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Mental Health Europe Position Paper on the ICD-10 Revision

The history of MHE and the Beyond the Bio-medical Paradigm Taskforce

For many years [Mental Health Europe](http://www.mhe-sme.org),¹ has been calling for wider recognition of the crisis of confidence in the increasingly biological/neurological approach taken by Western psychiatry as well as for action in order to change this culture within mental health services. We advocate for a human rights-based approach to health and disability and, as underlined in the United Nations Convention on the Rights of Persons with Disabilities,² the participation of persons with psychosocial disabilities and persons with mental health problems in decisions which affect their lives. Therefore, MHE believes that a key shift in mental health culture should involve the taking into account of the views, rights and lived experience of users of these services. In this regard, one of the main points of focus for MHE is the forthcoming revision of the International Classification of Diseases (ICD 10) which will become ICD-11 when it is adopted by the World Health Assembly³ in 2018.

In 2012, [MHE set up a Taskforce of experts](#) from its membership to investigate, debate and report on the development of the newest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5),⁴ its likely impact and alternatives to the wholly medical/biological approach to psychiatry that it assumes. The biomedical approach is defined as a conceptual model of illness that excludes psychological and social factors and includes only biologic factors in an attempt to understand a person's medical illness.⁵ A [position statement](#)⁶ on DSM-5 was published and a survey was carried out in March-April 2013 to gather responses from our members. Overall respondents agreed with the synopsis of the position statement, that the DSM-5 was negatively impacted by

¹ Mental Health Europe (MHE) is a European non-governmental network organisation committed to the promotion of positive mental health, the prevention of mental distress, the improvement of care, advocacy for social inclusion and the protection of human rights for (ex)users of mental health services, their families and carers. MHE's membership includes associations and individuals active in the field of mental health in Europe, including people with (a history of) mental health problems, as well as volunteers and professionals in a variety of related disciplines. For more information please see our website at: <http://www.mhe-sme.org/>

² The United Nations Conventions on the Rights of Persons with Disabilities was adopted by the General Assembly in 2007 and has been ratified by a majority of States, available at the following:
<http://www.un.org/disabilities/convention/conventionfull.shtml>

³ The World Health Assembly is an annual Forum attended by delegations from the member States of the World Health Organisation and is the main decision-making body of the WHO.

⁴ For more information on DSM-V, please see the following:
<http://www.dsm5.org/about/Pages/Default.aspx>

⁵ Definition taken from the Medilexicon: <http://www.medilexicon.com/medicaldictionary.php?t=55643>

⁶ Please see our website for the full text: http://www.mhe-sme.org/fileadmin/Position_papers/DSM_V_Position_Statement.pdf

attempts to influence people, and particularly health care professionals, to pursue purely bio-medical solutions including by ignoring alternatives to medication. Medication can of course be useful in the treatment of mental health problems but this does not mean that it should be the only form of treatment nor that it is the most effective nor the best option for every patient. Proposals for change included encouraging the use of alternative models to the purely bio-medical approach as well as the use of combinations of models.

Following on from this work, in 2014 the mandate of the task force was prolonged and widened and re-named the Beyond the Biomedical Paradigm Taskforce (BBP Taskforce). The Taskforce expanded their work on promoting a shift away from the biomedical approach and adopted a manifesto for change entitled the "[Bucharest Manifesto](#)".⁷ The manifesto was unanimously approved by the MHE board and gathered widespread support.

ICD-10 Revision/ ICD-11

According to the WHO, the ICD "is the standard diagnostic tool for epidemiology, health management and clinical purposes. This includes the analysis of the general health situation of population groups. It is used to monitor the incidence and prevalence of diseases and other health problems".⁸ From the outset MHE would like to stress that we are not opposed to diagnostic manuals, indeed we know that they can be of great benefit to practitioners in their work and are important in helping governments develop responsive health systems. However, we need to compile them and use them with caution. They are not "holy writ" and the worldwide outcry from service users and professionals about DSM-V was the culmination of increasing concern that the construction of categories was running far ahead of scientific evidence and sometimes flying in the face of both science and common sense, in addition to concerns about the influence of the pharmaceutical industry on these categories.

However, as with the DSM-V, the persons most deeply affected by diagnostics resulting from such manuals are those who use mental health services. Being labelled with a so called 'mental disorder' can have a profound impact on the lives of users as well as the treatment and care they receive. People with mental health problems are often discriminated against in society and socially excluded. Being diagnosed with a 'mental disorder' can have an impact on a person's relationships, social security and welfare entitlements, ability to be insured as well as their employment status.

Thus, the problem was and is that the approach being taken takes little or no account of the extremely varied experiences of individuals and the social and cultural circumstances in which their distress (and sometimes distressing) thoughts and behaviours occur. The individual is being subsumed into technical categories to which they have to subscribe in order to get help. There is further suspicion that this increasing move towards seeing people as the victims of an ever-expanding panoply of globally identifiable diseases is mainly in the interests of providers of large-scale technical solutions, eg. pharmaceutical companies. Thus, what started as tools for clinicians and researchers have, as a largely unintended consequence, become instruments in a power game with huge amounts of money at stake. The BBP Taskforce will be attempting to raise these concerns with the World Health Organisation (the WHO) – the international organisation mandated to prepare the ICD-10 Revision - to ensure that they are taken into account and that the process

⁷ For more information on the Bucharest Manifesto please see our website at the following: <http://www.mhe-sme.org/policy-work/bbp-task-force/bucharest-manifesto/>

⁸ As defined by the WHO at the following: <http://www.who.int/classifications/icd/en/>

involves people with lived experience of mental health problems as equal partners in its construction.

Safeguards

MHE believes that safeguards need to be put in place to ensure that diagnostic manuals, like the ICD, are understood to be a tool which should be used in an equal relationship of dialogue between the individual and the clinician, as well as carers when relevant. Such safeguards include the involvement of people with lived experience as equal partners in the construction process, ensuring that researchers and clinicians do not get "lost" in the wonders of technology and continue to see the individual human being in the context of her/his life. This approach necessitates the development of more user and carer friendly language, in partnership with representative organisations, which is essential for meaningful dialogue. A transparent process is also an important safeguard which promotes trust and requires the declaration of financial interests and the verification of the identities of those contributing to the revision.

Finally, upfront and honest guidance on the use of these manuals needs to reflect the provisional nature of the categories and the fact that they are socially constructed and that science has yet to find the biological marker for any specific diagnosis. Good doctors know this and see them as a basis for discussion, enquiry and an approach to treatment which is consensual and takes account of the whole person and their relationships. The manuals should come with a clear health warning and much clearer guidance on their proper use within the clinical relationship.

The Process

It is important to note that the WHO has endorsed the human rights-based approach to health⁹ and they should pursue this when revising the ICD. Initially, when the ICD-10 Revision process began, the WHO priorities were that the revision should be global, multilingual, multidisciplinary, transparent and free from commercial input. The WHO also recognised that users and their family members were direct stakeholders in the process and promised that opportunities would be created to seek the input of users, carers as well as civil society so that they could constructively contribute to the revision process.¹⁰

The WHO have opened up the process in the form of an online forum called the Global Clinical Practice Network (GCPN)¹¹ which allows mental health professionals from around the world to comment on the classification and symptoms. However, the Taskforce notes that although the Network is more participatory than the DSM-V process in that it is more global, it is only open to mental health professionals and there is no way of verifying who commentators are nor their interests, leaving the GCPN open to undue influence from pharmaceutical companies who have a

⁹The mandate of the WHO is based on the right to highest attainable standard of health, as outlined in its Constitution. The WHO has endorsed the human rights-based approach to health in the following documents: Health 2020: a European policy framework supporting action across government and society for health and well-being, WHO, 2012 available at: http://www.euro.who.int/_data/assets/pdf_file/0009/169803/RC62wd09-Eng.pdf and the OHCHR Technical Guidance on the application of a human rights-based approach to the implementation of policies and programmes to reduce and eliminate preventable mortality and morbidity of children under 5 years of age, which was designed in close collaboration with WHO, available at the following: www.ohchr.org/EN/HRBodies/HRC/.../A_HRC_27_31_ENG.doc

¹⁰ A Conceptual framework for the revision of the ICD-10 classification of mental and behavioural disorders, International Advisory Group for the Revision of ICD-10 Mental and Behavioural Disorders, World Psychiatry 2011; 10:86-92.

¹¹For more information on the GCPN please see: <http://www.globalclinicalpractice.net/>

vested interest in propagating the bio-medical approach. The only way that users, carers and civil society can give their views is in the form of the more limited function to comment on the most recent beta draft of ICD-11.¹²

Fatal flaws of the Revision

- Little to no meaningful involvement of users, carers or civil society

We believe it is important that the ICD strikes a better balance between scientific language and user and community friendly language. The process is complex and primarily targeted at governments and professionals; MHE believes that more should have been done to seek the views of users, carers and civil society. The Taskforce is only aware of one such project on user involvement which will be launched by the WHO Collaborating Centres in Lille and Montreal next year. While this project is welcome, it will have limited impact on the overall revision and has come into play much too late to make a real difference in the outcome. For the revision to be truly participatory, users, carers and civil society should be able to contribute constructively at all stages of the revision process. Involving users at this late stage and in such a limited way implies tokenism and a failure to really consider their perspective which is contrary to the UNCRPD.

- Lack of transparency

Although the GCPN is an interesting participatory tool for seeking the views of professionals, it does not make the revision process transparent. Lack of transparency is a common criticism levelled at WHO as acknowledged in a Revision Review commissioned by them in 2015.¹³ MHE is aware of the complexity and ambition of the ICD, however transparency should permeate throughout all levels of the revision process. The ICD must appear to be as objective and free from conflicts of interest as possible; this is the only way for a diagnostic manual to be credible as well as truly useful for all stakeholders.

- Prioritising health systems over the individual

While we understand that the ICD is used to facilitate vital work in helping governments develop responsive health care systems, MHE does not believe that labelling people and forcing them into categories is helpful. On the contrary, this approach can be detrimental for the recovery and appropriate treatment of persons with mental health problems. One size does not fit all and MHE supports a person-centred approach to healthcare where a holistic view is applied to a person and the individual needs of users are at the heart of mental health care systems. In addition, the ICD-10 Revision encourages completely natural human behaviour or personality traits to be treated as symptoms in certain cases. For example, 'Single Episode Depressive Disorder' is defined as a period of almost daily depressed mood or diminished interest in activities lasting at least 2 weeks accompanied by other symptoms such as changes in appetite or sleep. This diagnosis, which was

¹² To comment on the beta draft of ICD-11, please see:

<http://apps.who.int/classifications/icd11/browse/Account/Login?returnUrl=%2Fclassifications%2Ficd11%2Fbrowse%2FLogin%2Fen?@/>

¹³ Report of the ICD-11 Revision Review, 2015, available at:

<http://www.who.int/classifications/icd/reportoftheicd11review14april2015.pdf>

also criticised during the development of DSM-V, could easily be extended to periods of normal grief.¹⁴

- Reinforcing the biomedical model

The continued classification of so called 'mental disorders' in the current draft of the ICD-10 Revision presents itself as being without etiological orientations but is reinforcing the biomedical approach and will likely lead to further standardising of treatment which is inconsistent with a person-centred approach to healthcare.

- The global vs the local

We appreciate that the ICD as a global instrument needs to take a global approach, however the WHO admits that the universality of specific categories of so called 'mental disorders' is an inherent assumption of the ICD and that this assumption has not been proven.¹⁵ "Mental disorder" has its roots in social and cultural understandings as well as in individual distress and therefore the global approach, unmediated by local understandings, can set aside and/or undervalue social and psychological support developed from within local communities through lived experience. Attempting to apply a diagnostic tool, defined purely by professionals, universally and in a diversity of cultures is too crude an approach. WHO must acknowledge more fully the limitations of the global approach to diagnosis and encourage participant states and communities to offer commentaries which reflect local understandings, practice and cultural norms.

Going forward

The Taskforce understands that in the future, the ICD will not be revised in the same drawn out and complex manner, rather the revision process will be continuous. Although it might be too late for the current Revision, future revisions should adopt the above mentioned safeguards and provide opportunities to contribute to the shift away from the biomedical approach to mental health problems.

Calls for action:

Going forward **MHE calls on the WHO** to:

- Make the revision process truly participatory by involving users, carers and civil society in a meaningful and constructive way.
- Develop, in partnership with representative organisations, more user and carer friendly language.
- Ensure transparency at all levels of the revision process as well as ensuring that the identities and allegiances of health professionals who take part in the Global Clinical Practice Network are verified to prevent any conflict of interest.
- Ensure that guidance on the use of the ICD is clear and honest, positioning the use of diagnostics as an important tool in an equal relationship of dialogue between the user and the

¹⁴ DSM-5 grief scorecard: Assessment and outcomes of proposals to pathologise grief. Jerome C Wakefield, World Psychiatry 2013 Jun. 12 (2), 171-173, published online 2013 Jun 4, doi: 10.1002/wps.20053 PMCID: PMC 3683270) and Horvitz AV, Wakefield JC (2007), The loss of sadness. How psychiatry transforms normal sorrow into depressive disorder. London, New York: Oxford University Press.

¹⁵Op cit 10 at pg 88

clinician and emphasising the need to recognise the value and validity of local understandings, practices and cultural norms.

What the EU can do

As a party to the UN CRPD, the EU has a role in promoting the participation of persons with disabilities in decisions which affect their lives. MHE is aware that the European External Action Service (EEAS) coordinates Member State's engagement with the WHO on global health issues and feels that some of the above issues should be raised with the WHO.

We call on the EU, through the EEAS, to put pressure on the WHO to ensure that:

- The ICD revision process is transparent and participatory and meaningfully involves users, carers and civil society.

What MHE will do

MHE has decades of experience in supporting the growth of our member organisations and seeking their views, including in particular independent user organisations. We will continue to try to reach out to partners and offer our support in order to ensure that the views of users, as well as carers and enlightened professionals are sought in both a meaningful and constructive way.