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Editorial

The WHO intersectoral global action plan and epilepsy cascade target: Towards a roadmap for implementation



2022 marks an exceptional year for the global epilepsy community. Following over two decades of intensive global advocacy efforts at all levels [1], the 194 member states of the World Health Assembly unanimously adopted the World Health Organization (WHO) Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031 (IGAP) [2]. With five strategic objectives and 10 global targets, IGAP's declared 10-year goal is 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” [2]. Accordingly, this holistic global framework offers specific recommendations for concerted actions to be taken by the member states and their governments, the WHO Secretariat, as well as relevant national and international non-state actors. Guided by a multisectoral, person-centred, evidence-informed, human rights, and life course approach to neurological disorders, IGAP harbours unprecedented potential to ameliorate the lives of more than one billion people affected by neurological disorders worldwide [3], including over 50 million people with epilepsy [4].

IGAP's strategic objective 5 – to *strengthen the public health approach to epilepsy* – constitutes a unique opportunity and clear mandate for the global epilepsy community to take concerted and multipronged action in addressing the unmet needs of people with epilepsy. In a broader sense, the implementation roadmap we will draft to achieve epilepsy-specific IGAP targets could well serve as an *exemplar* or, as stated in IGAP, “an entry point for accelerating the strengthening of services and support for both epilepsy and other neurological disorders” [2]. The reason epilepsy has been highlighted as a public health imperative is apparent. Globally, more than 80% of people with epilepsy live in low- and middle-income countries (LMICs) [4]. Treatment gaps in LMICs frequently exceed 75%, as only one in four people with epilepsy receive antiseizure medications (ASM) and/or clinical care to adequately manage their condition [4]. The risk of premature death is threefold higher in people with epilepsy as compared with the general population [2]. The psychosocial sequelae associated with this public health emergency are enormous and exacerbated by the burden of stigma, myths and falsehoods, and discrimination surrounding the condition [5–8].

While these figures are alarming, there is ample reason for hope: medical consensus suggests that up to 70% of people with epilepsy could achieve adequate seizure control if provided with the therapeutic arsenal – including safe, effective, and affordable ASM – presently available for epilepsy [9]. Furthermore, approximately every fourth case of epilepsy is potentially preventable through effective measures

directed at minimization of modifiable risk factors, including perinatal injuries and infections, neurotropic zoonoses like neurocysticercosis, cerebrovascular accidents, and traumatic brain injuries [4]. Emerging public health initiatives aimed at integrating epilepsy care into community-based primary health care settings have proven feasible and efficacious across various LMICs [10–15]. Modelling studies suggest that public financing of ASM is cost-effective and would substantially reduce the burden of epilepsy in LMICs, for instance, averting up to 1 million disability-adjusted life-years (DALYs) per year in India alone [16,17]. Various community-based epilepsy awareness, education, and stigma reduction programs have been successfully piloted across regions [18–23]. Emergent telemedical and digital health tools are increasingly employed in LMICs to enhance epilepsy awareness, diagnosis, management, and enable improved data collection and research capacity [24,25].

Collectively, these findings and developments in the epilepsy space demonstrate how much impact can be generated with sufficient political will and effective and coordinated multistakeholder action. They also serve as an important reminder of how much work still remains to be done. Thus, further to its endorsement of IGAP, the International Bureau for Epilepsy (IBE) actively supports the aspirational *Epilepsy 90-80-70* cascade target put forward by the International League Against Epilepsy (ILAE) [26,27]. Launched to supplement IGAP and inspire a decade of action to achieve meaningful, measurable improvements in the care and treatment for people with epilepsy, the cascade target stipulates that, over the next 10 years, 90% of people with epilepsy will become aware of their condition as a treatable brain disorder, 80% will have access to ASM, and 70% of those treated will achieve adequate seizure control (Fig. 1) [28]. In recognition of the social determinants of health in epilepsy [29], the unmet psychosocial needs of people with epilepsy [30], and IBE's commitment to achieve a *transformational social change* for the 50 million people living with epilepsy worldwide [31], we hereby suggest to expand this cascade target further. We propose an extended *Epilepsy 100-90-80-70* cascade target, ensuring that “all (100%) people with epilepsy will experience an improvement in their quality of life” (Fig. 1). This overarching target – that no one gets left behind – should arguably be central to our efforts.

To arrive at a roadmap for implementation of IGAP and the *Epilepsy 100-90-80-70* cascade target, IBE recently launched its Strategic Plan 2022–2026 [31]. Committed to serve as the global voice for people with epilepsy, IBE will 1) position epilepsy as a public health priority, 2) empower and amplify the voice of people with epilepsy, 3) serve and

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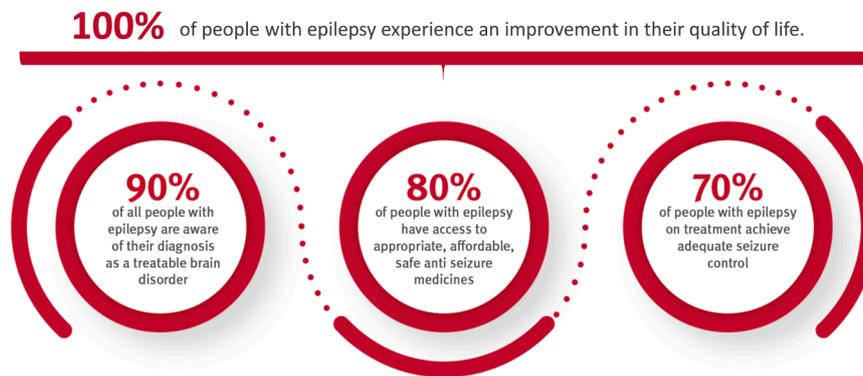


Fig. 1. The proposed revised 100-90-80-70 Epilepsy Cascade Target. *Adapted and modified from ILAE 2022 [28].*

support our chapters and committees in all regions. We seek to achieve this agenda by focusing on four strategic action areas. These comprise effective *global advocacy and awareness raising*, *community-driven knowledge creation and exchange*, *capacity-building* through training, education, and operational support for our regions and chapters, and *strong partnership development* to break down silos and position epilepsy within the broader public health policy dialogue [31].

As a regional example, the *Making Epilepsy a Health Priority in Africa* initiative is coordinating a series of pilot projects aimed at accelerating IGAP implementation in the African region. For this purpose, a Regional Committee on the Domestication of IGAP, including representation of people with epilepsy and other neurological disorders, was recently established. Ongoing activities include a *Trendsetter Project* with four countries (Mauritius, South Africa, Kenya, and Eswatini), launched to facilitate and document IGAP domestication processes at the national level. Moreover, a series of *Advocate's Toolkits* on effective advocacy action [32] and stigma reduction [33] were launched to strengthen capacity across African countries, equipping relevant organisations and epilepsy advocates in the region with state-of-the-art tools and culturally adapted and contextualized strategies to take effective action at national and community level. In alignment with the Strategic Plan, IBE's declared mission is to successfully scale, replicate, and adapt such best practice initiatives across all WHO regions.

To ensure our global epilepsy community can successfully 'walk the talk', we must be fully realistic about the long road and challenges still ahead of us. Crafting feasible implementation roadmaps for our ambitious goals includes honing in on actions that are 1) high-yield and *transformative*, 2) capture the contextualised *needs* of people with epilepsy, 3) address the *root causes* of existing treatment, inclusion, and research gaps, and 4) are *sustainable* beyond IGAP. Operationally, our implementation strategies must therefore be context-specific and actionable at ground level, which requires effectively leveraging available resources and scaling identified best practices.

Finally, we must consider critical barriers and pitfalls to our desired outcomes, and devise strategies to overcome them. For instance, how can we systematically and durably mitigate and prevent *stigma* at individual (internalized), community (interpersonal), and societal (institutional) levels as a major source of psychosocial distress and barrier to health seeking behaviour [33,34]? What mechanisms must be in place to fully involve and empower people with epilepsy as changemakers, such that *lived experience* becomes a guiding principle across our shared agenda? How will we narrow disparities in epilepsy care and reach *disproportionally affected populations*, including women, children, the elderly, people with disabilities, refugees, and those living in poverty and/or rural and remote areas [35]? Which diplomatic strategies, policy hooks, and partnerships must we pursue to effectively gear political will toward removing discriminatory legislation, *protecting human rights* of people with epilepsy, and launching comprehensive national epilepsy plans and brain health in-all-policies prevention programs? How can we

overcome difficulties associated with *building capacity* for epilepsy care in resource-poor communities and leverage existing models of care in a context-specific, integrated, and sustainable manner?

Overcoming these challenges will undoubtedly require more commitment, collaboration, and collective action than ever before. As the global epilepsy community, we must assume a leading role. To move the needle on IGAP, we must act in unison, synergistically, and unconstrained by traditional roles, silos, and boundaries. Perhaps most importantly, we must ask ourselves critically what IGAP and the epilepsy cascade target will mean to each and every one of us. How will we seize this unique opportunity and shared responsibility? Which measures can we take today to ensure that this year will truly inspire a decade of action?

Declaration of Competing Interest

The authors declare no conflicts of interest.

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