

IGAP UNPACKED

A Practical Guide to the World Health Organization's Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022 - 2031

Background

What is IGAP?

• IGAP is a **10-year roadmap** launched by WHO to effectively address neurological conditions and **improve the lives** of people with epilepsy and other neurological conditions worldwide. It consists of **5 strategic objectives** and **10 global targets**.

Why is IGAP important?

- First ever global action plan on epilepsy and neurological conditions
- Unanimously approved by all 194 member states of the World Health Assembly
- Unique multisectoral, person-centred, evidence-informed, human rights, and life course approach
- Includes epilepsy specific objective "to strengthen the public health approach to epilepsy"

How is IGAP relevant to you?

IGAP speaks directly to the mission, needs, and aspirations of the global epilepsy community. It is therefore a **powerful tool** to support, guide, and promote our work moving forward. In this practical guide, we outline a series of **proposed** actions to support IBE chapters and our community in optimally leveraging IGAP.

10-Year Goal

"To reduce the stigma, impact and burden of neurological disorders, including their associated mortality, morbidity and disability, and to improve the quality of life of people with neurological disorders, their carers and families."¹

Abbreviations: EEG=

electroencephalogram; LMIC= low- and middle-income countries; NCDs = noncommunicable diseases; PWE= people with epilepsy; SDGs= sustainable development goals

IGAP in Practice

Strategic Objective (SO) / Global Target (GT)	Relevance for Epilepsy Community ²	Proposed Actions for IBE Chapters
SO 1: Raise policy prioritization and strengthen governance GT 1.1: 75% of countries have National Plans/Policies/Strategies for neurological conditions GT 1.2: 100% of countries have functioning Awareness/Advocacy Programmes for neurological conditions	 Over 50 million people have epilepsy worldwide; 80% live in LMICs Epilepsies are in the top 5 causes of neurological disability The majority of those affected receive no or insufficient treatment Low public awareness of epilepsy as a treatable brain condition Insufficient government action (<30% of LMIC have national plans) 	 Use the <u>IBE Advocate's Toolkit</u>⁶ for policy advocacy actions (position papers, letters) holding governments accountable Unite chapters nationally for epilepsy awareness campaigns Engage key stakeholders (PWE, Ministries, WHO, ILAE) to define national IGAP priorities Build partnerships within neurology, NCDs, and intersectorally - beyond health
SO 2: Provide effective, timely and responsive diagnosis, treatment, care GT 2.1: 75% of countries have included neurological conditions in UHC benefits package GT 2.2: 80% of countries provide essential medicines / technologies for neurological conditions	 Epilepsy treatment gaps remain high (>75% in many LMICs) Antiseizure medicines are highly affordable (\$5/person/year) and effective (for 70% of all epilepsies) Insufficient neurological workforce (0.1 per 100.000 people in LMIC) and lack of tools (EEG) impair diagnosis 	 Policy advocacy actions to hold governments accountable Build health system capacity via educational interventions (e.g., for community health workers, teachers, traditional healers, and the public) Partner with local ILAE chapters
SO 3: Implement strategies for promotion and prevention GT 3.1: 80% of countries have ≥1 functioning prevention / brain health promotion programme GT 3.2: Global targets for prevention of neurological disorders are achieved	 25% of epilepsies are preventable² Preventable causes include stroke, infections (e.g., meningitis), birth trauma, and other brain injuries Fostering brain health³ and development can improve outcomes and quality of life 	 Raise awareness on epilepsy prevention (campaigns, educational activities) Position epilepsy within wider policy dialogues (establish cross-links to UN SDGs⁷, WHO NCD agenda)

IGAP in Practice (continued)

Strategic Objective (SO) / **Relevance for Epilepsy Community Global Target (GT)** SO 4: Foster research and innovation Robust epidemiological data on and strengthen information systems epilepsy are lacking in most countries Most existing research does not priorities / unmet needs GT 4.1: 80% of countries routinely collect include the voice of people with indicators for neurological conditions epilepsy GT 4.2: Global research on neurological Beyond medical variables, indicators conditions doubles for quality of life and lived experience are needed Generating this data is critical to IBE Knowledge Hub) address unmet needs and narrow the inclusion aap research funding SO 5: Strengthen the public health Epilepsy-related stigma exists at all \checkmark \geq societal levels, impairing quality of committed to this epilepsyapproach to epilepsy life and social wellbeing GT 5.1: 50% increase in epilepsy service Myths, false beliefs, and the maximum! coverage misinformation around epilepsy are GT 5.2: 80% of countries have replaced prevalent and key barriers to discriminatory legislation healthcare seeking > Discriminatory legislation must be removed to eradicate stigma and

safeguard human rights of people

with epilepsy

RF International Bureau for Epilepsy

Proposed Actions for IBE Chapters

- ✓ Know your community! Conduct needs assessment to identify real
- ✓ Get involved in IBE's forthcoming **Global Epilepsy Needs Survey**
- ✓ Exchange knowledge and best practices with other IBE chapters, including research activities (via
- ✓ **Lobby governments** for increased
- WHO and **all member states have** specific objective: leverage it to
- ✓ Raise awareness on / advocate against discriminatory legislation
- ✓ Use the IBE Stigma Reduction Toolkit⁶ for interventions (e.g., in schools, workplace)
- ✓ Build lived experience repository for use in social media/campaigns

What IBE is doing about IGAP

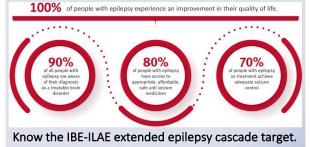
- Aligned with IGAP, IBE has launched its <u>Strategic Plan 2022</u> -26⁴, focusing on 1) advocacy/awareness, 2) knowledge creation, 3) capacity-building, and 4) strong partnerships.
- IBE has extended the IGAP-supporting Epilepsy Cascade Target⁵, ensuring that "100% of people with epilepsy will experience an improvement in their quality of life."
- IBE has contributed to the WHO Epilepsy Technical Brief² launched as a technical complement to IGAP.
- Aligned with IGAP, IBE is launching 3 flagship projects in 2023:
 - ✓ IBE Global Advocacy Action policy advocacy across regions
 - ✓ **IBE INVOLVE** involving people with epilepsy in all activities
 - ✓ **IBE Knowledge Hub** connecting our IBE chapters
- **IBE is partnering** closely with ILAE, WHO, OneNeurology and others to make IGAP a success.

Key Takeaways: Make IGAP work for your chapter!

- > **IGAP provides a global mandate** to close *inclusion, treatment, prevention*, and *research* gaps in epilepsy.
- > IGAP is a powerful tool to support your policy advocacy agenda and a key to hold policymakers accountable.
- > IGAP serves as an overarching framework: make it your own by leveraging those elements that matter most to your country, chapter, and community.
- IGAP is only the beginning: consider complementary policy frameworks (WHO NCD agenda, UN SDGs⁶) to make epilepsy central in global policy dialogue.
- IGAP adoption does not equal implementation: we must now put words into action to achieve our goals.

References & Tools

- Draft WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022 31 (1)
- (2) Improving the lives of people with epilepsy: a technical brief. (3)
- Optimizing brain health across the life course: WHO position paper
- (4)IBE Strategic Plan 2022 - 26
- (5) IBE Editorial The WHO intersectoral global action plan and epilepsy cascade target: Towards a roadmap for implementation
- IBE Advocate's Toolkit ; IBE Stigma Reduction Toolkit (6) (7)
- The United Nations Sustainable Development Goals



Adapted from: Winter et al., Seizure: European Journal of Epilepsy (2022)