

WHO Offices
Geneva
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8th April 2021

IBE Response to the WHO call for comment on the Intersectoral Global Action Plan (IGAP) Discussion Paper

General Comments:

International Bureau for Epilepsy (IBE) represents 50 million people with epilepsy, their care providers and care partners. The following comments came from consultations, survey data and written feedback received from IBE chapters in 85 countries representing people living in every region of the world.

People with epilepsy are grateful that Member States requested the Director-General to develop an Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022-2031.

Our collective impression is that the Discussion paper however does not reaffirm the WHA68.20 resolution which urged Member States to address the global burden of epilepsy, nor does it recognize the urgency for an intersectoral public health response to epilepsy and other neurological disorders that places the needs of affected people at the center and which emphasizes the critical role of tackling disease risk factors, primary health care, health system strengthening and sustainable access to affordable essential medicines in line with resolutions WHA62.12, WHA67.22 and WHA72.2.

There are significant discrepancies between the focus and intent of this Discussion paper and WHA 73.10 that clearly singled out epilepsy as a disorder with an unacceptably high health and social burden in need of specific attention. In this Discussion paper, there is little reference to epilepsy and the urgency that was identified in WHA68.20, EB146/12, A73.5, WHA73.10 and Epilepsy: A public health imperative (WHO, 2019) all of which identified epilepsy as a public health imperative. This omission of 'epilepsy' puts into jeopardy two decades of investments and progress by WHO that brought to the attention of Member States the injustice of institutional stigma and the unacceptable treatment gap in epilepsy.

We believe this Discussion Paper does not build on the proposal in the Resolution to optimize the prevention, treatment and care of neurological disorders by using epilepsy as an entry point for scalable solutions at the country level. This significant discrepancy between the intent of the Resolution and what is being proposed in the Discussion paper could lead to a missed opportunity to strengthen epilepsy services and utilize effectively synergies between epilepsy and other neurological disorders to improve the care and treatment of both.

Paragraph 5: use wording from WHA73.10: The risk of premature death in people with epilepsy is three times higher than in the general population (PP3).

Paragraph 6: Multiple studies have shown that the most common causes of hospitalization for children with neurological diagnosis are epilepsy (53% of all such admissions) and traumatic brain injury (17%). The overall risk of death in a child with epilepsy is 10 times higher than the general population. In children admitted to intensive care for any cause, the mortality rate is 3 times higher for children with a neurological disorder. Epilepsy, autism, cerebral palsy, developmental delay and headache disorders are the most common neurological disorders affecting children. Globally, in 2016, 52.9 million children younger than 5 years are estimated to have a development disability: 95% of these children live in low and middle-income countries. Meningitis was also among the top ten causes of global DALYs in children below the age of 10 in 2019. The Lancet Commission on adolescent health and wellbeing estimated in 2016 that just over a third of

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Man Mohan Mehndiratta (India), Ding Ding (China). **ILAE Representatives:** Sam Wiebe (Canada), Helen Cross OBE (UK), Ed Bertram (USA)



**International
Bureau for Epilepsy**

Office 0208
Nesta Business Centre
4-5 Burton Hall Road
Sandyford
Dublin D18 A094
Ireland

Ann Little
Executive Director
+353 1 210 8850
annlittle@ibe-epilepsy.org

ibe-epilepsy.org
internationalepilepsyday.org

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all adolescents globally are now growing up in countries that are NCD predominate and where the major adolescent burden now lies in mental and substance use disorders and chronic physical disability.

Paragraph 7: People with epilepsy representing 26 countries in Africa reported a significant treatment gap (as high as 85% in some countries) which included a lack of specialist neurological services at diagnostic and treatment level and poor access to key medicines. Furthermore, all 26 countries reported widely held misconceptions that epilepsy results from witchcraft, curses and other magical or supernatural forces. The lack of information and protective legislation, poor visibility for epilepsy and low political will in LMIC perpetuates stigma and discrimination and should be considered as a major contributing factor to the high burden and lack of prioritization of epilepsy by Member States and other duty bearers.

Paragraph 9: A cross-sectional observational study in Spain in 2020 reported that people with active epilepsy have a 2-3-fold increase in the cumulative incidence of COVID-19 compared with people without epilepsy and that epilepsy is a risk factor for COVID-19 related mortality amongst hospitalized patients. In addition, the impact of disruption to services caused by the pandemic are resulting in decreased vaccination coverage and increased delays in early diagnosis of otherwise potentially preventable/treatable neurological disorders including epilepsy. The impact of these disruptions is likely to increase needs for neurological services into the longer term.

Paragraph 10: In addition, in many countries epilepsy services are often subsumed within psychiatric and mental health services leading to inappropriate care and lack of attention – and funding – for the specific needs of people with epilepsy and missed opportunities to provide cost-effective essential medicines that could ensure that over 70% of people with epilepsy live seizure free lives.

Paragraph 12: Ensuring that appropriate health system building blocks are in place is particularly important to improving the quality of life of people with epilepsy and other neurological disorders. With only 24% of countries reporting stand-alone neurological health policies, the implementation of appropriate policy and legislative frameworks is crucial (including the appropriate categorization of epilepsy as a neurological rather than a psychiatric disorder) and should aim to ensure quality care, the provision of financial and social protection benefits (including protection from crippling and often catastrophic out-of-pocket expenditures borne by individuals and their families) and the protection, promotion and safeguarding of rights of persons with epilepsy and other neurological disorders. Comprehensive responses aimed at tackling neurological disorders should be firmly grounded in a social and economic determinants of health approach.

Paragraph 13: change to wording from Resolution WHA73.10 (PP2) “neurological disorders are conditions of the central and peripheral nervous system that include epilepsy, headache disorders, neurodegenerative disorders, cerebrovascular diseases including stroke, neuroinfectious/neuroimmunological disorders, neurodevelopmental disorders and traumatic brain and spinal cord injuries.”

Paragraph 15: This broader framework needs to be supplemented by signature initiatives, from a disease or region-specific level that can build on existing projects with concrete deliverables, measurable outcomes and associated budgets. Using epilepsy as an entry point there are scalable solutions from the WHO Programme on reducing the epilepsy treatment gap in China, Mozambique, Viet Nam, Ghana, Myanmar, etc. which can be leveraged to expand the skills of non-specialist health care providers to diagnose, treat and support people with epilepsy and other neurological disorders. (Epilepsy: A public health imperative; WHO, 2019).

Paragraph 17: Enhancing epilepsy prevention, treatment and access to care represents an important entry point for, and foundation to other neurological disorders. Epilepsy is an important symptom; a signal to poor brain health, and a symptom of many different neurological diseases (e.g. those mentioned e.g. stroke, as well as >130 genetic diseases). Epilepsy is a lifespan condition (infants to older adults) affecting all genders and every ethnic group. A list of actions to accelerate progress at the country level using epilepsy as the entry point can be found in EB146/12 paragraphs 22-28.

Paragraph 19: Move WHA68.20 to its own row (epilepsy is not a mental health condition) by adding a section called Neurological Disorders to Table 1: Resolutions and global commitments relevant to neurological disorders.

Add WHA73.10 to the table under Neurological Disorders.

Add WHA68.20 to table under Neurological Disorders

Add WHA73/5 to the table under Neurological Disorders (Report on synergies in addressing the burden of epilepsy and other neurological disorders)

Recommend that UN CRPD be added to Table 1 as this is a key document underlying the human rights model of disability.

We propose the following wording of the VISION to align with WHA73.10:

1. Brain health is valued, promoted, protected and prioritized with strengthened governance for epilepsy and neurological disorders and with representation in national health policies, plans and budgets.
2. Epilepsy and other neurological disorders are prevented and treated avoiding deaths and disability and improving quality of life through appropriate, affordable and quality services, essential medicines and ongoing research.
3. Social, economic and educational needs and freedom from stigma and discrimination for persons with epilepsy and other neurological disorders are prioritized and protected in legislation; such protection extending also to families and caregivers.

We recommend rewording the goal to include stigma and reinforce epilepsy as an entry point for improving care.

Proposed new wording of GOAL: To reduce the stigma, impact and burden of epilepsy and other neurological disorders, including associated mortality and morbidity, by leveraging the prevention, treatment and care of epilepsy as the entry point for improving the health, social services and quality of life of persons of all ages with all forms of neurological disorders.

STRATEGIC OBJECTIVES

Request that ‘epilepsy’ be added to all objectives to align with WHA73.10 (Global Action Plan on Epilepsy and Other Neurological Disorders).

1. To raise the prioritization and strengthen governance for epilepsy and other neurological disorders.
2. To provide effective, timely and responsive diagnosis, treatment and care for epilepsy and other neurological disorders.
3. To implement strategies to promote brain health and development and prevent epilepsy and other neurological disorders.
4. To foster research and innovation and strengthen information systems for epilepsy and other neurological disorders
5. We recommend a 5th objective be added addressing stigma and discrimination and promoting inclusion and equality for people with epilepsy and other neurological disorders. Stigma is a significant contributor to poor physical, mental and social health, lower educational and employment opportunities in persons with epilepsy and requires a multipronged strategy that is culturally appropriate, multisectoral and collaborative (Epilepsy: A public health imperative; WHO, 2019, p.77)

Add new Objective: To Address Stigma and Discrimination and Promote Inclusion and Equal Opportunities for People with Epilepsy and Other Neurological Disorders

- Addressing Legislation and Policy Gaps (new wording)
- Advocacy and addressing stigma (current section 1.1)
- Role of other sectors – particularly education and employment (new section)

To align with WHA73.10, add ‘epilepsy’ to each of the guiding principles (Global Action Plan on Epilepsy and other Neurological Disorders)

This is consistent with the goal of leveraging epilepsy prevention, treatment and care as an entry point and the intent of WHA73.10.

Epilepsy and other neurological disorders are associated with significant mental health implications (psychiatric and psychological) affecting children, youth, adults, older adults, care providers and care partners. This burden is missing in the guidelines.

In light of the learnings from the current pandemic, we suggest that an eighth principle be added to the Guiding Principles (viii) to protect access to and delivery of services and care for epilepsy and other neurological disorders during emergencies and times of crisis.

c) The lack of research results in most African countries impacts significantly on planning and implementation. Even basic information regarding prevalence is not available.

e) Empowerment of persons with epilepsy and other neurological disorders is critical in terms of the human rights model of disability. The reality is that many persons with epilepsy and other neurological disorders living in LMIC may be afraid to disclose that they are affected fearing discrimination, retribution and social ostracism. Stigma and discrimination in epilepsy often derives from a lack of knowledge and fear of the person experiencing a seizure and is compounded by the prevailing belief that this disease is contagious or the result of witchcraft, curses and other magical/spiritual sources. The current advocacy initiatives of IBE Africa should be seen as models for addressing these issues.

Paragraph 28: Specific attention needs to be made to address discriminatory legislation particularly in relation to driving (lifelong bans in many countries), access to education, employment, income support, disability, marriage and childbearing.

Paragraph 29: Common causes of epilepsy include prenatal or perinatal injuries, head injuries, stroke, neurological infections such as meningitis, encephalitis and neurocysticercosis and brain tumors. Epilepsy can be diagnosed at the primary care level and treated using cost effective medicines that are available on the WHO Essential Medicines List. WHO Programme on reducing the epilepsy treatment gap in China, Mozambique, Viet Nam, Ghana, Myanmar, etc. can be leveraged to expand the skills of non-specialist health care providers to diagnose, treat and support people with epilepsy and other neurological disorders.

In a survey of 85 countries, people with epilepsy identified the lack of prioritization and the lack of political will as the greatest need to be addressed. Removing epilepsy from this objective reverses two decades of investments in programmes by the WHO to reduce the epilepsy treatment gap. To align with WHA68.20 and WHA73.10 we need to put epilepsy back on the agenda: To raise the prioritization and strengthen governance for epilepsy and other neurological disorders.

The current Objective 1 should be reformulated to focus on national plans and financing with increased attention to addressing the out-of-pocket expenditure and achieving Universal Health Coverage.

Paragraph 30: Addressing the needs of people with epilepsy and other neurological disorders begins with addressing stigma and discrimination that act as barriers to seeking health care and which impact on all aspects of an individual’s life and wellbeing. Stigma is a significant contributor to poor physical and mental health in people with epilepsy and will need a multipronged strategy which is culturally appropriate, multisectoral and collaborative (Epilepsy: A public health imperative; WHO, 2019). Stigma

in epilepsy can delay appropriate health care seeking, access to care, health financing and availability of treatment.

Paragraph 31: In many parts of the world, people with epilepsy and their families are subjected to stigmatization and discrimination as a result of the misconception and negative attitudes that surround epilepsy, including the belief that epilepsy is the result of possession by evil spirits, witchcraft or that it is contagious. Stigmatization leads to human rights violations, social exclusion and poverty. In many communities, children with epilepsy may not be allowed to attend school, while adults with the condition may not be able to find suitable employment, marry or bear children (EB146/12 paragraph 5)

Paragraph 41: It is important to both address discriminatory laws, where they exist, but where there are no such laws add the “development of inclusive legislation” to protect people with epilepsy and other neurological disorders from discrimination and human rights violations.

Paragraph 42: Add people with epilepsy and other neurological disorders to the list of collaborators.

Paragraph 50: Recognizing that epilepsy is a highly treatable condition and that over 70% of people with epilepsy could live seizure free if they had access to appropriate anti-seizure treatment, the most cost-effective of which are included in the WHO Model List of Medicines (WHA 73.10 PP5). The low cost of effective interventions for epilepsy estimated at less than US\$ 5/per person/year (WHA73.10 PP7). Resolution WHA67.22 on Access to Essential Medicines, calls for action to enhance access to essential medicines and urges Member States to identify key barriers to access to affordable, safe, effective, and quality-assured essential medicines (WHA73.10 PP6).

Paragraph 62: Orient health systems to expand the prevention, management and care of neurological disorders building on existing epilepsy services as an entry point for expansion and to optimize synergies.

(ii) Reviewing epilepsy services to ensure that they are appropriately managed by experts with neurological training rather than as a mental health disorder and expand existing epilepsy prevention, diagnosis, treatment and care to provide access to services for other co-morbid neurological disorders.

Objective 2: To provide effective, timely and responsive diagnosis, treatment and care for epilepsy and other neurological disorders.

The current Objective 2 should be enhanced to place a clear focus on reducing the unacceptable, global treatment gap particularly for disorders such as epilepsy where effective treatments are available at very low cost, but which are still out of reach for over 70% of the affected population.

Paragraph 99: Use wording from WHA73.10: Epilepsy is a highly treatable condition and over 70% of the estimated 50 million people with epilepsy (WHA73.10 PP4) could live seizure free if they have access to appropriate anti-seizure treatment the most cost-effective of which are included in the WHO Model List of Essential Medicines (WHA73.10 PP5); estimated at less than US\$5/per person/year (WHA73.10 PP7).

Paragraph 114: In developing countries, a high proportion of population under the age of 30 highlights the need for significant investment in child/adolescent/transition to adulthood services including epilepsy specific support. In populations with an increasing proportion of older people the increasing prevalence of diseases such as dementia and Parkinson’s disease should be taken into account when planning services.

Paragraph 123: Epilepsy and other neurological disorders have a profound impact on individuals, parents, siblings and other family members and communities. Due to their chronic course, people with epilepsy and other neurological disorders often require ongoing care provided in large part by informal carers.

Paragraph 125: Challenges for carers include stress, role strain, financial burden, and social isolation and may vary depending upon the age of the carer and the age of the person affected. Carers and families of people with epilepsy and other neurological disorders are also burdened by stigma and discrimination.

Paragraph 126: Recommend that this section be expanded to recognize the needs of parents who support children with epilepsy and other neurological disorders. Supporting a child who is medically fragile, or who has a diagnosis of epilepsy, ADHD, Autism, Cerebral Palsy and/or developmental delay has emotional, physical, psychological, social, economic and financial implications for the entire family.

Objective 3: To implement strategies for the promotion of brain health and prevention of epilepsy and other neurological disorders.

Paragraph 141: In many regions of the world, children with epilepsy are banned from attending school altogether. This is an example where this broader brain health framework needs to be supplemented by disease or region-specific actions and indicators.

This section should be expanded to include preventing falls in the elderly, burns, drowning (people with epilepsy are at 15 to 19 times higher risk of drowning compared with people in the general population), status epilepticus and SUDEP.

The Discussion paper appears to have been written from a high resource setting perspective and based on demographic and epidemiological data predominantly arising from high income countries. The needs of 80% of people with epilepsy and other neurological disorders living in low and lower-middle income countries where risk factors, disease prevalence and resources differs considerably from those in high resource setting are not well reflected in this section.

OTHER COMMENTS

People with epilepsy are concerned that their needs are not well reflected and, in many instances, have disappeared entirely in this Discussion paper. There is a discrepancy between this Discussion paper and the wording in WHA68.20, EB146/12, A73.5, WHA73.10 and Epilepsy: A public health imperative (WHO, 2019) all of which identified the urgency of addressing epilepsy as a public health priority, listing concrete recommendations for the 'way forward'. Removing 'epilepsy' from the 4 objectives reverses two decades of investments in programmes by the WHO that brought to the attention of Member States the injustice of institutional stigma and the unacceptable treatment gap in epilepsy.

The burden of epilepsy is greatest in persons who live in low-income, less developed settings contributing to social and economic morbidity. To address the needs of people in LMIC (stigma, shortage of workforce, access to essential medicines) we recommend that the WHO/Brain Health Unit form an expert resource group to develop specific actions and indicators to be included in the next draft to better address the epidemiology and service provision in lower resource settings.

Throughout the document the focus appears to be the adult population with the needs of children and adolescents and the challenges of transitioning into adulthood neglected or poorly understood. Having a child onset brain condition negatively impacts long term adult outcomes. Addressing this negative trajectory needs to be recognized with specific indicators for children.

While it is important to pay attention to the promotion of brain health and addressing avoidable risk factors, the Discussion paper lacks the needed balance and specificity to address the two leading priorities of people with epilepsy and other neurological disorders namely:

1. Reducing the often crippling and catastrophic out of pocket expenditure incurred by individuals and families with epilepsy and other neurological disorders and
2. Closing the treatment gap by ensuring access to a trained workforce, essential diagnostics, medicines, and treatment.

To address these two critical issues, we recommend WHO/Brain Health Unit form expert resource groups with external expertise (including people with epilepsy and other neurological disorders) to draft a set of indicators.

As recommended in WHA73.10 (OP3.2), the Intersectoral Global Action Plan on Epilepsy and other neurological disorders should include ambitious, but achievable, global targets on reducing preventable cases of, and avoidable deaths, resulting from epilepsy and other neurological disorders, strengthening service coverage and access to essential medicines, improving surveillance and critical research and addressing discrimination and stigma.