

International Bureau for Epilepsy [IBE] position statement re: EB150/1, agenda item 7: (g)

Draft intersectoral global action plan on epilepsy and other neurological disorders (GAP) in support of UHC.

IBE is the only global voice for people with epilepsy. Founded in 1961, it now has a presence in over 100 countries worldwide; working together to achieve a transformational social change for our community.

IBE applauds the World Health Organisation for the production of a comprehensive, ambitious – but achievable – framework for action to address epilepsy and other neurological disorders over the next decade.

We are particularly appreciative of the inclusion of *Strategic Objective 5, to strengthen the public health approach to epilepsy* – which will allow member states and regions to scale up work already underway in our field.

Global target 5.1: By 2031, countries will have increased service coverage for epilepsy by 50% from the current coverage in 2021.

Global target 5.2: 80% of countries will have developed or updated their legislation with a view to promoting and protecting the human rights of people with epilepsy by 2031.

We fully agree that a well-functioning epilepsy care service presents a real opportunity for strengthening the management of other neurological disorders and can serve as an *entry point* for accelerating the provision of, and access to, services and support for both epilepsy and other neurological disorders. This is particularly true in lower and middle income settings, where 80% of people with epilepsy (PWE) live, and where treatment gaps exceed 75% in most low-income countries and 50% in most middle-income countries.

Therefore, we underline the critical importance of the below elements included within the draft and ask for your vocal support during the EB to showcase how epilepsy is an obvious starting point for implementation:

- 25% of the global burden of epilepsy cases are preventable.
- Epilepsy is treatable: More than 70% of people with epilepsy could live seizure-free lives if they had access to appropriate anti-seizure treatment, the most cost-effective of which are included in the WHO Model List of Essential Medicines. (Some cost as little as \$5 per person per year.)
- WHO, its member states and international partners have a long track record of work in epilepsy which can be scaled up and/or used as an entry point for other neurological disorders.
- Epilepsy interventions provide a quick return on investment.
- Epilepsy is an exemplar for how neurological disorders can be managed in a primary care setting, aligned to policy priorities on NCDs, PHC and UHC.
- There is an unprecedented opportunity to address the impact of epilepsy through a comprehensive response throughout and following the COVID-19 pandemic.
- 'Epilepsy and other neurological disorders' should be the terminology used across strategic objectives
 1-4, reflecting its role as an entry point/exemplar for other neurological disorders

We, at the International Bureau for Epilepsy are well placed and ready to assist the implementation efforts by:

- Educating and empowering people with epilepsy and their carers to engage more meaningfully in their own care, but also in policy/decision making, service delivery, research and development, etc.
- Engaging in and supporting advocacy on access to treatment and care
- Engaging in and supporting advocacy to influence legislative change
- Monitoring implementation of the Global Action Plan from the perspective of people with epilepsy

We are ready to support you with the information you need in advance of the EB and/or WHA, and to collaborate with you on implementation and monitoring. Contact IBE's *Chief Executive Officer*: donnawalsh@ibe-epilepsy.org or *Chair – Global Outreach*: marysecco@ibe-epilepsy.org

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