiding Principles on Business and Human Rights[16], business enterprises, as specialized organs of society performing specialized functions, are required to respect human rights. Service providers have a significant role to play in respect of Art. 19 of the UN CRPD. MHE requests that the Committee provide guidance on this important issue in its General comment as well as urge States:

- to enforce laws that are aimed at, or have the effect of, requiring business enterprises, particularly service providers, to respect Art. 19, and periodically to assess the adequacy of such laws and address any gaps;
- Provide guidance to business enterprises which provide services to persons with disabilities on how to respect Art. 19 as well as other rights in the UN CRPD.

[16] UN Guiding Principles on Business and Human Rights: Implementing the United Nations "Protect, Respect and Remedy" Framework, 2011.