

## 71st Session of the WHO Regional Committee for Africa

**Author:** International League Against Epilepsy (ILAE)

**Agenda item:** 18.6. Progress report on the implementation of the Framework for health systems development towards UHC in the context of the SDGs in the African Region

### **Statement:**

The International League Against Epilepsy, founded in 1909, is one of the oldest international professional associations in official relations with the World Health Organization with over 26,000 professional and scientific members based in 168 countries and territories. ILAE has worked closely with WHO for over 25 years on a campaign to bring epilepsy out of the shadows to achieve a world where no person's life is limited by epilepsy.

Globally, there are at least 50 million people living with epilepsy. People with epilepsy have a rate of premature death three times higher than the general population yet over 80 per cent do not have access to the life-saving essential medicines need to control their seizures. Stigma and discrimination, prevalence in most parts of the world, exclude people with epilepsy from everyday life, denying them of educational and employment opportunities and further compounding the physical, mental, and social impact of epilepsy for them and often also their families.

ILAE warmly welcomed the draft Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders circulated by WHO at the end of June. The five strategic objectives are all relevant to epilepsy (which should be made clearer in the document) and are well balanced and comprehensive. ILAE would like to congratulate the WHO secretariat for their hard work and for incorporating comments from people with clinical and lived experience expertise.

ILAE would though like to raise two key areas where we believe the document could be strengthened, both of which are very relevant to the African region where it is estimated that over 1 in 100 people have epilepsy and where epilepsy is the leading neurological condition for children.

Action to address epilepsy has been declared by WHO to be a public health imperative. It is therefore vital that an ambitious target to reduce the present unacceptably high burden of epilepsy is included in the action plan. The currently proposed target of increasing service coverage by 20% by the year 2031 is, in the view of ILAE, insufficient and will do little to reduce the high mortality, morbidity, and exclusion faced by people with epilepsy

ILAE would therefore like to propose that the current target is replaced by an outcome focused cascade target - 90-80-70 - that will not only incentivise intersectoral action and strengthening across the health system but, once achieved, would bring real and measurable change to millions of lives:

- 90% of people with epilepsy are aware of their diagnosis as a treatable brain disorder - achievable through public and professional education and diagnostic capacity building
- 80% of people diagnosed with access to appropriate, affordable safe medications - achievable based on the low cost of medications (USD5/per annum), and the huge success of demonstration projects as part of the WHO-ILAE-IBE Global Campaign Against Epilepsy
- 70% of those treated achieving adequate seizure control – for which multiple large cohort studies have provided a strong evidence base

A further target to incentivise governments to address legislation that discriminates against people with epilepsy and other neurological disorders should also be added to the action plan.

Finally, ILAE would also wish to see greater focus within the Global Action Plan on the specialised needs of children and adolescents transitioning into adulthood. This could be achieved by adding a seventh Guiding Principle on the need for specialised services for this age group rather than the current practice of adapting adult services and including the need for specialised care pathways and specific training for health and social care workers.

**Name:** Dr. Angelina Kakooza, Kampere, Uganda and Dr. Jo Wilmshurst, Cape Town, South Africa

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**Position:** Chair of ILAE Africa 2017-21 and Chair Elect of ILAE Africa 20121-25 respectively  
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