



ENIL Response to World Health Organisation (WHO) Action Plan 2014-2021 “Better Health for People with Disabilities”

Historically, disabled people have had little control or influence over the care and support they receive. Whilst there have been small pockets of success, the majority of disabled people are forced to be dependent on professionals when it comes to deciding the type and amount of support they will receive in order to meet their needs. If this is to change, we need the UN organisations and Member States to view the needs and demands of disabled people as a human rights issue, supported by the articles outlined in the UN Convention on the Rights of Persons with Disabilities. The European Network on Independent Living (ENIL) welcomes the overall aims and objectives outlined in the WHO Disability Action Plan 2014-2021 but asks that it goes further, in order to address a number of existing issues that continue to affect the lives of disabled people:

Comments on the vision, goals and objectives:

- The vision must also be inclusive for those who do not define themselves as ‘disabled’ but who are systematically oppressed by society’s failure to ensure their needs are met. For many individuals, they will not consider that the action plan is applicable to their situation nor will they recognise their inequalities are linked to the definition of a ‘disabled person’. We support the notion of using the definitions of the United Nations Convention on the Rights of Persons with Disabilities (UNCRC), in particular for explaining communication and discrimination. Whilst the Convention does not, as such, include a definition of ‘disability’, it does recognise that disability results from societal barriers; many people will be protected by the UNCRC even if they do not perceive themselves as disabled. In these instances, it will be the responsibility of the services they use to see the connection



between the individual's needs and the UNCRPD; therefore, it is imperative that WHO adopts the definitions of the UNCRPD, otherwise society will continue to marginalise and exclude disabled people, in particular: older people, individuals with intellectual disabilities, individuals with mental health problems and people who define themselves as Deaf.

- The Action Plan must promote the concept of 'experts-by-experience'. Disabled people are best placed to identify their needs and create a holistic support plan to meet their various, and potentially, fluctuating needs. Whilst it is important to recognise that disabled people and the health service have endured a fractious, difficult relationship – due to issues such as health services adopting a medical and tragic model of disability – we now have the opportunity to ensure disabled people, given the right level of resources and support, can become leaders of their own health and break away from the notion of being seen as a passive and dependent individual.

Comments on Member States' activities:

- An effort needs to be made to ensure we do not use assistive technology and community-based resources as an opportunity to replace choice and control. Advancements or funding cannot be provided as a result of cost-effective measures that ultimately lead to a reduction in other services which work towards equality and inclusion, and support full and equal participation for disabled people. It must be recognised that the aim of improvements to support services and technology is to advance the Independent Living agenda, ultimately leading to more choice and control. It is inevitable that some community-based resources and services will cease to function and operate, but this can only happen when the replacement or alternative service adheres to the principles of Independent Living.
- It is also important to recognise that, for many disabled people, their initial discussions about disability-related issues are



predominantly set within a health context. Their early interactions with health professionals will establish what path they will take throughout their life with regards to identity, understanding of inequality and their rights, the various services available and peer-related support. If we are to ensure disabled people are not marginalised, isolated and excluded from their communities, and in general society, then we need health services to work holistically and across all the different facets that affect disabled people, such as: social care, education, access to housing, employment, the transition between child and adult services. When services are integrated and processes are seamless, the holistic care and support provided does not need to be the focus of attention; therefore, the individual can lead their life according to their aims and aspirations. There is also a need to promote a positive concept of 'a disabled person' and the various links to empowerment.

- For many disabled people, they are unaware of the UNCRPD; therefore, it is difficult for people to realise their demands within a human right perspective. Member States need to actively promote the UNCRPD and not limit it to health; furthermore, wellbeing is associated with other specific aspects of life and it is the responsibility of the Member State to promote such connections and highlight the importance of meeting the needs of the individual holistically.
- There needs to be a clear understanding of disability-related issues when accessing health service, for example, the role of Personal Assistants during hospitalisation. Whilst health is paramount within this particular context, consideration and a proactive approach needs to be taken to ensure non-health related access needs are embedded within all health plans – this is to guarantee that disabled people will not be further marginalised when accessing health services due to disability-related matters.



Comments on WHO activities:

- The ideology of Independent Living must be embedded within all holistic care practices, especially health and social care. The concepts of Independent Living, societal barriers, personalised and self-directed services must be reflected in the ethos of all national and local programmes with a clear understanding from front-line staff to those in powerful and leadership positions. We know that the majority of disabled people are disempowered and are unaware of their rights; therefore, it is imperative that the services they access are knowledgeable of the rights-based approach to disability equality and should take a proactive approach to be involved in facilitating that learning.
- Furthermore, it is essential to clearly outline what is meant by terms such as: Independent Living etc. Organisations, local government authorities and disempowered individuals, including their families, have continually promoted an incorrect interpretation of what Independent Living means, leading to further marginalisation and isolation. There has been a misconception that Independent Living refers to 'participating and performing daily activities by yourself/on your own' – this has created a culture of fear and has manifested into disabled people and their allies becoming hesitant about being in control of their life or pursuing initiatives that promote the concept of Independent Living. It must be reinforced that Independent Living means 'having choice and control over how you want to live your life and ensuring you have the right level of support to do so'.

Comments on actions by international and national partners:

- It is important to ensure, across all objectives, that disabled people and their organisations are provided with opportunities to influence decisions, as well as lead on particular work streams and be included within research from the design phase to the analysis and recommendation of actions stage. It is one thing to declare an interest in doing this and another to make it a reality – Member



States will need to outline how this will work in practice, including the mechanisms to ensure it is not tokenistic.

- Where there is mention of national or powerful bodies participating in disability related discussions, we must ensure that it is true coproduction and partnership; whereby every member is equal and that engagement is representative of everyone who is or is considered to be disabled. This includes, but not limited to, identifying methods for engaging with seldom heard groups, individuals who do not consider themselves disabled but are covered under the UNCRPD and people who encounter multiple discrimination. There can be an overreliance to engage with the same organisations and people because of their knowledge, experience, resources or as a result of previous engagement – this prevents other groups within the community/society of having the opportunity to share their knowledge and contacts, ultimately leading to policies and services continually being influenced by one or a small group of people/organisations who, regardless of their previous work, will not be representative of all disabled people.
- Where possible, the education and training of medical and health students should be coordinated and delivered by people who use services – going further than just being ‘involved as providers’. Equally, the inclusion of disability into the curriculum must address issues of: empathy, behaviours and values. It is essential to acknowledge how traditional medical and health attitudes can have a detrimental effect on disabled people and their families. If professionals, and ultimately disabled people and their families, believe the health of a disabled person to be the primary reason for discrimination and disadvantage, it will reinforce the view that society perceives disabled people as abnormal and dependent upon medical professionals and carers, with cure or rehabilitation – and often the segregation of the individual within an institution for their own ‘protection’ – as the only means by which disabling



barriers can be overcome. If this continues, we will reinforce the familiar view of perceiving disability as 'a fate worse than death'.

Comments on targets and indicators:

- With regards to research, data must be collected and assorted into themes associated with disability and inequality. Disability is an integral part of culture, and yet the global barriers faced by disabled people can be thematic and experienced by many, regardless of health condition or background. Any data collected must not be used to create a hierarchy of impairment; instead it should make others aware of the position and status of disabled people within society, as well as share good practice. Areas of research could be:
 - What methods are Member States using to coproduce services with people who use services?
 - How many disabled people are employed in leadership roles within the health services?
 - Are local and national services commissioning Disabled People's Organisations to deliver aspects of care and support?
 - What methods are being used to integrate health and social care, as well as integrating health into the wider context?
 - What methods are being used to ensure the transition between child and adult services is seamless?
- With reference to provision of adequate support; it is worthwhile to create health plans in a narrative or journey context, with the information portrayed from individual's perspective. Using this method will ensure health plans and support packages are coordinated by the individual, easy to monitor and can be realised by those involved in the provision of health-related support.

European Network on Independent Living, 10 October 2013



About ENIL - the European Network on Independent Living

ENIL – the European Network on Independent Living is a cross-disability organisation, working across the European Union and neighbouring countries to promote independent living and the implementation of the UN Convention on the Rights of Persons with Disabilities. ENIL’s mission is to advocate and lobby for independent living values, principles and practices, namely for barrier-free environment, de-institutionalisation, provision of personal assistance support and adequate technical aids, all of which make full citizenship of disabled people possible. For more information, please contact the ENIL Secretariat at secretariat@enil.eu or visit www.enil.eu