



# IBE Epilepsy and Society Symposium at AOEC

New Delhi, February 2025

## IBE ASIA AND OCEANIA



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# SUMMARY

The 15<sup>th</sup> Asian and Oceanian Epilepsy Congress took place in New Delhi on 2023 February 2025.

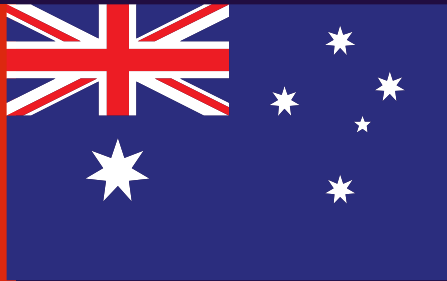
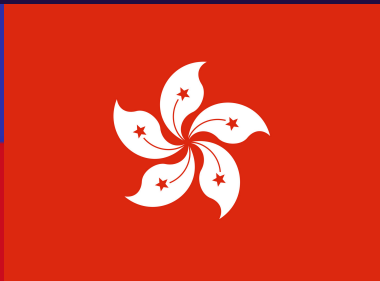
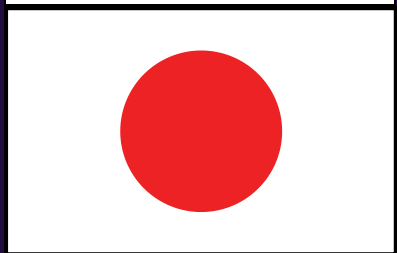
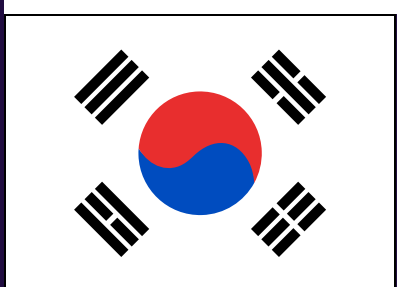
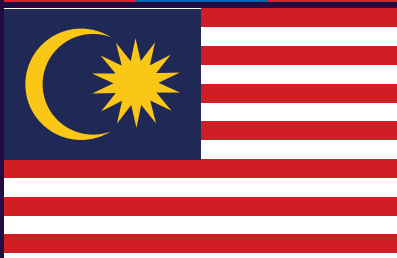
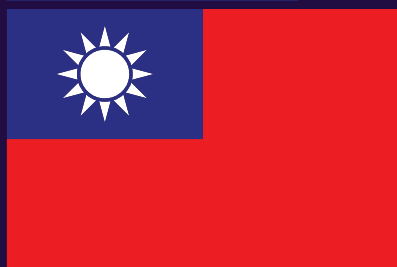
Alongside the Congress, the IBE held an 'Epilepsy and Society' symposium', opened by Regional Vice President Man Mohan Mehndiratta and Professor Gus Baker, Secretary General of IBE.

The symposium started with an update by Claire Nolan from IBE on the Global Epilepsy Needs Study [GENS], followed by a World Cafe exercise to further explore the challenges for people with epilepsy in the region, to share the work of our chapters, and to map what IBE can do.

This was followed by presentations on how IBE and its chapters can use the Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders [IGAP] to drive positive change in the region. A virtual presentation was made by the WHO Brain Health Unit, followed by a panel discussion with chapters.

The day ended with an Ideas Exchange Forum in which chapters shared many important awareness and advocacy actions to inspire and encourage their peers.

The Symposium built upon the IBE workshop, 'Leveraging Policy Frameworks for Epilepsy Advocacy Action in South East Asia and Western Pacific Regions,' held in Jaipur in 2023, which focused on the situation in India and included contributions from Nepal and Bangladesh. A short report of this workshop is included as an appendix.



# GENS: WHAT ARE THE UNMET NEEDS OF PEOPLE WITH EPILEPSY IN ASIA-OCEANIA

Claire Nolan, Head of Engagement at IBE, presented the Global Epilepsy Needs Study (GENS). This unique study gathered global data directly from people affected by epilepsy to pinpoint their unmet daily needs across ten life areas. Of the 15 GENS focus countries, the following were included from this region: India, Australia, South Korea, China, and Hong Kong SAR China.

## Research tools:

- A survey – completed by people with epilepsy over 18 years old, and caregivers of children (under 18 years old) and adults with epilepsy.
- Semi structured interviews – 5 people in each country to take part in an hour-long interview on different aspects of life with epilepsy.

The survey yielded over **5300 responses** from across the 15 focus countries from a diverse range of individuals. The study is still ongoing, with the remaining semi-structured interviews being conducted and data analysis underway.

The outputs of the study will be a research publication in **Epilepsia Open** and an interactive policy/advocacy report and dissemination toolkit.

## GENS benefits the IBE community by generating data that can:

- Facilitate comparison between countries and regions
- Shape the work and priorities of chapters
- Be used as a tool for IGAP implementation
- Strengthen the position of epilepsy advocacy

# GENS: WHAT ARE THE UNMET NEEDS OF PEOPLE WITH EPILEPSY IN ASIA-OCEANIA

## Next steps for GENS:

IBE will be working with MediPaCe, its research partner, to deliver focus groups exploring specific experiences and needs of different sub populations of people living with epilepsy, including women across the life course, people living with rare epilepsy, and the experience and needs of caregivers.

## Panel Discussion: Exploring GENS from a regional perspective

The panel was comprised of: Christine Walker (Australia), Boram Lee (Republic of Korea - South), Anchor Hung (Hong Kong SAR China), Bindu Menon and Nirmal Suraya (India). The following points were made by the panel:

- It was important to clearly articulate the benefits of the study and how it will impact the community, which increased number of respondents.
- The study is strong because it was co-created by people affected by epilepsy; involving people with lived experience is very powerful.
- In India, 'survey response assistants' were trained to support people with low health literacy to complete the survey face to face.
- There should be consideration given to publishing the GENS methodology as a best practice.
- GENS will generate national, regional and global data which should support the work of IBE, regional committees and chapters.
- The data will also allow us to position ourselves, with evidence, in discussions on neurology, brain health, etc. - going beyond epilepsy.
- There is appetite for more data collection in countries across the region.





# WORLD CAFÉ



**World Café exercise– exploring the needs of people with epilepsy in the South East Asia and Western Pacific regions, across five domains, including:**

- Employment and Financial Stability
- Learning and Education
- Family and Relationships
- Information and Awareness
- Mental and Brain Health

IBE Golden Light Award Winners introduced each topic, reflecting on their own experiences. These were: Anna Sullivan, Vinay Jani, Naziya Ramzan Ansari, Divyasiny Sharma and Yu-Ting Hsieh.

The participants then engaged in table discussions to explore:

1. What are the regional challenges for people with epilepsy [PWE]
2. What initiatives already exist in this area
3. What more can IBE to support/drive progress.



# MENTAL AND BRAIN HEALTH

## Challenges:

- Lack of evidence of PWE mental health and wellbeing needs.
- High cost of mental health services.
- Limited education of healthcare professionals on the mental health needs of PWE.
- Epileptologists too focused on addressing the burden of seizures and prescribing ASMs - which can worsen mental health problems.
- Limited time during consultations for specialists to address broader needs.
- Not enough mental health professionals in the workforce.
- Lack of connection between psychiatry and neurology services.
- Double stigma of epilepsy and mental health.
- Lack of awareness about mental health co-morbidities in epilepsy.
- Too much focus on biomedical model of care.

## Solutions:

- Ensure early intervention in children with epilepsy for emerging mental health problems.
- Train epileptologists and neurologists to better diagnose and treat mental health conditions.
- Raise awareness amongst teachers, employers, etc. so PWE are not stigmatised and mental health/wellbeing impacted.
- Advocate for an integrated, multi-disciplinary and holistic approach to care.
- Offer psychological and counselling services to PWE.
- Empower people with epilepsy to better self-manage.
- Optimise new technologies to provide personalised therapeutic interventions using AI.

## What can IBE do?

- **Generate evidence:** Analyse GENS mental health data to inform advocacy.
- **HCP education:** Work with ILAE to educate HCPs on addressing mental health conditions in PWE.
- **Empower PWE:** Work with chapters to develop courses for PWE and their caregivers on self-management.
- **Raise awareness:** Use awareness campaigns to improve understanding of mental health in epilepsy; consider a mental health workshop/conference.
- **Establish peer learning groups:** Chapters to exchange ideas on mental health advocacy, support group organisation, and stakeholder engagement.
- **Advocacy** – Use Corporate Council to push pharmaceutical industry for new drugs to have lower side-effect profile.

# EMPLOYMENT

## Challenges:

### Impact of epilepsy

- Lack of access to education can limit future job prospects.
- Epilepsy and epilepsy medications can impact a person cognitively, emotionally and behaviourally – impacting on job prospects.
- Difficult to define specific accommodations needed at work.
- Some jobs not suitable for people with epilepsy; organisational health and safety/risk management issues.
- PWE may be unable to drive to work.
- People with epilepsy more likely to be unemployed or underemployed causing financial burden.

### Impact of epilepsy stigma

- PWE worried about how to disclose their condition due to possible discrimination.
- PWE who don't disclose may not access workplace supports and services; or request reasonable accommodations.
- Lack of awareness in the workplace about epilepsy, seizure first aid, etc. amongst colleagues and employers.
- Epilepsy not considered a disability in some countries so limited workplace rights (or rights not enforced).

## Existing initiatives:

- Coaching PWE to tell their stories in the workplace (epilepsy ambassadors).
- Skills-building workshops for people with epilepsy.
- Training for employers and employment support agencies.
- Advocating for legislation to support people with epilepsy in education and employment.

## What can IBE do?

- **Generate evidence:** Analyse GENS data on work and income, to be used for advocacy/awareness raising.
- **Raising awareness:** Use awareness campaigns to improve knowledge on employment and epilepsy.
- **Support peer to peer learning:** Set up thematic/shared learning groups on epilepsy and employment for chapters (share best practice, guidelines, resources).
- **Advocacy:** Use IGAP to advocate for employment rights for PWE.
- **Capacity Building:** Provide training to chapters on how to counsel people with epilepsy and empower them to seek work.



# LEARNING AND EDUCATION

## Challenges:

- Over-protective families can negatively impact the educational attainment of the child with epilepsy.
- Academic challenges for children with epilepsy (e.g. cognitive issues and co-morbidities - ADHD, Autism, anxiety...).
- No seizure first aid training in schools can bring risk.
- Lack of understanding amongst teachers and other students can lead to stigma, discrimination and social exclusion (as well as self-stigma).
- Variability in how epilepsy impacts each child affected means tailored approach needed (in mainstream and/or special needs settings).
- Limited resources to provide reasonable accommodations to children with epilepsy at school.
- Fear of disclosure can lead to not accessing available accommodations.
- Epilepsy isn't always seen as a disability, limiting opportunities to access reasonable accommodations, supports and services.

## Solutions:

- Wide societal awareness raising needed (not just in schools).
- Incentivised training: In-school awareness programmes by IBE chapters and/or online courses for teachers (e-learning).
- Educate paediatric neurologists to work with families to support the child to attend school.
- Provide self-help, support groups or special sessions for children with epilepsy (e.g. memory/cognitive training).
- Advocate for reasonable accommodations for children with epilepsy.
- Find 'Epilepsy Ambassadors' within and outside of the school system.

## What can IBE do?

- **Raise awareness:** Use awareness campaigns to improve knowledge on education and epilepsy.
- **Support peer to peer learning:** Set up thematic/shared learning groups on epilepsy and education for chapters (share best practice, guidelines, resources, etc.)
- **Advocacy** – Work to define 'disability' in epilepsy and use IGAP to advocate for the right to education for PWE.
- **Capacity Building:** Develop flexible toolkits on epilepsy and education that chapters can adapt, and consider offering small grants to support school-based activities.
- **Educate healthcare professionals:** Partner with ILAE to help healthcare providers understand how to support children with epilepsy in school, including empowering families.

# FAMILY & RELATIONSHIPS

## Challenges:

- Epilepsy stigma can mean that people with epilepsy find it difficult to find a partner and marry in some cultures.
- Fear of being excluded or shunned means some PWE and their families reject the diagnosis, which can put their health at risk.
- Lack of knowledge in relation to sexual and reproductive for people with epilepsy, in many countries – increasing risk for women of childbearing age in particular.

## Existing initiatives:

- Counseling services and support groups (including family education programmes) are provided in many countries in the region.
- Advocacy and awareness raising from IBE chapters is ongoing.
- Training of HCPs to provide information, support and advice on these topics to PWE and their families.



## What can IBE do?

- **Generate Evidence:** Use GENS data on sexual and reproductive health to inform work in this area, as well as leading new research projects in this area.
- **Awareness Raising:** Use existing and new awareness campaigns to improve health literacy in epilepsy.
- **Educate HCPs:** Work with ILAE to educate HCPs on their role in supporting people with epilepsy in relation to their sexual and reproductive health.
- **Capacity Building:** Provide chapters with up to date knowledge, and an opportunity to share best practice, resources, etc. This could include further translation of IBE's website on women and epilepsy.

# WHO INTERSECTORAL GLOBAL ACTION PLAN (IGAP) ON EPILEPSY AND OTHER NEUROLOGICAL DISORDERS

How can we use IGAP to address the needs of people with epilepsy in our regions?

## **Presentation: IGAP - Overview and Progress Update [recorded]**

**Dr Neerja Chowdhary, Technical Officer, WHO Brain Health Unit**

*Dr Chowdhary presented an overview of the IGAP.*

- She showcased some of the tools that WHO has developed to support IGAP implementation, including the technical brief, implementation toolkit, access to medicines report and the global status report (to be launched in 2025).
- Donna Walsh said that WHO's main role will be in providing technical assistance. Therefore, the onus is on us to really drive action.
- Everyone was encourage to download and read the WHO resources.

## **Presentation: IGAP in the Western Pacific Region**

**Anchor Hung, Vice-President, Western Pacific, IBE**

*Anchor Hung introduced the Western Pacific region; where IBE has 22 chapters and a high degree of diversity.*

- She presented the results of a survey assessing IGAP implementation from 2022 to 2024. It focused on global targets 5.1 and 5.2 (which are specifically focused on epilepsy – access to care/human rights).
- The main point is that progress is happening. But most of the work was already planned or in progress before IGAP was adopted. So while IGAP has helped support our chapters' efforts in the region, it hasn't led to major changes in government action. Therefore, IBE needs to continue to lead efforts for implementation.

## **Presentation: IGAP – Learnings from a WHO Demonstration Project [recorded]**

**Prof. Ding Ding, China Association Against Epilepsy, China**

*Ding Ding explained China had led a WHO demonstration project, under an earlier epilepsy resolution: The Epilepsy Prevention & Control initiative.*

- It involved prescribing phenobarbital in rural China, where 50% of participants saw a reduction in seizures or became seizure free, showing how a small investment could yield huge outcomes in epilepsy care.
- Building on this, China is now developing a national epilepsy plan through IGAP. The goal is for 80% of people with epilepsy to be diagnosed and treated with medications covered by insurance and to have access to local hospitals that can manage epilepsy. People with drug-resistant epilepsy would be able to go to a specialist centre in a larger city. The plan also includes raising public awareness and acceptance of epilepsy.



# PANEL DISCUSSION

**Prof. Rajinder K Dhamija, Chair, National Taskforce on Brain Health, Government of India and OneNeurology Ambassador.**

Work in India has focused on the development of a **National Taskforce on Brain Health** where there is a clear focus on addressing the burden of epilepsy. We need to think more about how we can position epilepsy in efforts on brain health, neurology and NCDs – taking advantage of the momentum which is being created following the adoption of IGAP. In some countries this may be more realistic than advocating for a national epilepsy plan.

**Dr Jithangi Wanigasinghe, Epilepsy Association of Sri Lanka**

Jithangi said we should focus on quality, not just quantity. She explained that it's possible to meet the IGAP targets for improving access to treatment without actually changing the lives of people with epilepsy. She also pointed out that it's hard to make progress from a public health perspective because, in many countries, epilepsy is wrongly placed under 'mental health,' and the laws and systems in place aren't set up to support real change at national or regional levels.

**Prakash Singh Budhathoki, Nepal Epilepsy Association.**

Prakash stressed the importance of collaborating with the life science and pharmaceutical industry. Whilst such companies can provide grants or sponsorship to patient organisations, there are also key players in discussions on access to treatment. He said there are many companies in this region who could be engaged to partner in this work.

**Boram Lee, Korean Bureau for Epilepsy**

Boram said there is no Korean legislation supporting people with epilepsy, which leads to discrimination in society. The Korean Bureau for Epilepsy is leading a major push for adoption of **The Act of the Management of Epilepsy and Support for Patients with Epilepsy**. This work has been delayed, but IGAP should give bring renewed impetus. The legislation will soon be discussed before the government.

**Graeme Shears, Epilepsy Foundation Australia**

Graeme highlighted that, in Australia, IGAP helped secure government funding to support collaboration between national epilepsy organisations. Progress was slow until the funding was available, but now things are moving quickly through the **Epilepsy Smart Australia initiative**. For real success, it's important that IBE and ILAE chapters work together.

# IDEAS EXCHANGE FORUM

The following presentations were made by chapter members across the region:

- **Japan:** Dr Mayu Fujikawa of the Japan Epilepsy Association spoke about a new regional care system bringing together medical institutions and people with epilepsy to improve treatment through local collaboration.
- **Mongolia** (RECORDING): Prof. A.Tovuudorj, President from the Mongolian Epilepsy Association discussed IGAP implementation in Mongolia over the last two years, which has included establishing a specialist epilepsy centre and long-term video EEG monitoring.
- **Republic of Korea:** Dr Seung-Bong Hong, Director of the National Epilepsy Care Centre, shared how the Korean Epilepsy Support Centre was established in 2020 to address the significant shortage of specialist centres. It includes a unique epilepsy helpline for direct support.
- **Taiwan:** Hsiu-Chieh Lin of the Taiwan Epilepsy Association discussed how Taiwan is pioneering an epilepsy-inclusive society through effective promotion of social education on epilepsy.
- **Malaysia:** Dr Lai Siew Tim, from the Malaysian Society of Epilepsy, highlighted the impactful work of epilepsy support groups, mental health services, and advocacy initiatives driving real change in Malaysia.
- **Philippines** (RECORDING): Dr Adolfo Solis, President, Epilepsy Awareness and Advocacy Inc discussed their community projects such as the epilepsy manager programme, epilepsy school caravan and the one nation for Juan epilepsy project.
- **Hong Kong SAR China:** Dr Anchor Hung, IBE's Regional Vice-President, Western Pacific presented the key learnings and challenges as well as how to make progress going forward.
- **India:** Treasurer Pooja Nandi presented the Samman Association's (IEA Mumbai Chapter) patient-focused and public-focused programmes, as well as their effective school awareness programmes.
- **Hesperian Health Guides:** Aditi Malhotra, Writer and Project Lead, presented their Epilepsy Project; a book which emphasises the importance of community-based care for epilepsy and seizures in limited resource- and low literacy settings.
- **India:** GCS Shreemal, Chairman of the Pragya Epilepsy Wellness Society, described their dedicated building and campus, emphasising the expert team of doctors and staff who provide comprehensive care and support to people with epilepsy.

# FINAL DISCUSSION

## **How do we collaborate to most effectively address the needs of people with epilepsy in Asia- Oceania? Exploring capacity building needs of chapters**

*The following points were captured in the final discussion in relation to work IBE could prioritise in the region:*

- Focus on collaboration both within and between regions.
- Consider holding quarterly regional meetings to keep sharing ideas between IBE and its chapters and encourage chapters to use the IBE Knowledge Hub; particularly the new shared learning groups.
- Keep raising awareness—can we expand global IBE campaigns and support more local actions?
- Support countries in implementing IGAP, i.e. by providing letters of support and hosting webinars to share global best practices.
- Explore how we can connect with wider health areas like neurology, rare diseases, and NCDs—what can we learn and where can we join forces?
- Think about how epilepsy fits into disability discussions—a position paper could help shape this.
- Recognise and celebrate epilepsy advocates of all ages.
- Funding remains a challenge and is often specific to each country, so global fundraising training may not always work.



# APPENDIX

## IBE WORKSHOP

Leveraging Policy frameworks for epilepsy advocacy action in South East Asia and Western Pacific regions

*July 22<sup>nd</sup> 2023  
Jaipur, India*

The International Bureau for Epilepsy workshop, held on July 22nd, 2023, at the Marriott Hotel in Jaipur, India, focused on 'Leveraging Policy Frameworks for Epilepsy Advocacy Action in South East Asia and Western Pacific Regions'.

The workshop was designed to enable the epilepsy community to reflect on progress and strategise for future advocacy.

The workshop aimed to utilise the WHO's Global Action Plan (IGAP) and the United Nations Sustainable Development Goals (SDGs) for effective epilepsy advocacy action.

Participants included people with epilepsy, caregivers/families, advocates (from IBE chapters) and healthcare providers.

### **The workshop's objectives included:**

- Increasing knowledge of IGAP (specifically strategic objectives 1 and 5) and key UN SDGs relevant to epilepsy.
- Understanding how these policy frameworks can be leveraged for effective advocacy.
- Learning about IBE's activities and ways to get involved.

# LEVERAGING IGAP: POLICY PRIORITISATION

## IGAP Strategic Objective 1: Raise Policy prioritisation and strengthen governance

The workshop participants undertook in-depth discussions centred on strategically using IGAP to drive improvements in epilepsy care and support systems.

A key area of focus was IGAP's Strategic Objective 1, which emphasises the critical importance of raising policy prioritisation for epilepsy and strengthening governance structures to support effective action.

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Participants engaged in detailed exchanges, sharing the diverse realities of their respective countries/ regions concerning the existence and effectiveness of national epilepsy plans and awareness and advocacy programmes.

- It was evident that in many places, epilepsy is not explicitly included within broader national health programmes. This lack of specific inclusion often translates to a lack of dedicated policies, insufficient resource allocation, and a diminished capacity to address the unique challenges faced by people with epilepsy.
- A strong call emerged for a fundamental shift towards a "bottom-up" approach to advocacy. This approach empowers community-based efforts through the strengthening of IBE chapters and the mobilisation of other local organisations, recognising their vital role in driving change at a grassroots level.
- Participants identified several key challenges which hinder progress, including the complex interplay of political and cultural differences in the region (and even within countries), lack of education and awareness about epilepsy, scarcity of essential resources, and the consistent lack of political will to prioritise epilepsy on national agendas.

# IGAP: PUBLIC HEALTH APPROACH

## IGAP Strategic Objective 5: Strengthen the Public Health Approach to Epilepsy

This IGAP Strategic Objective focuses on increasing epilepsy service coverage and replacing discriminatory legislation.

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### **Epilepsy Service Coverage:**

- In Nepal, government health facilities provide free first-line medicines, but service recipients often prefer traditional healers or seek treatment in India.
- In India, socioeconomic inequalities create unequal distribution of resources, especially affecting access to care in villages and rural areas.

### **Replacing Discriminatory Legislation:**

- Significant issues persist regarding employment and marriage, despite the repeal of discriminatory legislation.
- Implementation and enforcement of such acts are lacking.
- Right to education and right to treatment access are often jeopardised.
- Driving restrictions are a concern, with people with epilepsy in India facing license revocation upon diagnosis.

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### **Key challenges to achieving Strategic Objective 5 include:**

- Lack of resources and budget allocation (e.g. in Nepal, where epilepsy is included under mental health, resulting in lower priority).
- The need for inclusive, non-discriminatory legislation.

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### **Measures to achieve this strategic objective include:**

- Awareness programmes.
- Meaningful participation of people with epilepsy in advocacy.
- Capacity building for community health professionals and social workers.
- Ensuring the supply chain of affordable ASMs.
- IEA initiatives for insurance and better legislation for epilepsy and driving could be shared as examples of best practice.
- Launch of initiatives on rights related to education and employment.
- Training people with epilepsy to hold governments accountable.
- Meaningful patient and public involvement (PPI)



# LEVERAGING THE UN SDGS

Exercise 2 involved leveraging the UN SDGs for Epilepsy Advocacy. the below table captures synopsised notes from our group discussions

SDGS	<div> <div>1 NO POVERTY</div> <div>4 QUALITY EDUCATION</div> <div>8 DECENT WORK AND ECONOMIC GROWTH</div> </div>	<div> <div>2 ZERO HUNGER</div> <div>3 GOOD HEALTH AND WELL-BEING</div> <div>6 CLEAN WATER AND SANITATION</div> </div>	<div> <div>5 GENDER EQUALITY</div> <div>10 REDUCED INEQUALITIES</div> <div>16 PEACE, JUSTICE AND STRONG INSTITUTIONS</div> </div>
RELEVANCE	<ul style="list-style-type: none"> <li>Schooling challenges such as limited support, bullying, stigma).</li> <li>Workplace challenges i.e. discrimination and underemployment.</li> </ul>	<p>Ensuring the right to health</p> <p>There is a need for cost-effective, holistic care that addresses the treatment gap but also ensure social care support.</p>	<p>Unique challenges for women with epilepsy.</p> <p>Need for more equitable inclusion of children with epilepsy in school and beyond (developing inclusive institutions).</p>
NEEDED ACTIONS	<ul style="list-style-type: none"> <li>Informational resources and educational programmes</li> <li>Need for more implementation research e.g. impact of addressing epilepsy in school curricula</li> <li>Empowering families of children with epilepsy (i.e. support groups).</li> </ul>	<p>Inclusion of PWE in advocacy strategy development.</p> <p>Campaign for refractory (and complex) epilepsy could be included under disability to enable access to government schemes.</p>	<p>Advocacy initiatives for caregivers, self-help initiatives (e.g., audiovisual resources) for PWE, leveraging telemedicine.</p>
KEY STAKEHOLDERS	<p>District authorities, teachers, parents, NGOs, politicians, administrators, psychologists, traditional/religious healers, PWE, education departments, service organisations, community health workers.</p>	<p>Local government &amp; community organisations e.g. the National Federation of People with Disabilities.</p>	<p>People with epilepsy and caregivers, local government and community-based organisations, ASHA community workers.</p>

# MOVING FORWARD: KEY ACTION STEPS

The IBE workshop in Jaipur provided a valuable platform for the epilepsy community to reflect on progress, share knowledge, and identify key actions to advance epilepsy advocacy in the South East Asia and Western Pacific regions. The discussions and outcomes of the workshop, centred on leveraging IGAP and the UN SDGs, will inform and drive future efforts to improve the lives of people with epilepsy.

## **Key action steps identified during the workshop include:**

- Need for more focused intersectoral advocacy by the regional epilepsy community (e.g. focus on sectors such as education, employment, etc.).
- Generate data-driven evidence for policy-makers.
- Ensure person-centred advocacy actions (giving a voice to PWE).
- Promote meaningful involvement of PWE in shaping advocacy actions.
- Train PWE to become 'ambassadors' or 'champions' - optimising engagement and utilisation of self-help groups.
- Share success stories and scale best practice within and across regions e.g. IEA work on insurance and driving.
- Learn from other communities e.g. autism advocacy
- Facilitate multi-stakeholder dialogue.
- Utilise local leaders to sensitise the rural community.
- Develop more innovative outreach programmes within and outside the epilepsy community incl. effective use of mass media.
- Work to further educate HCPs incl. community-based health professionals and social workers
- Overcome limited resources by following a 'train the trainer' model
- Ensure supply chain of affordable ASMs, whilst also focussing on prevention, as well as treatment of refractory epilepsies.

# IBE ASIA AND OCEANIA

NEW DELHI, FEBRUARY 2025

