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MHE's position paper on the public consultation on the mid-term review of the Disability Strategy

Executive Summary

MHE has prepared this more comprehensive position paper to accompany its response to the survey on the mid-term review of the Disability Strategy. In this position paper MHE notes the strengths and weaknesses of the Disability Strategy as well as the areas in the accompanying list of actions which have seen the most and the least progress. MHE concludes that given that the Disability Strategy was written before a number of important developments including the review of the EU by the Committee on the Rights of Persons with Disabilities, and that a full and comprehensive revision should take place. In addition, MHE assessed how the Disability Strategy could help persons with psychosocial disabilities and has found that unfortunately the Strategy neglects their needs by failing to acknowledge the barriers they face particularly in relation to their autonomy. MHE hopes that the mid-term review will be able to address this omission and make the Disability Strategy work for all persons with disabilities in Europe.

MHE calls on the Commission to:

- Ensure that the review process leads to a comprehensive revision of the Disability Strategy as well as an update of the accompanying list of actions which will fully reflect developments since its adoption including the recommendations received by the EU from the Committee on the Rights of Persons with Disabilities, the impact of austerity, the European Framework for Action on Mental Health and Wellbeing and discussions surrounding the proposed Social Pillar of Rights.
- Ensure that the revision of the Disability Strategy takes into account the needs of and barriers faced by persons with psychosocial disabilities with a specific action area on autonomy and a list of appropriate actions, in line with EU competency, which promote autonomy, reflect the recommendations from the Committee and aim to remove obstacles to the enjoyment of the rights in the following Articles of the UN CRPD: 5 (equality and non-discrimination) 12 (equal recognition before the law), 13 (access to justice), 14 (liberty and security of the person), 15 (freedom from torture), Art 17 (protecting the integrity of the person) and 29 (participation in political life).
- Meaningfully consult with DPOs and disability allied organisations at all stages when developing
 or reviewing key disability policies and policies which affect persons with disabilities which should
 include consultation on the formulation of surveys and questionnaires.

MHE calls on the EU to:

Adopt, in line with recommendations from the Committee on the Rights of Persons with
Disabilities, a strategy on the implementation of the UN CRPD, with the allocation of a budget, a
time frame for implementation and a monitoring mechanism.

Introduction

Mental Health Europe (MHE)¹ has responded to the consultation survey on the review of the Disability Strategy and has prepared this accompanying position paper to more fully articulate our views. MHE welcomes the public consultation and hopes, that in line with the recommendations of the Committee on the Rights of Persons with Disabilities (the Committee), the review will 'establish clear guidelines on the inclusion of the Concluding Observations with clear benchmarks and indicators'. MHE understands that the Disability Strategy is general in approach but in taking this approach it also fails to live up to the promise that it would work towards a barrier free Europe which is more inclusive for all. 1 in 4 persons will experience a mental health problem in their life time and mental health problems are one of the leading causes of disability in the EU.³ The denial of autonomy is a key obstacle that prevents persons with psychosocial disabilities⁴ in Europe realising their rights and in failing to address it in the Strategy, the Commission has neglected the needs of a large number of persons with disabilities in Europe. MHE hopes that the mid-term review will be able to address this omission and some of the limitations indicated in this position paper by making the Disability Strategy work for all persons with disabilities in Europe including persons with psychosocial disabilities. Furthermore, we hope that the review will lead to a proper revision of the Strategy which will reflect other developments since its adoption including the part it could play in the newly proposed Social Pillar of Rights. In addition, as was pointed out by EDF in its alternative reports to the Committee, to which MHE contributed⁵, the Disability Strategy is the only specific strategic plan aimed at implementing the United Nations Convention on the Rights of Persons (the UN CRPD) but is limited in its scope and is only intended as a strategy for the Commission. We also therefore urge the EU, in line with the recommendation from the Committee, to adopt a comprehensive strategy for the implementation of the UN CRPD which involves all its institutions, with the allocation of a budget, a time frame for implementation and a monitoring mechanism.⁶

Strengths of the Strategy and progress made

website at: http://www.mhe-sme.org/.

The Disability Strategy focuses on many key barriers to the enjoyment of the rights of persons with disabilities. Some of these areas of action are particularly important to persons with psychosocial

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. 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. For more information please see our

² Para 11 of the Concluding Observations on the initial report of the EU,2015, CRPD/C/EU/CO/1.

³Data and Statistics: Prevalence of mental disorder, WHO, available at: http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/data-and-statistics.

⁴ Psychosocial disabilities: An internationally recognised term used in policy work, in particular the United Nations Committee on the Rights of Persons with Disabilities to describe the experience of people who have long-term mental impairments which, in interaction with various societal barriers, may hinder the full realisation of their rights. MHE uses this term in policy work when referring to persons who fit the definition and are therefore protected by the UN CRPD. For more on the language used in relation to mental health, please see the MHE glossary at: http://www.mhe-sme.org/policy-work/glossary/.

⁵ EDF Alternative Report to the United Nations Committee on the Rights of Persons with Disabilities, 2014, available at https://www.dropbox.com/s/88lg96uknfgy8ps/2015%2003%2004%20EDF%20Alternative%20report%20final%20ACCESSIBL E.pdf?dl=0.

⁶ Para 9 of the Concluding Observations on the initial report of the EU,2015, CRPD/C/EU/CO/1.

disabilities including those on participation, equality, employment and health. Furthermore, MHE has reviewed the list of action and is appreciative of the fact that many key actions in the list of actions have been implemented albeit to varying degrees. MHE is particularly grateful for the actions specified which relate to access to healthcare and mental health and the efforts made by the Commission in this area over the past 6 years. The list of actions included specific reference to promoting modern mental health services and long term care facilities⁷ through the European Pact for Mental Health and Wellbeing and addressing the issue of work related disabilities with a particular emphasis on 'work related disabilities for reasons of mental disorder'. MHE believes that given the knowledge gained since 2010, that these action points should be updated to reflect developments in European mental health policies including the newly adopted European Framework for Action on Mental Health and Wellbeing. The language could also better reflect the language of the UN CRPD by referring to psychosocial disabilities rather than 'mental disorders'.

Another key area that the EU has championed is de-institutionalisation (DI) including through financial support lent through the European Structural and Regional Funds and its active collaboration with the European Expert Group on the transition from institutional to community-based care which has included financial support, the organisation of EEG training seminars for desk officers and other Directorate Generals interested in the issue as well as training seminars in Member States who wish to use the funds to support the transition. EU action in this area, where properly implemented, has led to greater enjoyment of the rights of people with disabilities to live and be included in the community. However, MHE would advise that the Commission could further promote DI by supporting the spread of good practices of community based mental health services via transnational funding including through the Health Programme and that this should be reflected in the updated list of actions. MHE believes that the EU action on DI should serve as a best practice example of how the EU can take a leadership role and support progress on a human rights issue in which it has limited competence.

Having said this, MHE is cognisant that a simple ticking the boxes exercise to see which actions were implemented does not actually measure the tangible benefits for persons with disabilities which have resulted from the Disability Strategy. Our members have expressed concern about how the Strategy can have an impact on the ground in Member States and how this can be monitored or evaluated. MHE suggests that the Commission should consider carrying out an evaluative review which examines how the Disability Strategy and its actions have helped persons with disabilities in Europe.

The invisibility and autonomy of persons with psychosocial disabilities

The Disability Strategy, as mentioned above, takes the approach of being broad in terms of persons with disabilities but for a strategy to be truly inclusive it needs to recognise the difference between different persons with disabilities and the different and diverse barriers they face in society. Persons with psychosocial disabilities are often overlooked when disability policies are adopted because visible disabilities and the barriers that persons with them face, such as accessibility and mobility

⁷ Given the importance placed on de-institutionalisation in the Strategy, MHE takes long-term facilities to mean facilities which support community inclusion and are not institutional.

For more information on MHE's position on independent living and community inclusion, please see our submission to the Committee on Article 19 of the UN CRPD available at the following: http://www.mhe-sme.org/fileadmin/Position_papers/MHE_Contribution_-_Art._19_UNCRPD.pdf.

⁹ There are a number of models including the Open Dialogue and Trieste models which are widely recognised as effective for reducing hopsitalisation and institutionalisation. For more information on Open Dialogues, please see the following: http://www.mindfreedom.org/kb/mental-health-alternatives/finland-open-dialogue. For more information on the Trieste model, please see the following: http://www.triestesalutementale.it/english/mhd_department.htm.

issues, are seen as the primary barriers to inclusion. However, removing mobility and accessibility barriers does little to help a person with a psychosocial disability who has been put under guardianship and confined to an institution where he or she is forced to take medication against their will and denied a whole host of other rights including their rights to marry, have a family and vote. The primary responsibility for these violations and abuses rests on Member States but the EU has a co-ordination and leadership role which has remained largely underused in respect of these issues.

There is little in this strategy which promotes autonomy which is an underlying principle of the UN CRPD and is central to persons with psychosocial and intellectual disabilities realising their rights in Europe. There is only one limited action point on promoting good practices on legal capacity but MHE believes that efforts in this area at EU level have focused primarily on persons with intellectual disabilities. To date, as far as MHE is aware, little outside the Disability High Level Group and the Work Forum has been done to spread good practices which would benefit persons with psychosocial disabilities. There are a number of ways that the Commission and the EU could advance the understanding of autonomy, its relationship to the use of coercion in mental health treatment, and Article 12. These could include cross-national training programmes to educate the judiciary and medical professionals across Europe and financial support for joint actions which could help Member States who are interested in implementing good practices on supported decision-making for people with psychosocial disabilities. There are also missed opportunities in the section on participation which does not address the limitation of voting rights for persons with psychosocial and intellectual disabilities in EU elections in some Member States. MHE strongly urges the Commission to revise the Disability Strategy to include autonomy as an area of action and update the accompanying list of actions accordingly. Action points targeting barriers faced by persons with psychosocial disabilities should promote autonomy, reflect the recommendations from the Committee and aim to remove obstacles to the enjoyment of the rights in the following Articles of the UN CRPD: 5 (equality and non-discrimination) 12 (equal recognition before the law), 13 (access to justice), 14 (liberty and security of the person), 15 (freedom from torture), Art 17 (protecting the integrity of the person) and 29 (participation in political life).

More room for improvement

MHE appreciates that the Disability Strategy was adopted at a time when the EU had yet to conclude ratification of the UN CRPD and had not yet been reviewed by the Committee. However, with the passage of time a number of omissions have become more evident. MHE has identified the following as areas where there is significant room for improvement in the Disability Strategy:

- **Political participation:** As noted above, a glaring omission within the section on participation is the issue of political participation. The denial of the right of persons with psychosocial and intellectual disabilities to exercise their right to vote disenfranchises them from the EU. The fact that citizens of the EU with disabilities are discriminated against and denied their right to vote in European elections should be a key concern for the EU.
- Optional Protocol: There is no mention in the Disability Strategy of the Optional Protocol which if ratified would allow persons with disabilities within the European Union to lodge complaints with the CRPD. MHE believes that this would provide a key mechanism for the citizenry to seek implementation of the Convention and make complaints if the EU breaches the UN CRPD. The Committee called upon the EU to ratify the Optional Protocol and the review of the Disability Strategy provides an opportunity to consider this important next step.

• Austerity: Even though the Disability Strategy was adopted at the height of the financial crisis, there is no mention of austerity measures. MHE and other European NGOs including EDF and the European Network on Independent Living (ENIL) have been monitoring the impact of the crisis and austerity measures on persons with disabilities which has led to cuts to disability benefits and a worsening of situation for many. This situation can be more pronounced for persons with psychosocial disabilities who, although they should be entitled to the same benefits as other persons with disabilities, are sometimes treated differently because they are not viewed as having a disability. Any review of the Strategy should include an acknowledgement of the affects of austerity measures on persons with disabilities particularly on health services, access to healthcare and cuts to disability allowances.

Areas where there has been limited progress

While the Commission has been very active in some of the action and implementation areas, it has been less effective in others. Areas where MHE has seen limited progress include:

- Awareness raising –MHE is grateful to the Commission for providing us with funding under its Rights, Equality and Citizenship programme. By funding MHE the Commission has certainly contributed to awareness raising about the barriers faced by persons with psychosocial disabilities. However, simply funding NGOs that work on disability is not enough and the EU should be using its authority to push this agenda forward to battle discrimination and stigma given that it is the root cause of many of the barriers to inclusion. It should also be recalled that Committee recommended that the EU develop a comprehensive campaign to raise awareness about the Convention and to specifically combat prejudices against persons with psychosocial disabilities.
- Education: The educational and support needs for students with psychosocial disabilities at
 all levels of education are often overlooked. MHE believes that more should be done at EU
 level to promote inclusive education for students with psychosocial disabilities and to
 encourage Member States to provide support to such students on the same basis as other
 students with disabilities.
- Employment- in MHE's view, the Commission has not lived up to its promise to exploit the Europe 2020 Strategy to promote employment for persons with disabilities and now with plans to limit the number of Country Specific Recommendations the ability to do so will be reduced significantly. There are successful best practices which can help persons with psychosocial disabilities find appropriate and quality employment such as the Individual Placement and Support (IPS) method. The Commission should promote such best practices and they should feature in the proposed long-term unemployment recommendation when it is drafted.
- Support for families and informal carers: MHE appreciates that this element was included in the participation section of the Disability Strategy as family members are often the primary

¹⁰ Impact of the Crisis and Austerity Measures on Health Systems and Disadvantaged Groups, Mental Health Europe Contribution to European Public Health Alliance – Working Document – 2012, available at: http://www.mhe-sme.org/fileadmin/Position papers/Impact of the Crisis and Austerity Measures on Health Systems and Disadvantaged Groups.pdf. Report on the Impact of the Crisis on the Rights of Persons with Disabilities, EDF, available at: http://www.edf-feph.org/Page Generale.asp?DocID=13854&thebloc=13856. MHE is part of the Alliance against Disability Cuts led by ENIL, for more information about the recent work of the Alliance please see: http://www.enil.eu/news/enil-press-release-eu-alliance-against-disability-cuts-news/.

¹¹ To learn more about the IPS method, please see MHE's previous work on the Tried and Trusted Project, available at the following: http://www.mhe-sme.org/our-projects/past-projects/tried-and-trusted/.

carers of persons with disabilities. However, our members believe more could be done to help families and informal carers through more robust support at EU level for education, support and flexible working hours. We hope that in the update of the actions there could be a stronger link to the discussion around a 'work-life balance' for those with caring responsibilities.

Meaningful consultation with DPOs and civil society

The Committee recommended that the Disability Strategy be reviewed 'in close consultation with representative organisations'. MHE believes that the questionnaire intended to seek the views of DPOs and civil society is limiting and does not allow for meaningful consultation. In the future, MHE hopes that DPOs and disability allied civil society will be consulted on the drafting of questionnaires or surveys intended to feed into discussions on key disability policies or policies which affect persons with disabilities. This will ensure that the right questions are asked and that more space is given to adequately respond to such important review processes.

Calls to action

MHE calls on the Commission to:

- Ensure that the review process leads to a comprehensive revision of the Disability Strategy as well
 as an update of the accompanying list of actions which will fully reflect developments since its
 adoption including the recommendations received by the EU from the Committee on the Rights of
 Persons with Disabilities, the impact of austerity, the European Framework for Action on Mental
 Health and Wellbeing and discussions surrounding the proposed Social Pillar of Rights.
- Ensure that the revision of the Disability Strategy takes into account the needs of and barriers faced by persons with psychosocial disabilities with a specific action area on autonomy and a list of appropriate actions, in line with EU competency, which promote autonomy, reflect the recommendations from the Committee and aim to remove obstacles to the enjoyment of the rights in the following Articles of the UN CRPD: 5 (equality and non-discrimination) 12 (equal recognition before the law), 13 (access to justice), 14 (liberty and security of the person), 15 (freedom from torture), Art 17 (protecting the integrity of the person) and 29 (participation in political life).
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MHE calls on the EU to

 Adopt, in line with recommendations from the Committee on the Rights of Persons with Disabilities, a strategy on the implementation of the UN CRPD, with the allocation of a budget, a time frame for implementation and a monitoring mechanism.

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