



Dear Dr Ren,

12 August 2021

### **Draft Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders**

The International Child Neurology Association (ICNA), the International League Against Epilepsy (ILAE) and the World Federation of Neurology (WFN) are the three leading global organizations in the area of brain health, representing professionals worldwide based in over 130 countries. The ILAE and WFN are non-state actors in official relations with WHO and all three organization have a long history of working collaboratively with WHO at global, regional, and national level.

All three organizations warmly welcome the draft Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) that WHO released for consultation at the end of June. We congratulate the WHO secretariat for their work on this excellent draft and for incorporating many of the suggestions made during the consultation on the Discussion Paper.

ICNA/ILAE/WFN believe that the final IGAP could be strengthened further in a number of areas and would like to jointly propose three key recommendations for your consideration. Each organization will also be submitting more detailed comments through the consultation portal. This letter represents our joint aspiration to see changes in these important areas.

#### **Recommendation 1**

We would like to recommend that the **targets** be significantly strengthened to ensure that the IGAP is sufficiently aspirational to inspire the action needed over the next decade to achieve the well-articulated vision in paragraph 19.

We would wish to see Strategic Objective Target 5.1 change significantly from the current incremental target to a cascade target focused on achieving real change for people with epilepsy through a strengthened public health approach. We believe that by setting an ambitious, evidence-based cascade target, intersectoral action will be enhanced and thus provide multiple entry points through which services for epilepsy and other neurological disorders can be strengthened.

<b>Target 5.1 Epilepsy 90-80-70<sup>1</sup></b>
(1) 90% of all people with epilepsy are aware of their diagnosis as a treatable brain disorder and (2) 80% of people diagnosed with epilepsy can access appropriate, affordable, safe antiseizure medicines and (3) 70% of those treated achieve adequate seizure control.

<sup>1</sup> Inspired by and based on the evidence presented in <https://gatesopenresearch.org/articles/3-1502>

We would also like to recommend an additional Target Area under Strategic Objective Target 5 (new 5.2) to incentivize countries to review their existing legislation. Stigma and exclusion place a burden on people with epilepsy and other neurological disorders. Without addressing the discrimination that is often enshrined in law, it may be impossible to achieve the improvements in quality of life that were envisioned when member states unanimously supported Resolution 73.10.

<b>Target 5.2</b>
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All countries have reviewed their existing legislation, particularly in the areas of education, driving, employment, marriage, and fertility, with a view to addressing and amending clauses that discriminate against people with epilepsy and other neurological disorders by 2031.
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**Recommendation 2**

We would jointly like to recommend that the WHO consider amending the current text in a number of areas to ensure that the **relationship and synergies** between epilepsy and other neurological disorders are more clearly and evenly articulated.

We would like to recommend an amendment to the Goal in paragraph 21 as well as additional text into the Overview section to ensure that the entry point that epilepsy potentially offers for strengthening services for other neurological disorders is properly understood and utilized appropriately.

<b>Goal Paragraph 21</b>
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In order to achieve the above stated vision and goal, prevention, treatment and care of epilepsy and other neurological disorders should be developed wherever possible utilizing entry points and synergies to achieve the best results for all.
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<b>Suggested text to be inserted into the Overview</b>
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A number of diagnostic and therapeutic technologies as well as many preventative, pharmaceutical, psychosocial and research approaches are shared by epilepsy and other neurological disorders. These synergies lend themselves to be entry points for accelerating and strengthening services and support for epilepsy and other neurological disorders.
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### **Recommendation 3**

Children and adolescents transitioning into adulthood have physical, social, psychological, and educational needs that differ significantly from those of adults. Disease incidence, prevalence and treatment dosing also differ across the life course.

While we appreciate the specific mention of children and adolescents in the Overview section, we feel that more is needed to emphasize the specialized nature of the care and treatment needed for this age group and would recommend:

- The phrase 'across the life course' be added to Objective 2 such that it would read throughout the document as: Objective 2: To provide effective, timely and responsive diagnosis, treatment and care for epilepsy and other neurological disorders across the life course.
- The addition of a seventh Guiding Principle (Paragraph 23) on the need for focused, specialized, and age-appropriate care for children and adolescents transitioning to adulthood rather than a reliance on the adaptation of adult services
- Addition of a paragraph on the need for specific care pathways (including appropriate engagement and involvement with the education sector) for children and adolescents transition to adulthood in Section 2.1
- Addition of a paragraph on the need for specialized training of health care workers who care for children and adolescents transitioning to adulthood in Section 2.3

Once again we would like to congratulate you and your team on an excellent draft and for incorporating many of the comments that were made on the discussion paper.

All three organizations stand ready to provide academic, clinical, and lived experience expertise to support WHO secretariat in the finalization and implementation of this important IGAP.

With warm regards,



Prof Samuel Wiebe  
President, ILAE



Prof William Carroll  
President, WFN



Prof Jo Wilmshurst  
President, ICNA