Advocate's toolkit

for making epilepsy a priority in the Americas

PAHO Pan American Health Organization
World Health Organization Americas Region

IBE International Bureau for Epilepsy

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WASHINGTON, D.C., 2024

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Foreword

It is an honor to be invited to write this foreword on behalf of the International Bureau for Epilepsy (IBE) and to share my epilepsy journey because I am grateful that I was able to receive treatment to stop my debilitating seizures.

I grew up in Chile. When I was 6 years old, I had my first seizure, and with a diagnosis of epilepsy my life changed abruptly from one moment to the next. I began to have seizures daily; I even had multiple seizures in the same day. I had to stop going to school, and my routine changed completely. I remember having to wear a helmet to protect my head because of the number of seizures I had. I was given different medications, but even with increased dosages, I still lived in crisis. I remember going to the neurologist, having different tests and the feeling of constant drowsiness due to the medications. My epilepsy was difficult to manage, but thanks to the constant support of my family and my neurologist, and the treatment I received, I was able to stop having seizures. It was a slow and lengthy process in which I was able to return to school, and begin to have a more normal routine, and little by little they were able to lower the dose of the medications. At age 18, I was able to stop all medication. Miraculously, I have remained seizure free!

The experience I had during my childhood is the reason I chose to dedicate myself to the area of children's neurorehabilitation, working with babies and children to help them to improve their motor function and quality of life. I have been working as a pediatric physiotherapist since 2013 and completed an MSc in Clinical Neuroscience at University College London in 2020.

I am committed to using my personal experience to help other people with epilepsy. I created a physiotherapy volunteer program in the Chilean League Against Epilepsy. I also had the privilege of sharing my personal experience as a participant in a closed consultation with the World Health Organization, giving my feedback and comments regarding the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP).

I realize I am very fortunate to have had access to timely treatment, and to have the support of my family to cope with my epilepsy. If I had not had access to the medical treatment I needed, my life story would have been completely different. Today, I am happily married, and we are parents to a baby girl.

I passionately believe that all people with epilepsy should have all the necessary opportunities to develop fully, and that this toolkit will help achieve this goal. This toolkit will serve to empower people in the Region of the Americas to conduct epilepsy awareness and advocacy campaigns. I invite everyone who is reading this text to take an active role, which will help meet the objectives of the global action plan (IGAP) and, in the long term, improve the quality of life of people with epilepsy in our communities.

Sincerely,

Valentina Kahn

IBE International Golden Light
Award Recipient 2021

Preface

Epilepsy, a neurological condition characterized by recurrent seizures, is a public health concern that demands our urgent attention, not only because of its high prevalence, but also because of its profound adverse impact on the lives of individuals, families, and communities.

In the Region of the Americas, prioritizing epilepsy is not simply a clinical necessity but a moral imperative. Epilepsy affects 5 million people in the Region, transcending geographical boundaries and social status. It is a condition that can affect anyone, irrespective of age, gender, or background. Yet, despite its widespread distribution, epilepsy often remains shrouded in stigma and misconceptions.

Advocating for epilepsy in the Americas is crucial for several reasons. First and foremost, we must ensure the preservation of human dignity. By prioritizing epilepsy, we affirm our commitment to fostering a society where everyone, regardless of their health condition, can lead a life of fulfillment and purpose. Through advocacy, we can pave the way for increased awareness, early diagnosis, and improved access to quality care, thus mitigating the negative societal impacts of this condition.

Prioritizing epilepsy also embodies our commitment to inclusivity and equality. It acknowledges that every person, irrespective of their health status, has the right to participate fully in society, pursue an education, and engage in gainful employment. By removing barriers and promoting understanding, we create an environment where individuals with epilepsy can thrive and contribute meaningfully to their community.

This kit provides the tools for civil society organizations, communities, and individuals to unite in a shared commitment to prioritize epilepsy and work toward a future where no one faces the challenges of epilepsy alone.

As we embark on this advocacy journey, let us remember that our collective strength lies in our empathy, understanding, and determination. Together, let us strive to make epilepsy a priority in the Americas, fostering a region where health equity is not just an aspiration, but a reality for all.

Dr. Anselm Hennis

Director

Department of Noncommunicable
Diseases and Mental Health

Pan American Health Organization

Acknowledgments

This toolkit was jointly developed by the International Bureau for Epilepsy (IBE) and the Pan American Health Organization (PAHO), with input from the Americas Toolkit Steering Group which was composed of persons with epilepsy, caregivers and care partners, IBE chapters across the Americas, and professionals working in the field of epilepsy. The authors wish to thank all involved stakeholders for their valuable insights and contributions to the toolkit; in particular, the families with epilepsy, for sharing their lived experiences, perspectives, and commitments to making epilepsy a health priority in the Americas and across the globe.

Through an initial needs assessment and formation of a multi-stakeholder expert steering group, stakeholders provided their perspectives on resources that were currently available to them, stories, testimonials, and best practices they wanted to share. They identified areas where they were seeking support, and opportunities for additional collaboration. This toolkit was developed based on that input as well as on feedback on initial drafts of the toolkit.

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Introduction

Who is this toolkit for?

This toolkit was developed for you as a member of civil society to help you become more comfortable with basic advocacy strategies that will prepare you to promote epilepsy as a public health priority at the community, national, and regional levels. It was developed to encourage the active involvement of stakeholders: people with epilepsy, their family members, epilepsy organizations, other non-profit organizations, and people working to raise human rights issues related to epilepsy. Using the strategies and templates found in this toolkit will help you to construct a successful advocacy strategy.

This toolkit aims to assist you and your staff at the community, national, and regional levels to plan, implement, and monitor the parts of the advocacy strategy that are most relevant to your context. It is not meant as a stand-alone guide on how to carry out advocacy activities. Instead, it provides key prompts for reflection and discussion, basic advocacy pointers (the theory), and essential tools to help you and your team to work your way logically through the different stages of an advocacy planning cycle. Making epilepsy a priority is now or never!

MODULE **1** **The big picture**

Looking for information on persons with epilepsy and advocacy?
START HERE

Not sure where to begin?
START HERE

MODULE **2** **Planning your advocacy**

MODULE **3** **Taking action**

Looking for advocacy ideas?
START HERE

Want more information about regional and international advocacy efforts you can join?
START HERE

MODULE **4** **Expanding your reach**

Tools and resources

Looking for advocacy templates, tools, and ideas for workshop organisation?
CHECK THESE OUT

What is advocacy and why is it important?

ad·vo·ca·cy

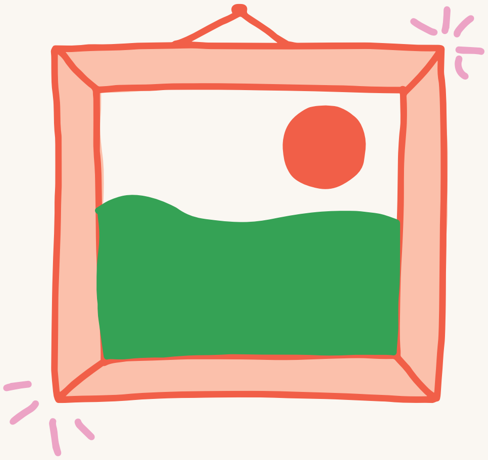
['ad-və-kə-sē] noun

the act or process of supporting a cause or proposal

What's the difference between formal "advocacy" and simply raising awareness about the importance of an issue like epilepsy? It often comes down to whether the effort is aimed specifically at changing behavior and/or policy. The table below describes various types of influencing actions, how they differ from each other, as well as who the target tends to be.

AWARENESS RAISING	**Definition:** **Informing and educating people** about a topic or issue with the intention of influencing attitudes and beliefs *(1)*.	**Key characteristics:** Action taken to inform or educate people about a topic or issue but not necessarily aimed at specific behavioral or policy change.	**Key audiences:** Individuals; for example, persons with epilepsy, their families, healthcare providers, traditional healers, educators, "the public."
ADVOCACY	**Definition:** The act (or process) of supporting a specific **change in behavior or policy**.	**Key characteristics:** Actions that attempt to influence policy-makers and stakeholders by increasing both public attention and private pressure/incentives on a certain issue.	**Key audiences:** Policy-makers and "duty bearers" (e.g., government or other leaders) or other key stakeholders (e.g., hospital administrators, the media, or teachers and school administrators).
POLICY ADVOCACY	**Definition:** The act (or process) of supporting a **change in a specific public policy**.	**Key characteristics:** A particular kind of advocacy with the goal of changing or updating public policies to reflect a specific desired change.	**Key audiences:** Policy-makers, duty bearers, policy custodians, government officials.
CAMPAIGNING	**Definition:** Actions, events and activities aiming to **achieve a change and/or raise awareness** on a defined issue by working with larger organized groups of people.	**Key characteristics:** A number or series of organized advocacy and communication activities that build public support for change. Can include all or some of the above tactics.	**Key audiences:** Can be all of the above but focuses on gaining broad public support to create pressure for change.

With **awareness-raising**, you are often asking people to pay attention, to think about something in a different way, to consider someone's situation, or to contribute to a conversation about something. **Advocacy** is moving your audience toward a desired behavior or policy change. **Policy advocacy** has a specific policy or law in mind that you want to change and a plan for how to bring about that change. So how could you build on your existing awareness-raising work and move toward more advocacy work? Adding or amending existing policies can be transformational for people with epilepsy; specifically, policies that restrict full participation or those that are discriminatory. These policies can be related to access to education, employment, driving regulation, income support programs, and access to medications.



MODULE 1:

The big picture

Learning objectives

1. Identify the key epilepsy facts for the Region of the Americas.
2. Access a copy of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031 also known as the IGAP.
3. Identify the IGAP global targets relevant to epilepsy: 5.1 and 5.2.
4. Identify the importance of the UN Sustainable Development Goals (SDGs).

In this first module, we ask you to think about the big picture which will help you to plan the change you want to see. There are many areas you can focus on as an advocate for persons with epilepsy – eradicating stigma and discrimination; reducing the treatment gap; or improving access to education, employment, and other basic services. How are you going to decide what to do? What are your key messages? Who do you need to convince? Are "they" going to listen to you? Who might be able to help you achieve your objectives? How long will this process take?

Whether you are a small community group or a large organization, **the first place to start is understanding the big picture of epilepsy as well as how it plays out in your own community or country**. This section looks at some basic facts and key epilepsy messages, as well as how different people can become changemakers. Let's start with the numbers and facts.

KEY FACTS – Epilepsy in the Region of the Americas

WHAT IS EPILEPSY?

Epilepsy is a **noncommunicable, chronic brain condition** that affects people of all ages *(2)*.

- Epilepsy is one of the **most common neurological conditions** worldwide.

WHO HAS EPILEPSY?

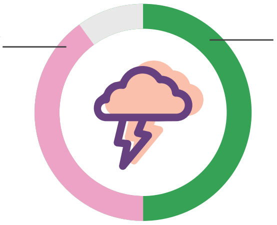
50 million people worldwide have epilepsy.

5 million people in the Americas live with epilepsy *(3)*.

EPILEPSY AND DISABILITY

Epilepsy represents 0.5% of the disease burden in the Americas, measured in disability-adjusted life years (DALYs). Likewise, **it is responsible for 0.8% of total disability in the region**, ranging between 0.2% in Canada and 1.6% in Honduras. At a subregional level, epilepsy is associated with a lower percentage of disability in North America (Canada and the United States) and a higher proportion in Latin America and the Caribbean.

IMPACTS OF EPILEPSY



30–40% of children with epilepsy have an intellectual disability as the most common comorbidity.

Up to **50%** of persons with epilepsy can experience co-occurring conditions such as anxiety and depression *(4)*.

Persons with epilepsy have **up to three times higher risk of premature death**, including from fires, accidents, suicide, and sudden death than that of the general population *(2)*.

- Persons with epilepsy and their families **suffer from deep stigma and discrimination**, which impacts their access to health care, education, and employment and can lead to human rights violations.

There is lack of legislation for protection of these rights and to guarantee universal access to health care. Still today in many countries, the quality of life for people living with epilepsy and their family members is impacted by the stigma linked with the disease.

EPILEPSY PREVENTION, CARE, AND TREATMENT ARE LACKING

25%

of epilepsy cases are preventable

These are caused by prenatal and perinatal complications, stroke, central nervous system infections (such as malaria, cysticercosis, and river blindness), and traumatic brain injury from accidents *(3)*.

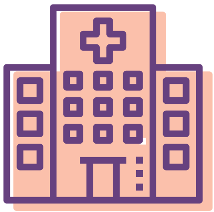
Stroke is the main preventable cause when a person experiences their first epileptic seizure in adulthood *(5)*.

THE TREATMENT GAP

>50% of people with epilepsy in Latin America and the Caribbean do not receive the medical treatment they need for their seizures, yet **two-thirds** could live seizure free with proper treatment *(6)*.

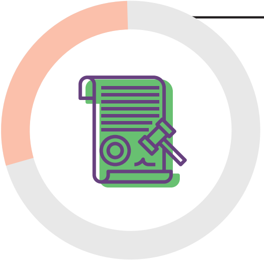
TREATMENT IS AVAILABLE BUT NOT EASY TO ACCESS

62% of countries in Latin America and Caribbean reported having at least one anti-seizure medication... Most of the time, these are only available at the secondary and tertiary levels of care, which makes it very challenging for people to access at the primary care level *(6)*.



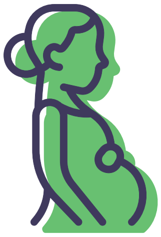
EPILEPSY IS NOT PART OF MOST PUBLIC HEALTH AGENDAS

A poor healthcare system and irregular drug supply chains in many countries leaves healthcare providers without the skills and tools for properly diagnosing and treating epilepsy.



Two-thirds of countries in Latin America and the Caribbean do not have a program or plan for epilepsy care and **only 29%** do have an appropriate legislation on epilepsy.

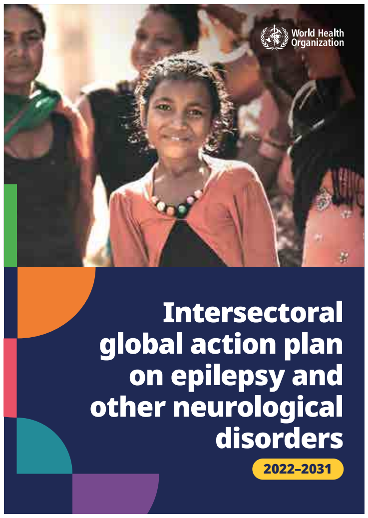
Improving the quality and accessibility of healthcare systems is also urgently needed for prevention: ensuring women receive the care they need during and immediately following delivery, and ensuring all women and children are immunized. There is evidence to show that the rates of epilepsy have decreased dramatically in high-income countries in the Region (Canada and United States) with the improvement of healthcare systems. **Rates of epilepsy can be seen as an indicator of the quality of the healthcare system.**



Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (2022–2031) (IGAP)

A key milestone, achieved in May 2022, was the launch of the World Health Organization's Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031 (IGAP). Unanimously adopted by all 194 WHO Member States, IGAP contains a specific strategic objective "to strengthen the public health approach to epilepsy," providing a mandate for policy-makers to improve epilepsy service coverage and remove or update discriminatory legislation to safeguard the rights of persons with epilepsy and other neurological conditions.

This toolkit leverages this progress and gives you the strategies you will need to put IGAP into action to achieve a transformational social change for people with epilepsy.



World Health Organization

Intersectoral global action plan on epilepsy and other neurological disorders

2022–2031

IGAP Strategic Objective 5:
Strengthen the public health approach to epilepsy

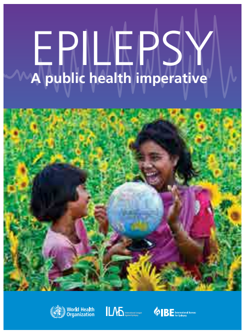
IGAP Global Target 5.1
By 2031, countries will have increased service coverage for epilepsy by 50% from the coverage in 2021.

IGAP Global Target 5.2
80% of countries will have developed or updated their legislation with a view of promoting and protecting the human rights of people with epilepsy by 2031.

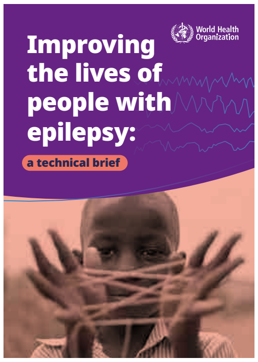
Urgent action needed *(7, 8)*

- Promote epilepsy as a public health priority.
- Strengthen the programmatic and legal framework for the care of people with epilepsy, according to national conditions, and give the proper protections of rights.
- Support advocacy efforts using innovative approaches, including optimizing social media, to improve public attitudes, reduce stigma, and promote the rights of persons with epilepsy.
- Invest in health and social care systems to improve access to care.
- Ensure appropriate services at the first level of care, including the consistent availability of basic medicines, diagnostics, and other health products.
- Promote brain health and prevent neurological disorders across the life course, including analyzing and addressing the root causes of the disease and its determinants.

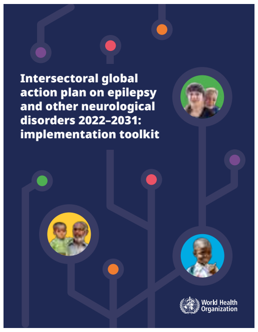
Other WHO resources


EPILEPSY
A public health imperative

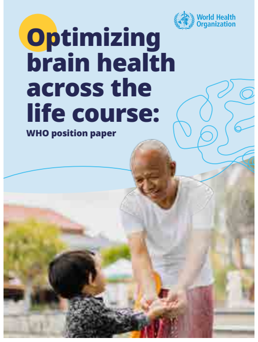
Another very useful resource is Epilepsy: a public health imperative, developed in 2019 by WHO in collaboration with the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). This global report on epilepsy summarizes the available evidence on the burden of epilepsy and the public health response required at global, regional, and national levels.


World Health Organization
Improving the lives of people with epilepsy:
a technical brief

The WHO epilepsy technical brief Improving the lives of people with epilepsy: a technical brief aims to strengthen action for epilepsy and complements the IGAP. The technical brief presents the key information on epilepsy and recommends actions to policy-makers and other stakeholders. Using the concept of levers for change introduced by the Operational Framework for Primary Health Care, it identifies actions on the policy and operational levels that stakeholders should take to strengthen services for people with epilepsy using a person-centered approach based on human rights and universal health coverage.


Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031: implementation toolkit
World Health Organization

Neurological disorders make up a significant part of disease burden globally. The Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031: implementation toolkit operationalizes the implementation of the Intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 (IGAP), directed at reducing the burden and strengthening services for people with neurological disorders.


World Health Organization
Optimizing brain health across the life course:
WHO position paper

Optimizing brain health across the life course is a WHO position paper on optimizing brain health across the life course. It can be used as a technical complement to IGAP.

On the following pages the globe icon is used to reference a specific IGAP section. You can read the full IGAP document here.

The role of the NGO

Nongovernmental organizations (NGOs), such as IBE chapters in the Americas, can help to bring different stakeholders together to advocate for changes in laws, practices, and perceptions. NGOs can advocate for stakeholders to collect baseline country-level data, track progress, and monitor government commitments to international resolutions and agreements. Data can be collected from multiple sources, including registries and disease-specific reporting systems, surveys, and administrative and clinical data sets. NGOs can play a key role in bringing persons with epilepsy, their families, the public, teachers, employers, policy-makers, and health professionals together to advocate around key messages.

> **#152.** “People with epilepsy and organizations that represent them should be empowered and involved in advocacy, policy, planning, legislation, service provision, monitoring and research in epilepsy.“

> **#162.** “Activate national networks and lobby administrators, policymakers, and other stakeholders to integrate care for comorbidities (i.e. physical and mental health conditions) as an integral part of epilepsy treatment and care services.”

NGOs can play a critical role of helping persons with epilepsy and families in their communities. They also play an important role in helping to empower persons with epilepsy to seek out appropriate care, find their voice, tell their story, and help to advance change.

IGAP Strategic Target 5.1 By 2031, countries will have increased service coverage for epilepsy by 50% from the current coverage in 2021.

> **#143.** “Epilepsy is a highly treatable condition and more than 70% of people with epilepsy could live seizure-free lives if they had access to appropriate anti-seizure treatment, the most cost-effective of which are included in the WHO Model List of Essential Medicines.”

> **#144.** “Wide treatment gaps may result from a combination of decreased capacity in health care systems, the inequitable distribution of resources and the low priority assigned to epilepsy care. Factors that widen this gap include staff shortage, limited access to anti-seizure medicines, lack of knowledge and confidence of primary care health workers in the management of epilepsy, misconceptions, and stigma.”

> **#145.** “Primary care provides a platform to address the health needs of people with epilepsy through a person-centered approach. With political will and a combination of innovative strategies, epilepsy prevention, diagnosis and treatment can be integrated into primary health services in cost-effective ways, even in low-resource settings.”

FOCUS ON: Service coverage

Service coverage for individuals with epilepsy is essential for their well-being. It refers to the availability of services and support that enables people to receive necessary care and access treatment. PAHO has provided these data to guide advocacy work in your community. Here are some key aspects of service coverage related to epilepsy:

- Severe shortage of neurologists, with 0.03 neurologists per 100 000 people in low-income countries of the Americas vs. 4.74 per 100 000 in high-income ones *(9)*.
- Rural populations face even greater hurdles, with treatment gaps twice as high. Medication access is a major issue, with stockouts common and primary care providers lacking epilepsy expertise *(9)*.
- The association between epilepsy and socioeconomic deprivation is bidirectional: healthcare spending by people with epilepsy and their families, often out of pocket in many low- and middle-income countries, can result in financial hardship and poverty. People with epilepsy tend to have lower income and poorer education and health outcomes than the general population, factors which affect them throughout their whole lives *(9)*.
- Up to 70% could become seizure-free with access to affordable anti-seizure medicines (USD 5/year). But progress requires addressing larger health system weaknesses beyond medication availability alone *(4)*.
- Progress is being made to close epilepsy treatment gaps in the Americas through innovative initiatives by PAHO/WHO Collaborating Centers.
- Both Chile and Honduras collaborate actively with PAHO/WHO to support the IGAP, through activities like needs assessments, guideline implementation support, analysis of treatment gaps and models, building research capacity, and training health workers on the WHO mhGAP module. They showcase how localized yet coordinated actions can contribute to enhancing epilepsy care.
- Honduras: The PAHO/WHO Collaborating Center at the National Autonomous University has implemented community interventions in Salamá since 1997. This public health approach – training volunteers, improving medication access, raising awareness – helped increase coverage from 15% to 38% by 2011. The treatment gap declined from 53% to 13% in the same period. Neurocysticercosis-related epilepsy also dropped from 37% to 14%, showing the success of integrated interventions *(10)*.
- Chile: The PAHO/WHO Collaborating Center Chilean League Against Epilepsy has expanded training programs to build capacity on epilepsy management. This includes online courses for 46 institutions (2149 participants) and in-person training for 53 groups (2696 participants). Awareness and anti-stigma campaigns reached over 1.5 million people on social media. The Collaborating Center also contributed to evaluating the impact of the PAHO Regional Epilepsy Strategy and Plan of Action 2011–2021, finding increased country investments in epilepsy programs *(11)*.
- PAHO/WHO and IBE and ILAE have been working collaboratively to develop legal mappings throughout the Region of the Americas and determine best legal practices to build a manual and model legislation to support the advances on the legal protection of the rights of people with epilepsy.

Other policy frameworks

The United Nations Sustainable Development Goals (SDGs)

The Sustainable Development Goals (SDGs) are a call for action by all countries – poor, rich, and middle-income – to promote prosperity while protecting the planet. They acknowledge that ending poverty must go together with strategies that build economic growth and address a range of social needs including education, health, social protection, and job opportunities, while tackling climate change and environmental protection *(12)*.

The SDGs lay out a framework of priorities and international commitments for the sustainable development of all counties. Put more plainly: they are the universally agreed "road map" and global goals for international development and environmental reforms for the period 2015–2030. The 17 Goals were adopted by all UN Member States in 2015, as part of the 2030 Agenda for Sustainable Development. This includes all 35 PAHO Member States. Used as a basis for most government and donor development strategies, the SDGs are an important tool for epilepsy advocacy.

Goal 3 relates to Health (and 3.8 specifically on universal health coverage), but there are several SDGs of direct relevance to the global epilepsy community. Throughout this toolkit, you will find references to ways the social condition for people with epilepsy can be leveraged through the implementation of the SDGs. It can be a way to engage policy-makers on their current priorities, as well as to come together and connect with other advocates such as those focused on disabilities, mental health, education, women and children, or human rights, who are also basing their advocacy messages around these same SDG commitments.

SDG 5 – Gender equality

advocacy in action

The world of sexual development, menstruation, contraception, fertility, and pregnancy is complex, but when you have epilepsy, there are extra issues you need to know about.

Advocates can go to the IBE website https://womenandepilepsy.org/ for extensive information for women with epilepsy.

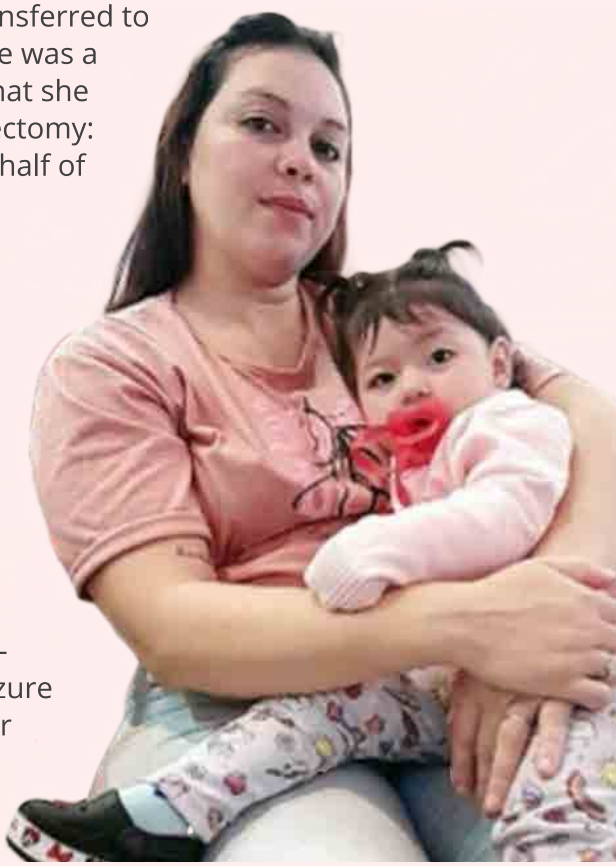
advocacy in action

SDG 3 – Good health and well-being

The story of Zamira (Argentina)

My daughter Zamira started having seizures on the third day of life. She was diagnosed at a pediatric hospital of Resistencia, Chaco, a province in northern Argentina. Two months after failing to control her seizures, she was diagnosed with refractory epilepsy, and had to spend two months in neonatology and intensive care. Neuroimaging showed that Zamira had been born with hemimegaloencephaly, a rare brain malformation that affects one cerebral hemisphere. She was transferred to a tertiary hospital in Buenos Aires to see if she was a candidate for epilepsy surgery. It was there that she had her first surgery. It was a left hemispherectomy: a radical operation that consists of removing half of the brain, at only two months of age.

All of this was possible within Argentina's publicly funded healthcare system, where health is a human right and protects the right of people, like my daughter, to have access to health through, among others, the Epilepsy Law, the Law on Rare Diseases, and adherence to the UN Convention on the Rights of Persons with Disabilities with constitutional status.



Since her operation, Zamira has been seizure-free for 16 months and instead of six anti-seizure medications, she only takes two. Zamira is our light, she is an incredible little girl, she has taught us many things. She is a very happy child with a great desire to live. All this is possible due to the expertise of having access to specialized professionals in primary care and in advanced epilepsy surgery centers, a robust health system, and universal coverage of access to health.

SDG 3 – Good health and well-being

Ensuring access to affordable, physician-directed, person-centered quality care (United States)

The Epilepsy Foundation engages on many policy issues to help ensure timely, affordable, and consistent access to health care and epilepsy medications. This has included enactment and protection of the Affordable Care Act, Medicaid, Medicare, and Veteran Affairs (VA) Epilepsy Centers of Excellence, as well as reducing health disparities. Regarding treatments, efforts include coverage of all U.S. Food and Drug Administration (FDA)-approved epilepsy treatments including through Medicare's Six Protected Classes policy, reducing out-of-pocket costs, and step therapy and prior authorization reform.

In the United States, the Affordable Care Act ensured coverage for people with preexisting conditions like epilepsy and expanded the availability of health insurance coverage to millions of previously uninsured or underinsured Americans. Medicaid has remained an entitlement program, and despite efforts to block grants, funding for the VA Epilepsy Centers of Excellence has tripled in the past few years. Medicare's Six Protected Classes has been protected despite threats. An out-of-pocket cap in Medicare Part D was enacted as part of the Inflation Reduction Act.

Monitoring "out of stock" medications (Canada)

The Canadian Epilepsy Alliance (IBE) worked with the Canadian League Against Epilepsy (ILAE) along with other groups in Canada to advocate for change to the reporting system for the drug supply for consumers. After many meetings with Health Canada and Members of Parliament changes were made to the reporting structure. Health Canada changed the reporting structure so there is mandatory reporting of all shortages of all drugs. Also, all shortages are listed with the date of the shortage, the reason for the shortage, and the estimated date of when the drug will be back in stock. The website www.drugshortages.ca was created and made available to healthcare professionals. Health Canada offers pharmacies and physicians the opportunity to subscribe to learn about any shortage updates. It is a huge step to keep people with epilepsy safe with proactive notification of any drug supply interruption.

Think about the following

- What facts and figures do you have on epilepsy in your country?
- Are there any laws, policies, or legislation that positively or negatively affect people with epilepsy in your country?
- Has your organization used facts and figures for advocacy? If not, how could you do so?
- Who have you worked with that was instrumental in getting others to listen to you? Are there community or national leaders, or local celebrities, that might help you to convince others?
- Are there other organizations that support the epilepsy cause or can be supportive if mobilized? What about organizations working on noncommunicable or neurological diseases?
- Have you developed a directory of other organizations or NGOs in your country that share your goal to improve the social condition of people with disabilities, or for women and children?
- Are there other approaches you can think of? What are they?

The time to act is now!

While epilepsy is a challenging issue to address, the time has never been better for advocates in the Americas to raise their voices, work together, and demand solutions. Epilepsy is treatable. Medication can be made affordable and basic epilepsy care can be provided at the primary care level for all people. All countries across the Americas have ratified IGAP and the UN SDGs. We now have the opportunity to raise awareness, hold governments accountable, and create meaningful national implementation plans.

Advocating for policy change

Policy advocacy focuses on changing laws, practices, or public policies.

Do you want an increased budget for government subsidized anti-seizure medications? Are you demanding that an existing law be upheld, like the right to an education for all children, including children with epilepsy?

When working with high-level officials, it is important to do your homework and anchor your advocacy asks on trusted data, research, and compelling arguments. Some good places to start are the WHO information kit on epilepsy, WHO epilepsy technical brief, or IBE IGAP unpacked guide.

As in any other disease, prevention, early detection, and quick attention are the most effective interventions, and legislation should give proper protection to the right to health, particularly when "health" is to be considered "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" *(13)*. The right to health, totally relating to the described concept, represents the "enjoyment of the highest attainable standard of health." Legislation to implement the right to health as a human right needs to consider all the needed interventions to procure health in a holistic and comprehensive manner and not just give access to medical attention when disease appears.

Policy-makers can be busy, so it is a good idea to bring both a problem and pose a solution. Often, it can be very useful to write or commission a report that explores the current situation, documents the problems it creates, and then suggests solutions for this problem. In the report you can include interviews with government officials, educators, health professionals, persons with epilepsy, their families, and even other NGOs.

PAHO has been collecting information to develop a regional legislative map in all its Member States. They have been working with the PAHO/WHO Collaborating Centers in the Region, and other civil society global organizations (IBE and ILAE) and specialized lawyers from different countries, to confirm the existing legislation and to categorize existing laws and regulations to then determine best practices, gaps, barriers, obsolescence, loopholes, and other areas of opportunity to regulatory advances. With the results of the legal mapping, a model legislation and a manual of good practices are going to be developed and released to support the evaluation of strengths and maturity of legislation at the national level. A legal database to systematize and allow the ample consultation of the information collected is also being constructed by PAHO and will be released as soon as the information of the legal mapping is available.

Even though legislation and regulatory measures are important, this is not a silver bullet alone. Legislation should be implemented, evaluated, and reviewed, and civil society can be involved by monitoring the implementation and documenting the impact. Civil society can promote the periodic review of laws and regulatory frameworks. Legislation that is not implemented is just good will.

Strengthen legislation to protect the rights of people with epilepsy

In many parts of the Americas, people with epilepsy and their families suffer from stigmatization due to ignorance, misconceptions, and negative attitudes surrounding the disease. They often face serious difficulties in education, employment, marriage, driving regulations, and reproduction.

> **#149** "People with epilepsy and their families across all resource settings are subjected to stigmatization and discrimination as a result of the misconceptions and negative attitudes that surround epilepsy, including the belief that epilepsy is the result of evil spirits or that it is contagious."

> **#150** "Stigmatization leads to human rights violations and social exclusion. In some settings, children with epilepsy may not be allowed to attend school, while adults may not be able to find suitable employment or to marry."

Innovative strategies are needed to support policies and laws for people with epilepsy, improve public attitudes, and reduce stigma, while fully respecting the human rights of people living with epilepsy.

The protection and promotion of human rights is essential for people with epilepsy, particularly those with associated disabilities. Despite the progress made in the Region of the Americas, obstacles persist in many countries, such as limitations on access to health services, restrictions on personal freedom, lack of job opportunities, educational exclusion, and confinement in psychiatric institutions. Often, legal instruments are available, but they are not applied in practice.

Stigma testimonials from people with epilepsy

KATIA (EL SALVADOR)

“I was 16 years old when I started having seizures. They could not give me an accurate diagnosis. After almost a month of having three or four seizures a week they told us that I was ‘epileptic’. I felt fear, anger, guilt. It was difficult to accept, it was difficult to control. Even now, 25 years later, it is difficult to fight ignorance: I have lost jobs, I have been stigmatized even by doctors telling me not to get pregnant, that I should not pursue a career, as in my condition that was useless. Now, at 41 years old, I have two wonderful children and I am a psychologist. It is necessary to normalize epilepsy, to show that you can have a ‘normal’ life with proper control.”

PAOLA (MEXICO)

“I am the mother of two little ones with epilepsy, a neurological condition that came to me without warning, without suspicion, without imagining. It started when my daughter was 2 years old, and my baby was 4 months old. It was a very hard blow to assimilate, to see your children so tiny being subjected to studies, anesthesia for the MRI (not once, many times), finding the right neurologist, learning to observe any ‘abnormal’ movement, explaining it to people, at school, taking care of everything in detail. Despair and frustration to see them in a seizure: the pain is so great, truly each seizure feels like a stab to the soul. The lack of empathy and knowledge, the myths, mockery, and discrimination. It is a daily struggle with ignorance. That is why, day by day, I seek to raise awareness. I will not remain silent.”

CLAUDIA (PERU)

“My son has had epilepsy since he was 6 years old. It changed our life and we had to learn to live with it. At school we are often discriminated against because they think that having a condition must be visible, and in epilepsy, in some cases, it is not like that. The teachers do not know how to teach people with epilepsy. If they find out the diagnosis, they isolate them – it is easier for the teachers not to try to teach them with the excuse that they are ‘ill’. Many times, we have been told that it is witchcraft, that it is our fault, that we should ‘not do this, not do that’, even though they do not live with us and do not know what it is really like to live day to day, let alone what we as a family feel.”

FERNANDO (MEXICO)

“I am 53 and have lived with epilepsy for 27 years. They told me that I had the ‘grand mal disease’, that it was contagious. I have lost friends, had difficulty finding a girlfriend, and I have been discriminated against. They have given me remedies such as drinking deer blood, they have cleansed me, and no remedy has worked. Even specialist neurologist doctors do not know the origin of my seizures; they say it is of unknown cause. The only thing I have are controlled seizures, yet people say that I am possessed by the devil – in the twenty-first century.”

GEORGE (JAMAICA)

“My family was told to apply an old leather shoe to my nose and mouth to stop the seizure.”

CAROLINA (CHILE)

“I am a mother and caregiver of a little girl with refractory epilepsy, which has been a difficult path in every way. I left my job to be able to take care of her; her father left us because he did not accept her condition. It is a long but not impossible road – we always do our best so that she can make progress with her therapies and lead a relatively normal life. My daughter is a warrior. At only 2 years old, she has had to live a lot in hospitals, but always keeps her unwavering smile.”

DARMITA (UNITED STATES)

“One of my biggest challenges is adequate care and support from family and friends. Having a disability has been difficult to accept as it is. Since epilepsy is one of those ‘unseen’ disabilities, it is easy for people to dismiss your needs and the care that comes along with having epilepsy. Along with the challenges we face, there are also plenty of misconceptions associated with epilepsy. I’ve heard people refer to a seizure as ‘having a fit’, or saying seizures are not real, seizures are contagious, people can control their seizures, and epilepsy only affects children. None of these are true, and it is my priority to share accurate information about epilepsy and seizures.”

CAMILIA (CUBA)

“I started having seizures in 2005 which were caused by Rasmussen encephalitis. From the age of 7, I began to write and perform children’s stories with a puppet I built and named ‘Purpurina’. I am committed to talking about my own experience of living with epilepsy and cerebral palsy. My greatest wishes are to be free of seizures and to publish my stories and see them converted into plays for children!”

Legislation

advocacy in action

Colombian Law 1414, Protection for individuals suffering from epilepsy

The objectives of the legislation are:

- To enhance public education on epilepsy, thus decreasing fear and misconceptions about the disorder in Colombian society.
- To improve diagnosis and treatment of epilepsy by providing diagnostic facilities and modern anti-seizure medication.
- To eliminate discrimination and to improve access to education and employment for people with epilepsy, thus addressing the above-mentioned difficulties.

Canada's Policy/Program memorandum 161

Policy/Program memorandum 161 was initiated by civil society, parents, healthcare providers, labor unions, school board personnel, and government officials to support school-age children with prevalent medication conditions like asthma, diabetes, anaphylaxis, and epilepsy. This policy supports 15 000 students with epilepsy in Ontario, Canada, allowing them to fully access school in a safe, accepting, and healthy learning environment. The policy was developed to empower students, as confident and capable learners, to reach their full potential for self-management of their medical condition(s), according to their Plan of Care.

A Plan of Care contains personalized information and preventive strategies for each student with epilepsy. It includes a training plan for school staff and school board personnel. The Plan of Care is co-created, reviewed, and updated by the parent(s) in consultation with the principal and designated staff and the student (as appropriate), during the first 30 school days of every school year and, as appropriate, during the school year.

Policy/Program memorandum 161 is an example of advocacy in action. It was developed by an intersectoral team to enhance safety and to promote disclosure and inclusion, allowing students with epilepsy to participate fully in school.

Purple Day Act - The Government of Canada

The Government of Canada formally approved the Purple Day Act in June 2012, respecting a day to increase public awareness about epilepsy. The Act recognizes that throughout Canada in each and every year, the 26th day of March is to be known as "Purple Day." On 26 March, people are encouraged to wear the color purple to indicate their support for people with epilepsy and to increase public awareness of this disorder.

Cassidy Megan, founder of Purple Day for Epilepsy, is pictured here with Canadian Prime Minister Justin Trudeau (2012). Cassidy Megan was the recipient of the IBE/ILAE Social Accomplishment Award in 2023 to recognize her outstanding commitment to raising awareness about epilepsy globally.

Driving legislation needed in the Caribbean

In some countries of the English-speaking Caribbean, driving has not been permitted for people with epilepsy. English-speaking Caribbean laws created in the 1930s reflected medical and societal opinions and treatment capabilities of the time. Legal mapping exercises have shown that not much has changed legislatively since then, though better treatments are now available, so it may be appropriate to review and update these current regulations laws. The lack of provisions to allow people with epilepsy to drive after an adequate predetermined period of seizure control may constitute stigma enacted in law.

Islands separated by a few miles can have markedly different regulations. The French dependencies of Martinique and Guadeloupe follow a two-year restriction for private motorists. It may be shorter after physician evaluation. United Kingdom dependencies of the British Virgin Islands, Turks and Caicos Islands, and the Cayman Islands follow a one-year restriction. United States territories follow U.S. rules, typically a one-year restriction, and the Dutch-speaking Caribbean islands (including Sint Maarten, Aruba, and Bonaire) follow the Netherlands' one-year restriction. People in the Caribbean now rely heavily on driving their own cars for work and leisure. Updating the current punitive legislation would enable people with epilepsy to travel to work to earn a living and help reduce stigma and discrimination against them.

advocacy in action

SDG 8 – Decent work and economic growth

Protecting the rights of workers in Canada

A young woman from Canada was employed by a school board as an educational assistant. Her role was to provide support to a child who was in a wheelchair. She fully disclosed that she had epilepsy during the hiring process but was immediately fired after she had a 30 second focal seizure at her workplace. She met with staff at her local epilepsy agency and together they filed a legal motion to challenge her termination. She won the lawsuit, received back pay, restored her dignity, and returned to the same workplace. This was possible because there is human rights legislation in her country protecting the rights of workers.

Think about it

What type of legislation does your country have to protect people with epilepsy in the workplace? Are you able to identify other organizations that are working to ensure that people have the legal right to a safe workplace?

MODULE 2:

Planning your advocacy

Learning objectives

1. Identify the root cause of the problem.
2. Identify steps for developing an advocacy plan.
3. Access templates to help with your planning.
4. Identify ways to monitor and evaluate your plan.

There are many actions that can be taken to advocate for change, so deciding which ones to prioritize can be tricky. Should you focus on educating healthcare providers on epilepsy symptoms and medications? Should you advocate for government funding to support programs for persons with epilepsy? Should you engage with communities to reduce the stigma around epilepsy? All of these have the potential to have a real impact on people's lives, but which ones are best positioned for civil society? What external and internal factors will influence the success or failure of your efforts?

This section will walk you through the steps needed to develop your ideas and plan your advocacy. We will look at how to understand the root of the problem and identify external and internal factors that will influence your plan. Once you have a clear picture of the situation, you will be ready to identify the goals, objectives, key messages, primary audience, key performance indicators, activities, and resources required to launch your work. Then we will look at developing a results framework and ways to identify and manage risks. You will learn how to develop and implement an effective monitoring and evaluation framework to measure the impact and track progress of your advocacy intervention.

PART I: Assessing the situation

What is the problem you are trying to solve?

It is hard to plan the best route, know when you have reached your destination, or when you might have taken a wrong turn, if you do not have a specific address.

The first thing you need to do is identify the problem you are trying to solve. WHO has specific IGAP targets related to reducing stigma and removing discriminatory legislation, closing the treatment gap, improved treatment and care, prevention, and brain health promotion. Those global targets still leave significant space for Member States (national governments) and advocacy organizations to identify the most important, relevant, and feasible reforms in their local and/or national context. For example, you have noticed that many persons with epilepsy in your community are not getting the medications they need and believe that barrier to be the greatest short-term challenge facing the epilepsy community in your region. But how can you make a practical difference in a reasonable amount of time? It is a big problem with many different causes and possible solutions. Below, we walk through ways to develop a practical plan for tackling the issue you have decided will be at the heart of your advocacy work.

Think about the specific problem you want to focus on. Below are two planning tools: the "Five Whys" and a "Problem Tree." These tools can help you to dig deeper and understand why the problem you are trying to solve exists. You can use either or both, but it is useful to include your whole team in answering these questions so you can benefit from different perspectives.[1]

Baseline data – where are we now?

What if you are not sure "Why?" there are challenges with epilepsy in a community? Go to the source. Sometimes, conducting surveys of persons with epilepsy, healthcare providers, and/or the local community members can help you to explain "Why" communities and families need help. Conducting one-on-one key informant interviews with those same persons with epilepsy and local healthcare providers, as well as larger focus group discussions with 6–12 people, can help you and your organization identify the problems and priorities in your community. This can also provide you with baseline data – information about your target population at the start of the program. Baseline data might be on how many people are currently receiving care at a clinic, or how many people report that they trust the local hospital to treat them. Once you have completed your advocacy, you can conduct this survey again, the results of which can give you concrete figures as to whether your work has made a difference. Conducting this baseline mapping and monitoring and evaluation exercise is very useful for future advocacy, organizational learning, and even fundraising, so that you can show potential donors the impact you were able to achieve. **Collecting baseline data can also help you to understand the situation from different perspectives and generate information that is useful for project planning.**

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[1] See Annex 3 for more information on how to organize a successful advocacy planning workshop with your team or additional stakeholders.

The “Five Whys”

We have identified the problem, but why does it exist? The next step is to examine the causes of the problem. The “Five Whys” exercise simply asks the question “Why?” to help drill down to the root cause of an issue. It helps you to define your specific advocacy objectives.

With the “Five Whys,” you simply state the problem you have identified and then ask, “Why?”. You can do this five or more times – however many you need to get to the point of identifying true root causes.

- Persons with epilepsy are not getting the medications they need. **Why?**
- Because local clinics do not have the medications needed. **Why?**
- Because healthcare facilities do not see many persons with epilepsy and therefore do not see the need to stock the drugs. **Why?**
- Because persons with epilepsy often do not visit local health clinics. **Why?**
- Because they do not know what to say at the clinic. **Why?**
- Because of a lack of knowledge about epilepsy among individuals with epilepsy and their families, in local communities, so they are unaware that epilepsy is treatable. **Why?**

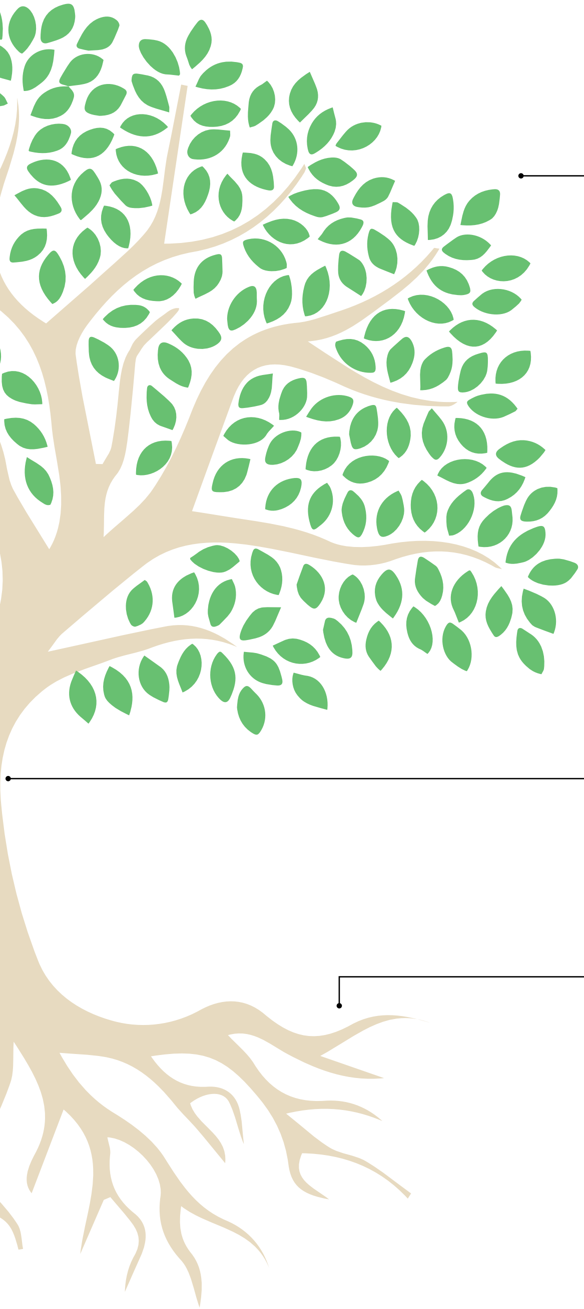
Addressing the lack of medical care is a huge issue. But planning a targeted advocacy campaign to educate healthcare providers and local communities to reduce the stigma around epilepsy may be a more realistic first step.

If you look at the above example, you can see how a lack of availability of medications is not just about the drugs supply. The deeper you go, the clearer your advocacy objectives will become.

As advocates and civil society, you can determine which of these “because” statements are indeed the biggest problem in your context. In the next section, we will look at how to determine where you can have the greatest impact to bring about real change.

Problem tree

A problem tree is a visualization of the main problem and its causes and effects. This tool allows you to see the problem more clearly, to break it down into more manageable chunks, and to prioritize your advocacy targets and clarify objectives. The real benefit of the problem tree is the discussion and debate that it helps to facilitate with you and your colleagues about the "root" causes of the problem and the consequences, or the branches, of that problem.



EFFECTS

- Healthcare facilities do not have the medications they need
- Healthcare facilities do not see many persons with epilepsy and therefore do not see the need to stock the drugs
- Not many persons with epilepsy visit healthcare clinics
- Healthcare providers do not always have sufficient training to diagnose or treat epilepsy
- Persons with epilepsy visit traditional healers first
- Persons with epilepsy face discrimination and human rights violations

MAIN PROBLEM

Persons with epilepsy in your community are not getting the treatment and medications they need

ROOT CAUSES

- Fear of discrimination or distrust discourages persons with epilepsy from visiting healthcare facilities
- Persons with epilepsy, their families, local communities, traditional healers, and healthcare providers lack knowledge about the condition
- Already weak healthcare systems do not prioritize prevention and treatment
- Significant stigma is attached to persons with epilepsy (belief in witchcraft or the supernatural as causes)

It is important to remember that the words or phrases you start with in the middle are not so important, as the rest of the tree will help you to define that problem. Once you have your picture, you can stand back and ask yourself "is this accurate?," "what do we see as the main causes?," and "what effects do we want to have the most influence on?"

Analyzing the situation: Political, Economic, Social, Technological, Legal, Environmental (PESTLE)

So, you have an idea of what you want to do, but what about external factors that may be out of your control? Which factors could you harness for your purpose? Looking at the big picture will help you to plan practical and achievable results.

P

POLITICAL

What is the current political situation in the community? Are there conflicts? What role does the local government play in health care? Where is epilepsy care provided?

E

ECONOMIC

What does epilepsy care and treatment cost? Is it affordable? What is the local and national budget for health care, specifically epilepsy care?

S

SOCIAL

What are local perceptions of persons with epilepsy? What role do elected officials and/or religious leaders play?

T

TECHNOLOGICAL

Do most people in your community use technology such as cell phones, radios, or computers? Can they access social media and websites?

L

LEGAL

What are the legal frameworks that influence persons with epilepsy? What are the key laws, practices, or rules that affect their lives? Which do you need to be aware of when planning events, programs, and advocacy?

E

ENVIRONMENTAL

How will the weather impact your advocacy planning?

A note on pre-disaster planning: learnings from the COVID-19 pandemic

The circumstances around COVID-19 highlighted the problem with the lack of pre-disaster planning in many places. Movement restrictions – and therefore access to medication – can be a challenge for many persons with epilepsy in such cases. As a result, for many the focus was shifted to seizure care and awareness. During times of crisis such as a natural disaster, conflict, or a pandemic, funding and resources are often cut off or diverted to the emergency. What this demonstrates is the urgent need for pre-disaster planning and emergency response procedures, like the ones that exist for other conditions such as ensuring the provision of dialysis. Regardless of the disaster – whether flood, pandemic, political unrest, or drought – advocating for inclusion of the provision of care for people with epilepsy in disaster risk reduction strategies is key. Does your local community have such a plan? What about at the district or national level?

Below is an example of what a PESTLE analysis might look like. Sitting around a whiteboard, or even a piece of paper with colleagues, and jotting these thoughts down can help to identify important factors for your planning.

P

POLITICAL

- ☐ Elections scheduled for May
- ☐ Current city government has been active in national Sustainable Development Goal discussions
- ☐ Current healthcare system is underperforming and drug delivery is lacking

E

ECONOMIC

- ☐ Local community lacks job opportunities
- ☐ Recent economic downturn means less funding for healthcare programs
- ☐ National government is considering expanding healthcare budget

S

SOCIAL

- ☐ Strong stigma around epilepsy
- ☐ Primary care for majority of the community
- ☐ Famous actor/actress recently announced they are living with epilepsy

T

TECHNOLOGICAL

- ☐ Most of the local community does not have access to the Internet
- ☐ Mobile phones are prevalent and a useful tool for reaching large numbers of people

L

LEGAL

- ☐ There is no adequate legal protection for the rights of persons with epilepsy
- ☐ It is not recognized as a public health concern
- ☐ National government has publicly committed to IGAP and UN SDG 3

E

ENVIRONMENTAL

- ☐ Rainy season has been worse than usual, making many roads impassible
- ☐ Lack of pre-disaster planning for access to medication during natural disasters and pandemics, such as COVID-19

For those interested in a different tool that provides similar insights, be sure to try out a “SWOT analysis” (assessing your organization’s strengths and weaknesses as well as external opportunities and threats). SWOT is a widely used strategy tool borrowed from the business management community; templates and guidance for how to use SWOT are easily findable with a quick Internet search.

PART II: Defining a goal and objectives

Now that we have looked at the problem and the big picture, we are in a better position to identify a goal. A **goal** is a general statement of the change you seek to affect in the world (or in your community!).

As an example, we will look at the problem of availability of epilepsy medication and treatment.

So, your goal will be:

Persons with epilepsy in our community will have better access to treatment and medications.

Objectives then tell us what we need to do to achieve that goal. Since your goal is better access to treatment and medications, your objectives should define specific tactics to achieve this goal.

We have already looked at some of the problems that contribute to your goal in the “Five Whys” and Problem Tree exercises. Turning these problems around into solutions can help us see what your objectives might be. For example, some of the key factors that lead to lack of access and treatment are:

- Lack of training by healthcare providers in hospitals and clinics – increase training for healthcare providers in hospitals and clinics.
- A large stigma around persons with epilepsy due to a lack of understanding – change knowledge and attitudes around persons with epilepsy.
- Children with epilepsy are not being included in school activities.

Let’s be SMART about the objectives we identify!

SMART objectives

Once you have a general idea of what you want to do, it is important to make sure your objectives are SMART:

S	M	A	R	T
SPECIFIC	**MEASURABLE**	**ATTAINABLE**	**RELEVANT**	**TIME-BOUND**
What is your target population? A town? A hospital? Women aged 19–30?	How will you know when you have achieved the objective? Can you track progress?	Will you be able to achieve this objective? Is it realistic?	Does it respond to the greatest needs of the community?	When will you achieve this objective?

Your objectives are going to help you make decisions about which activities to undertake, with whom to work, and how to get the job done. Getting them right is important. In general, having two to four objectives will help to keep your advocacy program manageable. It is also a good idea to use action words, such as to develop, to create, to promote, to establish. Remember, we are not listing activities or outputs (i.e., a report was written, a workshop was held); we are instead identifying the social change we want to see.

Your objectives for your goal of ensuring that “persons with epilepsy in our community will have better access to treatment and medications” might be:

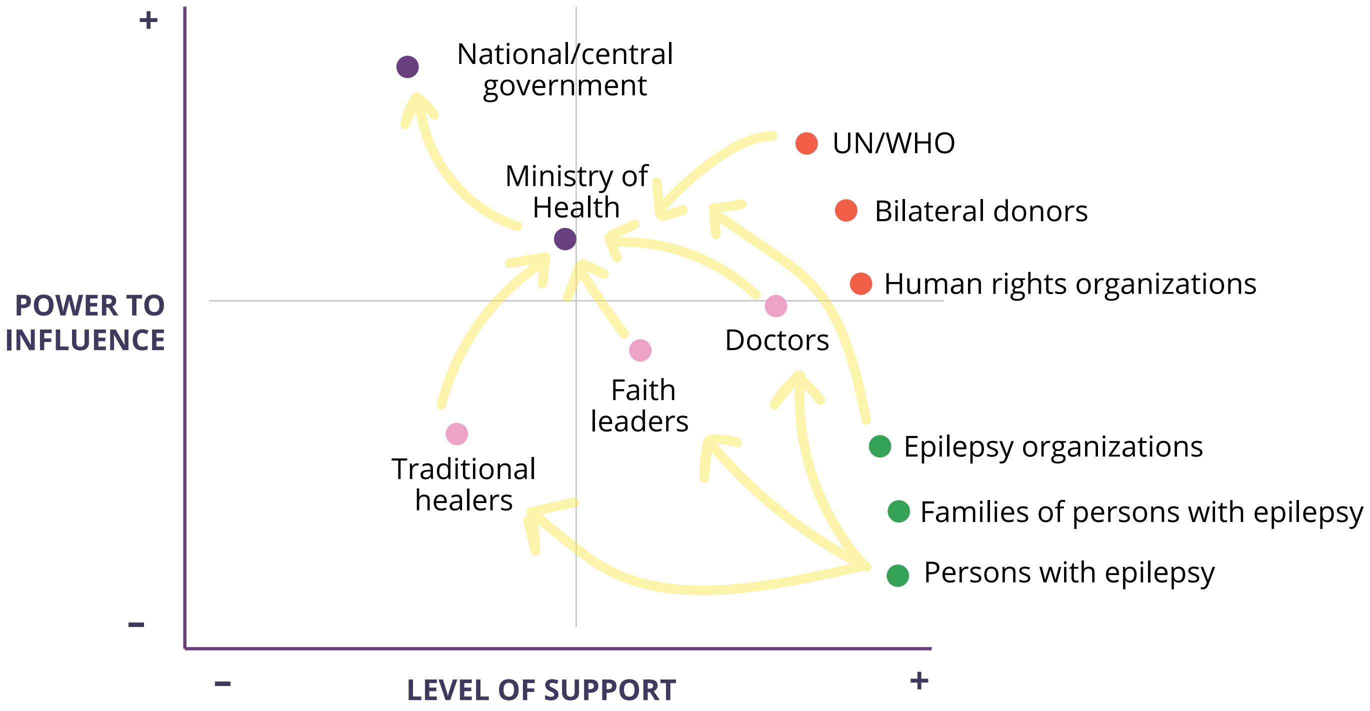
1. **To promote greater public awareness** through the formation of a local volunteer group. The group will hold six public events to share information and advocate for the rights of persons living with epilepsy by the end of the second quarter.
2. **To shift local norms and attitudes** around persons with epilepsy by engaging 10 community leaders, such as elected officials, primary care providers, teachers, community leaders, in a series of three meetings and sharing the outcomes through various media outlets by the end of the year.

Conducting a stakeholder analysis: who are you going to work with … and work around?

Now that you have your objectives, it is important to determine who might best support you and who might hinder you. You may want to engage local policy-makers and elected officials, but what if they have no interest in working with you?

Generally, you have two types of stakeholders: decision-makers and influencers. Decision-makers can change a law, practice, allocate budget, or decide where public attention is focused. Influencers can help you reach the decision-makers and convince them to make the change you want to see. As an example, if you are trying to convince a reluctant hospital director to make a change (your target decision-maker), you might activate community activists and media (influencers) to generate pressure on the director to take action. While your advocacy work will likely have many stakeholders that you need to account for in your planning, not all are necessarily your target audiences. You may only need to directly engage with a few key stakeholders while still accounting for others, or design strategies where third-party influencers (rather than your organization) shape certain key stakeholders' behavior indirectly.

The chart below shows the level of support and power of each of your main stakeholders. With each of them, think about where they sit on the chart. A local Ministry of Health official might be powerful, but not supportive, whereas persons with epilepsy might be supportive but not powerful acting alone.



Looking at all your stakeholders on the chart, who can you work with to help build your power to reach those with greater levels of influence? If you bring together persons with epilepsy to hold a public event, sign a petition, or invite a government official to a public meeting, you will have more influence over that official than if you act alone.

When will we know we have succeeded?

As with any complex effort at social change, defining "success" is not always a simple process. In some cases, we know what we are trying to achieve and can somewhat easily track whether we have achieved our goals: a new law or regulation is passed, increased budget is made available to support our causes, or key officials are replaced or sanctioned for poor performance. But in many other cases, defining and tracking "success" can be more difficult and murkier. How exactly do we know when public attitudes or norms have shifted? When are we able to confidently say that officials truly "support" our cause? Or that "systems have been reformed"? There is often no easy answer.

One approach to reducing that uncertainty is to define key performance indicators (KPIs) to help track whether our advocacy efforts are working. KPIs are metrics that directly or indirectly link to advocacy goals and tell us that we are likely making progress. Ideally, the KPIs should follow the SMART methodology of being specific, measurable, attainable, relevant, and time-bound, just as our objectives do.

S	M	A	R	T
SPECIFIC	**MEASURABLE**	**ACHIEVABLE**	**RELEVANT**	**TIME-BOUND**
Have you targeted a specific area for improvement?	How will you know you have succeeded?	Can the goal be accomplished? Is it realistic?	Does this seem worthwhile? Is this the right time? Does this match our other efforts/needs?	When will the result be achieved? (your action may have a scope of anywhere from weeks to years).

Using the example of improved access to medicines, a KPI for your advocacy work in a region could be defined by the following SMART characteristics:

Specific: Medication stockouts are reduced by 20% at local primary health care facilities.

Measurable: Working in cooperation with the regional health department, we will conduct inexpensive monthly surveys of select clinics to assess current drug stock levels.

Achievable: We know this is possible based on recent engagement with public health officials in the region if we help them better manage their drug procurement processes.

Relevant: Persons with epilepsy tell us that improved drug stocks would significantly improve their care.

Time-bound: We are setting our goal to achieve our reduction in drug stockout rates in the next six months.

PART III: Bringing it all together into an advocacy plan

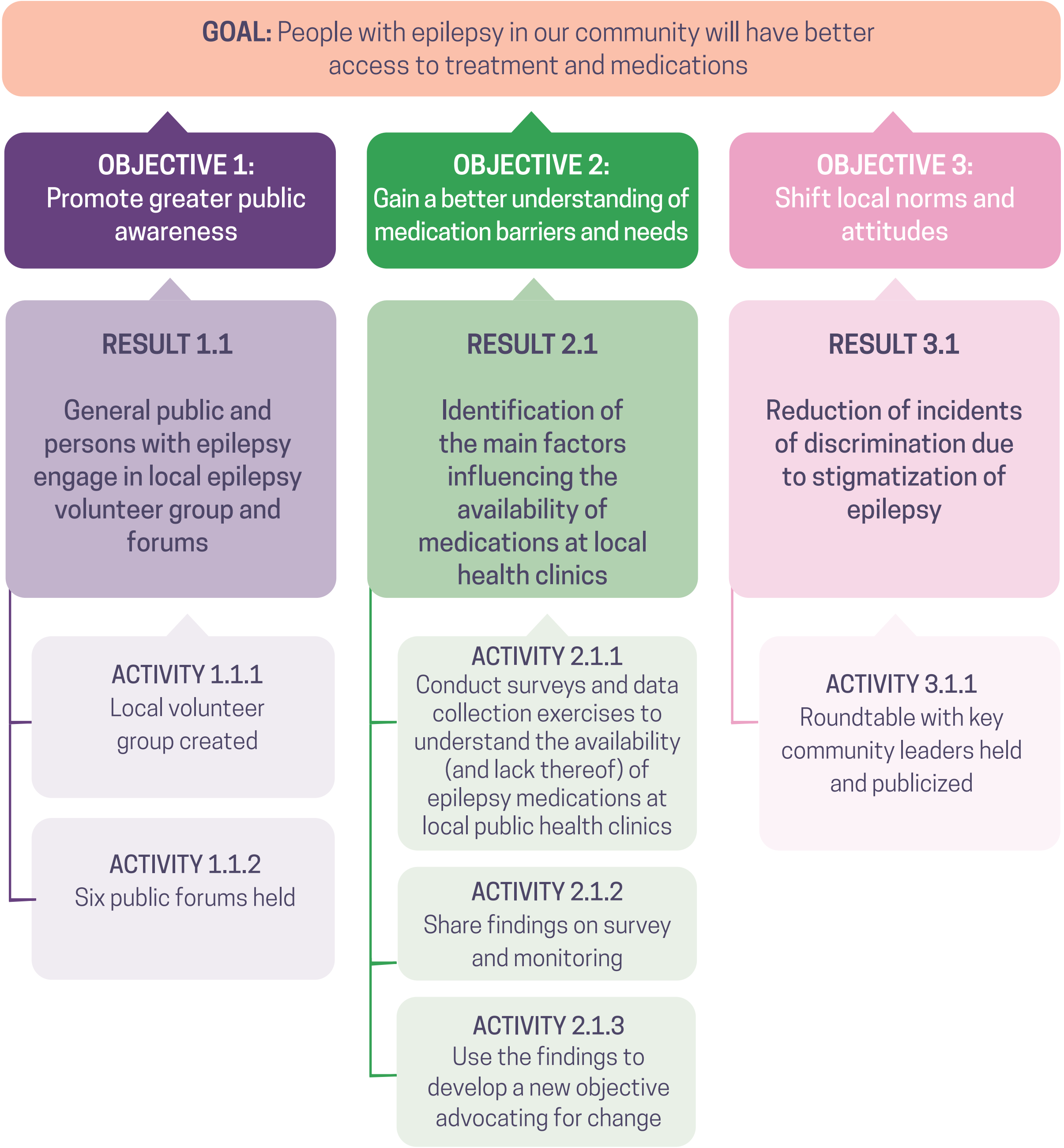
We have defined our goal, set our objectives, and identified our key stakeholders and our KPIs. We can now fill in the table below and begin to finalize our advocacy plan.

GOAL:	Persons with epilepsy in our community will have better access to treatment and medications		
OBJECTIVES	1) Promote greater public awareness of the treatment gap.	2) Improve availability of epilepsy medication.	3) Shift local norms and attitudes about the need for persons with epilepsy to be treated at public health clinics and as persons with rights to be treated equally.
ACTIVITY (OUTPUT)	Local volunteer group created and held six public forums (one/month).	Conduct surveys and data collection exercises to understand the availability (and lack thereof) of epilepsy medications at local public health clinics.	Community leaders' roundtable series.
KEY STAKEHOLDERS	General public, persons with epilepsy, and famous/high-level guest speakers.	Persons with epilepsy, hospitals and healthcare providers, pharmaceutical companies, Ministry of Health.	10 community representative members: traditional healers, community leaders, local government officials.
RESOURCES NEEDED	Volunteer organizer staff, information and advocacy materials for volunteers to share, location to hold events, food and beverages for events.	Survey questionnaire, staff to conduct the survey, staff to analyze data and write report on findings.	Location to hold roundtable, staff to engage and recruit community members and to organize and facilitate training, food and beverages for events.
KEY PERFORMANCE INDICATORS	Reported cases of discrimination due to the stigma of epilepsy reduced by 25% in the local community by year 2.	Identification of the main factors influencing the availability of medications at local health clinics.	Number of articles published in local media on outcomes of roundtable and number of social media posts about roundtable. 15% increase in number of people diagnosed and treated at local health clinics in 12 months following training.

Results framework

Once your plan is in a simple-to-review format, it is useful to take a step back and assess whether you are happy with it, feel it will contribute to achieving your goal, and feel it is realistic and achievable. It is also important to list the resources that you will need to execute your plan, as this can help you to measure available resources against plans and help inform your fundraising goals as well.

It is also helpful to look at your plan in a results framework. This can show us the connection between the goals, objectives, results, and activities. The model below is simple, but you can have more or fewer results and activities under each objective.



GOAL: People with epilepsy in our community will have better access to treatment and medications

OBJECTIVE 1: Promote greater public awareness

RESULT 1.1
General public and persons with epilepsy engage in local epilepsy volunteer group and forums

ACTIVITY 1.1.1
Local volunteer group created

ACTIVITY 1.1.2
Six public forums held

OBJECTIVE 2: Gain a better understanding of medication barriers and needs

RESULT 2.1
Identification of the main factors influencing the availability of medications at local health clinics

ACTIVITY 2.1.1
Conduct surveys and data collection exercises to understand the availability (and lack thereof) of epilepsy medications at local public health clinics

ACTIVITY 2.1.2
Share findings on survey and monitoring

ACTIVITY 2.1.3
Use the findings to develop a new objective advocating for change

OBJECTIVE 3: Shift local norms and attitudes

RESULT 3.1
Reduction of incidents of discrimination due to stigmatization of epilepsy

ACTIVITY 3.1.1
Roundtable with key community leaders held and publicized

How can you manage risks?

When working in any situation, there is always the risk you do not succeed. In some situations there can be very real material risks at play, including political risks, financial risks, or reputational risks. As a final step in your advocacy planning, brainstorm all the risks that you can imagine. We will put these in the left-hand column. Moving through each risk, note the level of the risk and the likelihood that it will happen, and then think about what you can do to mitigate these risks. The most important risks to focus on are the high impact, high likelihood risks.

Risk	Impact level	Likelihood	Mitigation
Local leaders refuse to participate in program	High	Low	Seek advice and lean on people in your network that are perceived favorably by local leaders to have a discussion about their views on what is needed before presenting any plans
Local elections will be held during the program timeline and local officials will not want to engage in any discussions	Medium	Medium	Flexible dates and plans will allow you to shift the project timeline or include activities, like election pledges, into program tactics
Persons with epilepsy will remain distrustful of hospitals and clinics	Medium	High	Create an open forum to discuss the problems and issues that persons with epilepsy face and ensure their role in planning the program. Include ongoing engagement between medical staff and persons with epilepsy.

Monitoring & evaluation framework (M&E)

The M&E framework aims to support advocacy organizations in planning, implementing, and evaluating their epilepsy advocacy efforts. It provides guidance on:

1. Defining goals and objectives
2. Selecting key indicators
3. Developing an M&E plan
4. Collecting and analyzing data
5. Reporting findings and lessons learned

1. Potential goal areas could include:

- Adopting the IGAP at the country level
- Improving health policies, budgets, and access to medicines
- Reducing stigma and ensuring rights

2. Selecting key indicators

Process indicators: Activities completed; people reached.

Output indicators:

- Policies enacted; budgets changed (number of countries adopting epilepsy policies)
- Legislation passed (number of countries updating rights-based epilepsy laws)
- Awareness campaigns conducted (number of media articles, social media reach)
- Health workers trained (number of workers completing WHO mhGAP module)

Outcome indicators:

- Change in epilepsy treatment gap
- Change in knowledge, attitudes, and practices
- Quality of health services and care coordination
- Service coverage and access to medicines

3. Developing an M&E plan

The plan specifies timing and methods for gathering data on indicators from sources like surveys, reports, focus groups. It assigns roles and resources to systematically track progress.

4. Collecting and analyzing data

Rigorously gather and analyze quantitative and qualitative data to objectively track progress and document experience.

5. Reporting findings and lessons learned

Reporting allows assessment of progress against objectives, while capturing lessons for improvement. Share internally and with partners, donors, and stakeholders.

An M&E framework is integral for successful advocacy efforts, providing a model to systematically plan, track, report on, and learn from initiatives to improve epilepsy care. Adjusting approaches based on empirical data and stakeholder perspectives will lead to better outcomes over time.

SDG 4 –
Quality education

advocacy in action

Promoting epilepsy education and seizure safe schools in the United States

Issue: General awareness-building and ensuring access to care, support, and safety for students and others with epilepsy.

Action: The Epilepsy Foundation and other epilepsy organizations have launched a nationwide initiative to pass Seizure Safe Schools legislation in the entire United States. The model bill has five key components: requiring school personnel to complete a seizure recognition and first-aid response training; mandating that the Seizure Action Plan is made part of the student's file and made available for school personnel and volunteers responsible for the student; ensuring that any FDA-approved medication prescribed by the treating physician is administered to the student living with epilepsy in the school setting; educating and training students about epilepsy and first-aid response; and a Good Samaritan clause. The number and structure of these components varies state-by-state.

Results: A bipartisan Congressional Epilepsy Caucus was launched in the U.S. House of Representatives in February 2023. Efforts to grow the House Caucus and get a complementary caucus launched in the U.S. Senate continue. Funding is included in the annual federal spending bill for the U.S. Centers for Disease Control and Prevention (CDC) to address the public health challenge of epilepsy. As of November 2023, nearly half of all states and the District of Columbia have passed some form of Seizure Safe Schools law or resolution. Most of this requires that school personnel, including school nurses, complete training on how to recognize seizures in students and to respond with appropriate seizure first aid. There are ongoing efforts to pass similar legislation in the remaining states.

SDG 4 – Quality education (continued)

advocacy in action

Fostering epilepsy education for high school students in Uruguay

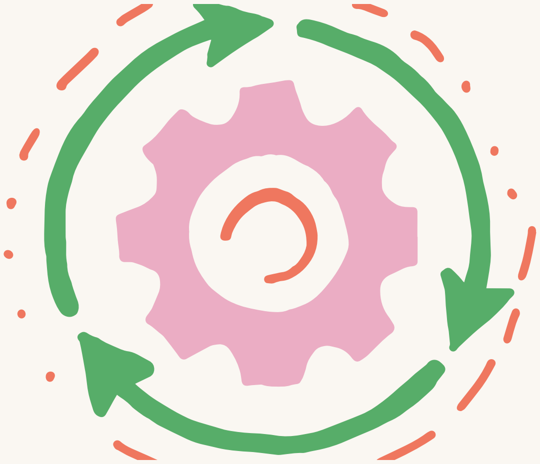
Issue: Public knowledge around epilepsy and seizure first aid remains poor, particularly in rural and remote areas. Schools represent an underleveraged entry point to promote epilepsy literacy, dispel myths and misconceptions, and counteract stigma and discrimination from an early age.

Action: Students of the degree in Clinical Neurophysiology (Technical EEG) of the University of the Republic (UDELAR), with the support of the Uruguayan League Against Epilepsy (LUCE) and the Uruguayan Association Against Epilepsy (AUCLE), carried out an educational extension project for 2nd and 3rd-year students in high schools in the interior of Uruguay. Interactive workshops with audiovisual material were held to provide basic information on epilepsy and proper management during seizures. The first experience was carried out in the high schools of Ombúes de Lavalle in the department of Colonia, "José Luis Invernazzi" in the city of Piriápolis, department of Maldonado, and "Eduardo Fabini" in the city of Minas, department of Lavalleja. Some 105 students participated and reported their own experiences and knowledge about epilepsy. Myths and erroneous beliefs in this regard were discussed, as well as risk factors including sleep deprivation, alcohol, and drug use.

Templates

Annex 2 of this toolkit includes the following templates to help you to work through different scenarios to plan your advocacy:

- Identifying care pathways
- Identifying content for an epilepsy awareness campaign
- Reaching your target audience
- Planning a stigma reduction intervention
    - » The Five Whys: getting to the root of the problem
    - » Problem tree
    - » PESTLE assessment
    - » Stakeholder assessment
    - » Advocacy plan
    - » Results framework
    - » Risk assessment



MODULE 3:

Taking action

Learning objectives

1. Identify different types of advocacy actions.
2. Identify ways to work with the media.
3. Understand the importance of relationship-building.

Once you have established your advocacy goal, objectives, and key stakeholders, you will want to look at the specific activities you will undertake. There are many ways to work toward change. The following is a collection of ideas that you may be familiar with, and if not, will hopefully bring inspiration.

Types of advocacy actions:

Awareness-raising

Awareness-raising is all about getting your audience to see and understand the problem, a potential solution, and their role in both. Healthcare providers at your local hospital might tell you that your effort to establish a training program with them is not needed because they do not currently serve very many people with epilepsy. However, you might know for a fact that there are many persons with epilepsy in your community who, for various reasons, do not seek medical attention at this hospital. What can you do to make your healthcare providers aware of their community's needs? Any activity that helps to share your key messages, start new discussions within your community, or educate key stakeholders is "awareness-raising."

Mobilizing

Mobilizing involves bringing groups of people together to amplify their voices around a common message or to create a public request for reform. This could include a "walk for epilepsy," an epilepsy awareness day, a public petition for greater government funding for advocacy awareness programs, or recruiting volunteers to hand out informational flyers.

Campaigning

A campaign is a focused advocacy plan that speaks to a larger group of people, generally the public at large, and seeks to engage them in sending a message to a specific stakeholder or achieving a specific goal. Campaigns often have several activities happening at the same time. For example, organizing persons with epilepsy, the public, and educators to write letters to local government officials to ensure education rights are protected.

Campaigning often includes a communication aspect such as posters, flyers, stickers, headbands, bracelets, short videos, or a collection of online stories. It can make use of social media. It can be a video challenge asking people to post their videos on your social media page or website, take pictures of themselves doing a dance, or repeating your key messages.

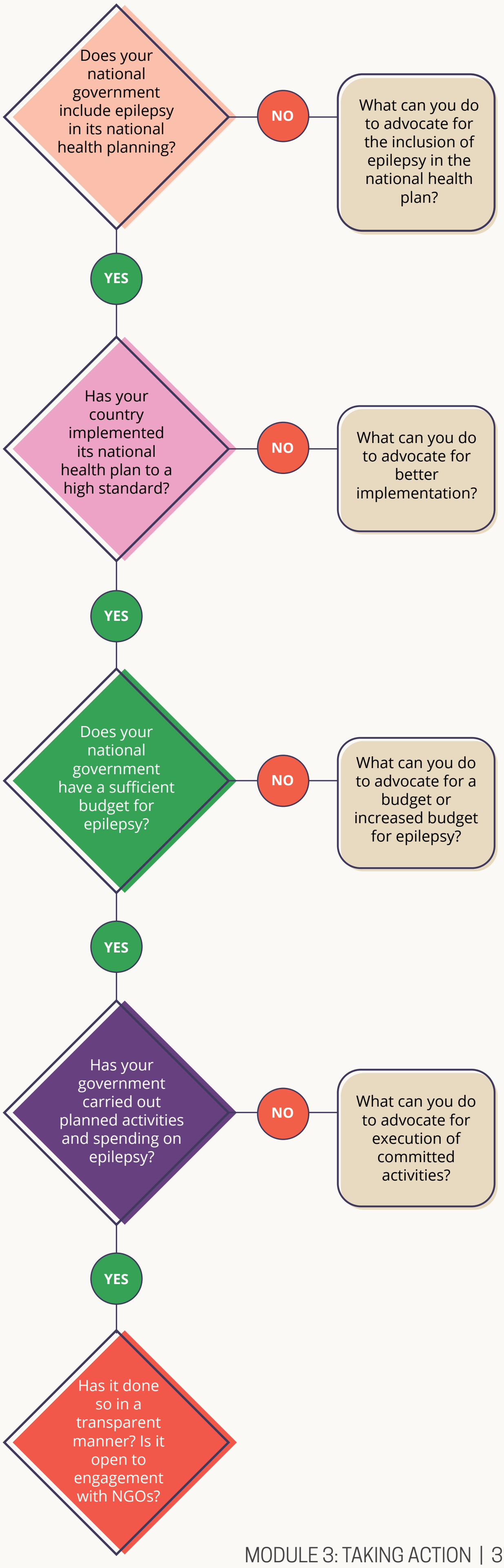
Public monitoring and social accountability

Monitoring is a great way to gain leverage over your stakeholders, as it looks at formal or public commitments they have made or ensures that promises or commitments are being fulfilled. You can do this by asking people to call a hotline when they are turned away from health services, jobs, or schools. Registering the issues that are reported helps you to prioritize your advocacy efforts. You can also interview people leaving a hospital and ask them questions such as: was their service affordable, what kind of treatment did they receive, and were they able to obtain medication? You can share concerns with hospital administrators and work with them to implement a health equity plan of action. You can then take these results to the hospital administration, the local government, or at the national level to help you advocate for greater access to health care for persons with epilepsy.

Monitoring can also take the form of a report, which compares commitments to actual progress. Your government has committed to taking coordinated action under the World Health Assembly resolution on IGAP. What have they done to make epilepsy a priority and implement IGAP? Are there publicly available national strategies for achieving progress against those IGAP international commitments that you can track and monitor? How many IGAP targets has it implemented and what percentage are complete? Are they on target or behind? Sharing this information publicly and calling on governments to act – while at the same time bringing stakeholders together to suggest solutions and offer their help in taking coordinated action – highlights the problem and provides approaches to reduce the treatment gap.

Advocacy action flow chart ▶

Unsure of where to focus your advocacy efforts? Working through this flow chart can help you determine where your policy advocacy actions can have the most impact. These questions are just a start. Even when we achieve policy goals, there are always others to work on. Our advocacy must continue until all the needs of persons with epilepsy are being met.



Does your national government include epilepsy in its national health planning?

What can you do to advocate for the inclusion of epilepsy in the national health plan?

Has your country implemented its national health plan to a high standard?

What can you do to advocate for better implementation?

Does your national government have a sufficient budget for epilepsy?

What can you do to advocate for a budget or increased budget for epilepsy?

Has your government carried out planned activities and spending on epilepsy?

What can you do to advocate for execution of committed activities?

Has it done so in a transparent manner? Is it open to engagement with NGOs?

advocacy in action

In Colombia

Carolina, who has lived with epilepsy since childhood, has experienced stigma in her family, in school, and at the workplace. Accepting epilepsy as a reality, Carolina chose to embrace her epilepsy diagnosis as a "lifestyle." She was able to successfully complete her studies and now works as a specialized lawyer in Colombia. To confront the prevalent myths and stigma she has encountered over the past 40 years, Carolina decided to form an educational foundation for people with epilepsy and disability in support of the persons and families who live with the diagnosis: "Education is the most powerful tool that human beings have to get ahead, so today I want to tell parents and people with epilepsy that it is possible to live with epilepsy and get ahead."

In Trinidad and Tobago

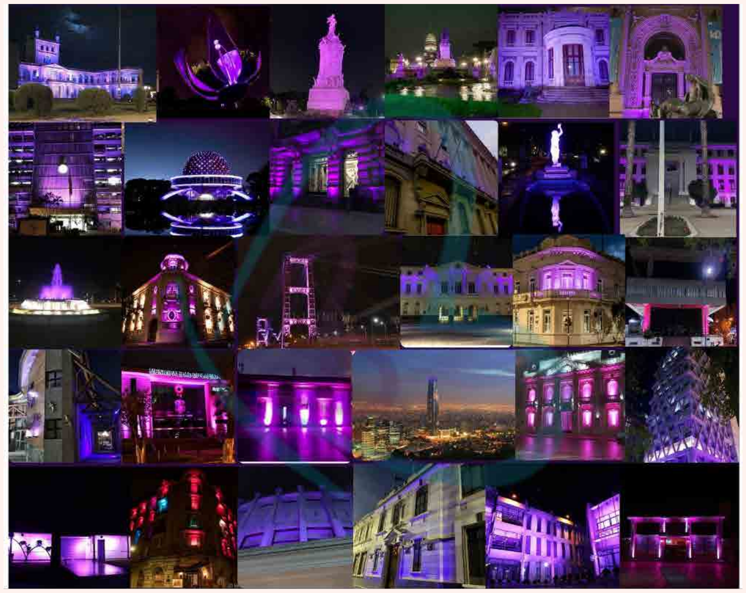
Nichole is President and Founder of the Seizure Awareness Foundation of Trinidad and Tobago (SAFTT). Her journey with epilepsy began in 2006 when her then 6-year-old son Ezekiel had his first seizure while sleeping. At that time there was little information available publicly. No one was talking about epilepsy, so Nichole resolved to do something to help break that silence.

In 2014, she and a few like-minded colleagues formed SAFTT, a non-profit organization established to educate, empower, encourage, and advocate on behalf of persons living with epilepsy and to raise awareness of the disorder through their "Seizure Smart" lecture tours and through public outreach, an annual conference, and by using social media.

SAFTT has collaborated with the Ministry of Education and has been afforded the opportunity to take the Seizure Smart lecture tour to 15 schools where there are students or staff members affected by epilepsy. They have also done lectures in churches and organizations and successfully hosted Seizure Awareness conferences in 2018, 2019, and 2022. They also conducted their first Epilepsy Symposium for care providers and persons living with epilepsy in 2019.

Nichole and her team of medical consultants, both local and abroad at SAFTT, are committed to creating Seizure Smart schools, organizations, communities and a Seizure Smart Trinidad and Tobago.

In Argentina



Starting in 2020, during the pandemic, the Hemispherectomy Foundation (Fund Hemi), and other epilepsy patient organizations in Latin America, decided to join **Purple Day** to bring epilepsy out of the shadows. Every year on 26 March, epilepsy stakeholders, advocates, healthcare professionals, and committed decision-makers wear purple clothing and illuminate public spaces in purple lights. At the same time, there are outreach activities, workshops and talks, and media coverage in print and on radio and TV. Using press releases adds significantly to this outreach because it gives facts and debunks myths. People with epilepsy and their family members and social networks wear purple as a sign of solidarity.

Purple Day gives individuals with epilepsy and their family a way to tell others that epilepsy affects them. It is an opportunity for people with epilepsy and their caregivers to meet with policy-makers in the government, with media, with alliances involving healthcare centres and schools. These meetings help to strengthen the capacity for individual advocacy and help to build networks. They also empower people with epilepsy to become advocates, spokespeople, and champions. All in all, it is a powerful day of visibility to debunk myths, show support, and spread the truth about epilepsy. It will help the entire community to make epilepsy a public health imperative.

In Chile

At the 19th Pan American and Parapan American Games held in Santiago, Chile, in 2023, the epilepsy chapters invited athletes from the Chilean Team to tape videos with people with epilepsy. Everyone donated their time, and the campaign ended with a family cycling event that gathered more than 1500 people who chanted together the campaign's motto: "Epilepsy Doesn't Stop You." This alliance around sports practice brought together outstanding athletes and epilepsy champions, generating press and media attention that multiplied the message. With conviction, effort, and low costs it is possible to organize educational activities that help reduce stigma and discrimination.

Engaging the media

Ideally, an advocacy effort's media strategy amplifies and supports the core advocacy goals rather than becoming an end in and of itself. In other words: media coverage should rarely be an explicit goal of an advocacy campaign, but media coverage can absolutely help achieve a campaign's core social change goals.

This toolkit will not seek to summarize the vast amount of "media strategy" resources available to advocacy organizations; instead it will highlight a few core principles that advocates should consider in designing their media strategies:

- **Media loves a human story.** Epilepsy is an issue that (sadly) tells a very human and often heart-breaking story. It is important to translate your complicated policy issues and advocacy "asks" into stories about the real-life impact on real people. Be careful, however, to work with media outlets to ensure they treat human stories with the respect and dignity they deserve.
- **Reporters and editors will often care more about their perceived priority issues and headlines, not yours.** In other words, you will need to make your epilepsy advocacy "fit" around what they feel is deserving of a headline. If epilepsy is not important to them, perhaps debates around universal health care in the country or access to education are. If so, how can you position epilepsy within that broader debate to grab the attention of reporters and editors?
- **Non-traditional media are gaining influence.** Today, the media landscape is changing rapidly; instead of a 1200-word piece in the newspaper, what might be more influential is a post to an influential social media group. By using techniques such as PESTLE to analyze which media are most important to the people you seek to influence, advocates may discover that non-traditional media are more important than the newspaper, television, and radio. This is increasingly true for younger actors in an ecosystem, who are often "born digital" and more likely to place importance on social and online media relative to traditional media.

FOCUS ON: Investing in relationship-building

Advocacy strategies often center on the idea that by finding ways to communicate compelling evidence, arguments, and data to decision-makers, we will be able to convince them to embrace policy changes rooted in that evidence. But not always. Research suggests that the messenger matters just as much, if not more, than the actual message (the information, stories, or research) that they present to decision-makers. So, while your research, data, and arguments need to be compelling and sound, do not forget that investing in relationship-building with your target audiences and stakeholders may matter just as much for eventual success. In the context of epilepsy advocacy, it is particularly important not to forget that persons with epilepsy themselves may often be the most powerful and persuasive advocates and messengers.

advocacy in action

The performance of your life (Chile)

Educational campaigns to reduce stigma in epilepsy have been targeted to health personnel and the community (families, teachers, students) as a fundamental way to increase awareness and knowledge about epilepsy. The Chilean League Against Epilepsy, an IBE chapter, was fortunate to collaborate with an advertising agency that developed and implemented an educational campaign using social media. More than 100 singers, actors, and influencers that were very recognizable by the public taped videos with educational messages about epilepsy including how to "act/perform" during a seizure. The campaign message was seen over 13 million times, reaching 68% of the people in Chile.

All contributions were free of charge and were posted on a website along with educational information. A closing live-streamed activity was hosted by a neurologist and a well-known actor who gave his testimony, reaching huge impact numbers on national and international media, including newspapers, radio, and TV. In 30 days, the campaign reached millions of views, obtained international awards, and turned into an example of a successful collaboration for education and community involvement.

advocacy in action

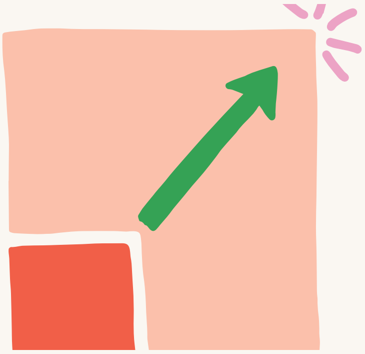
SDG 16 – Peace, justice, and strong institutions

Improving epilepsy knowledge in the Uruguayan police force

Issue: Police personnel, who operate in the community, are often the first contact for support in multiple health situations that require immediate assistance. However, awareness levels around epilepsy and seizure first aid remain low, which can compromise the safety of people with epilepsy.

Action: The Uruguayan League Against Epilepsy (LUCE) and the Uruguayan Association Against Epilepsy (AUCLE) targeted police students and officer students for an educational intervention to enhance epilepsy knowledge among community-level police officers. Conducted in collaboration with the National Institute of Police Education and the epilepsy section of the Faculty of Medicine, University of the Republic, the initiative involved two-hour classes, including videos and discussions, for 300 police cadets and 90 high school graduates in police officer training. Impact assessment comprised pre- and post-intervention evaluations using a brief multiple-choice questionnaire on epilepsy knowledge, practices, and attitudes.

Results: Assessments showed that after the education there was an enhanced understanding of seizure management and how a person may respond immediately after a seizure. The collaboration between institutions proved effective in reaching the target population, with participants exhibiting favorable attitudes toward people with epilepsy. The activity successfully improved practical knowledge about epilepsy, particularly relevant to their community-level duties.



MODULE 4:

Expanding your reach

Learning objectives

1. Preparing to work with national governments.
2. Understanding the budget process.
3. Working with regional and international organizations.

There are many organizations working on epilepsy across the globe, in particular the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE), and even more that advocate for improved health care. In some cases, partnering with organizations or networks that have a larger reach can help get your specific messages heard. Can you work together and incorporate your messaging into their communications? Sometimes this can be achieved through networking, building on connections, or simply doing some research and sharing concrete information, such as a report or advocacy materials, with possible partners to explore ways to integrate efforts.

What can you do together?

Partnerships can:

- Create national networks or engage in existing networks around health care or other broader agendas under which epilepsy fits, to raise your issue.
- Draft joint letters to decision-makers and share them with the media or on social media.
- Release a joint press statement around important dates or before important conferences or decisions are made.
- Collect signatures to support a specific request to the government.

There is also the added benefit of networking itself:

- Sharing information or best practices, increasing your connections, and learning from other experiences.
- Having a network of like-minded individuals passionate about health care can bring a sense of camaraderie and be a source of inspiration in what is often a difficult fight for change.
- Amplifying your voice through these partnerships will help you to have your issue heard on a wider stage.

advocacy in action

SDG 10 –
Reduced inequalities

Issue: Promote Health Equity by Improving Access to Seizure Detection Devices (United States)

Action: The Epilepsy Foundation of Minnesota advocated for Medicaid coverage of FDA-approved seizure detection devices.

Results: Enacted in May 2023, a new law allows individuals and families on Minnesota Medicaid to have seizure detection devices covered as durable medical equipment if they are medically appropriate based on the recipient’s medical condition and if they are identified by the recipient’s healthcare provider as likely to assist in reducing harm or death from seizures or provide necessary data for diagnosis or treatment. The new law will protect the well-being and safety of people with epilepsy, help reduce the risk of sudden unexpected death in epilepsy (SUDEP), and promote health equity as it helps protect the most vulnerable and low-income residents.

Working with national governments

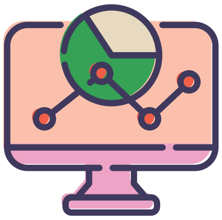
A key stakeholder and often a target of advocacy is the national government. It is important to assess who in various public sector bodies might be willing to support your cause, and who might be more of an adversary. The stakeholder analysis should help you with this.

An important strategy is to collaborate with decision-makers on developing practical plans for implementing the often general and high-level international commitments political leaders have made around epilepsy. By helping them do their jobs better – and in the process helping them generate positive reports to international bodies on their government's implementation of political commitments – you can build significant trust and social capital with these key actors. The same principles apply to engaging with opposition political parties that might someday be in power: the more you can offer them concrete solutions and proposals, the more they will trust you in the future.

A guide to the kind of commitments governments are likely to have – and what to do with them

Your national government likely has made public commitments around epilepsy, such as ratifying an international human rights convention, publicly supporting the World Health Assembly Resolution on IGAP, or committing to achieving universal health coverage under the SDGs.[2] These public goals can be a great way to leverage and build on existing work. While most of these commitments are legally non-binding, they do offer political leverage to advocates who can publicly question why their governments are failing to follow through on key reforms they publicly signed up to. This potential public embarrassment can help to spur action.

There are different ways to monitor commitments. The type of monitoring you choose will likely depend on how much of a priority the commitments already are for your government, how important it is politically for them to deliver on this commitment, and your current level of access to the government (as well as their willingness to engage with you).



Monitoring, put simply, is researching which international or national-level commitments[3] your government has made that will help to advance your agenda. The IGAP, of course, is one key commitment, but you can also look at the SDGs and other overarching public health commitments. The public commitments your government has made are more likely to draw attention of other peer governments, the international organizations that house and support the commitment, and the press.

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[2] See the section on "Working with (and through) international bodies" on page 48 for a more detailed look at these and other key actors on the international stage.

[3] This can be done on the local level as well if there are such commitments.

Sometimes these commitments have explicit milestones; for example, to do XX by 20XX. Looking at this information and then tracking your government's performance will allow you to plan advocacy activity, such as a public report that notes areas of progress as well as where the government is falling short of its commitments (e.g., the government has publicly committed to increase funding for medications and yet only one meeting has been held since the promise was made two years ago). You can also use social media to share your findings, or even create a website for the public to comment and report on their experiences or views of the commitments. Sharing monitoring reports or simply an eye-catching table with key stakeholders (such as active development partners in your country, key public figures that are supportive of your cause, and the media) can help to get your message out.

Lobbying is another way to have impact and influence local or national decision-making. In its simplest form, lobbying is when you have identified a small group of key decision-makers and you work to influence their actions (e.g., their votes, decisions, or policy statements) directly. For example, if you know the Ministry of Health is releasing its upcoming budget, and you have a contact who has helped you secure a meeting with someone relatively high up in the ministry, you might seek a meeting to explicitly pitch to the official on specific budget allocations supporting epilepsy priorities. This is slightly different from regular advocacy, as it is very focused on the person or group making key decisions at a specific point in time. Where you have the right kind of access, lobbying can be very effective.

FOCUS ON: The politics of government budgeting – how to get budget allocations to change

For advocates focused on public policy priorities such as epilepsy research and treatment, there is perhaps no more important “field of action” than national and local budgets. As budget advocates have observed for decades, budgets are where policy-makers and politicians reveal their true agendas and priorities regardless of campaign promises, speeches, and public pronouncements: https://internationalbudget.org/wp-content/uploads/2019_Report_EN.pdf

While effective epilepsy advocacy will naturally include “asks” around primary health systems strengthening, improved diagnostics, and more extensive access to treatment and medication, those asks will fall short in practice if they are not accompanied by increased resource allocations from government – both personnel and financial. As such, budget advocacy is an essential tool in the epilepsy advocate’s toolbox and a crucial tactic for matching increased political will for prioritizing epilepsy treatment and stigmatization efforts with the funds required to actualize those commitments. The International Budget Partnership, an international civil society network working to enhance the budget advocacy skills of organizations in dozens of countries, has a set of tools and resources that are highly recommended for advocates. Other resources worth reviewing include the sector-specific, specialized civil society advocacy networks that push for greater public spending in key human development sectors in low- and middle-income countries. In nutrition, Scaling Up Nutrition offers interesting and impactful approaches to pushing for greater government spending on the nutrition community’s key asks.

On universal health, you can check out: https://www.paho.org/en/topics/universal-health or https://www.uhc2030.org/what-we-do/voices/state-of-uhc-commitment/.

Working with (and through) regional and international bodies

Epilepsy advocates should focus not only on their “home turf” of national, regional, and local government but also explore whether and how engaging in global policy-making and advocacy forums can advance their work at home. The benefits of navigating global mechanisms such as the United Nations, WHO, PAHO, and regional “clubs” of governments such as the Organization of American States (OAS), (https://www.oas.org/en/), can potentially outweigh the investment of time and resources if advocacy plans are tight, targeted, and well-executed.

One of the major reasons for advocates to engage in global policy is to advance and push for government adoption of political and policy principles that align with the advocate’s goals. Statements and resolutions signed by governments – even if legally non-binding – help create political space in home countries for advocates to push for more ambitious reforms.

If you want to have impact on the regional or international level, you are going to need partners. Luckily, there are more and more advocacy organizations with whom to engage and collaborate on working groups, joint campaigns, and collective epilepsy strategies. You may also want to check out the Health Diplomacy e-learning modules on the IBE website: https://www.ibe-epilepsy.org/initiatives/e-learning-modules/.

The Pan American Health Organization

The Pan American Health Organization (PAHO) is the specialized international health agency for the Americas. It works with countries throughout the region to improve and protect people’s health. PAHO Headquarters is in Washington, D.C., and PAHO has offices in 27 countries and 35 Member States in the Region of the Americas.

PAHO plays a crucial role in advocating for epilepsy awareness and management within the Americas. As the Regional Office for the Americas of the World Health Organization (WHO), PAHO focuses on promoting health and improving health care systems. In the realm of epilepsy, PAHO engages in advocacy efforts to raise awareness about the condition, reduce stigma, and enhance access to quality care.

In 2011, PAHO’s 51st Directing Council approved the Strategy and Plan of Action on Epilepsy 2012–2021. A significant aspect of PAHO’s work involves working with Collaborating Centers on epilepsy. This may involve organizing conferences, workshops, and training sessions to enhance the skills and knowledge of healthcare providers in the region. For example, Webinar: What we know about Epilepsy and COVID -19 in the Region of the Americas.

PAHO also participates in awareness campaigns to reduce the stigma associated with epilepsy and improve understanding within communities. In 2018, PAHO organized a subregional meeting on improving the management of epilepsy and its comorbidities in the Caribbean. Through these multifaceted approaches, PAHO works toward fulfilling its mandates and creating a supportive environment for individuals living with epilepsy in the Americas. PAHO recognizes epilepsy as a major public health concern and is committed to cooperating with Member States and with organized civil society as they work toward improving care and quality of life for people with epilepsy. PAHO is supporting the expansion of interventions to address the needs of people with epilepsy particularly at primary health care, using tools such as the WHO Mental Health Gap Action Program (mhGAP). To that end and due to the limited availability of specialists in the management and treatment of epilepsy, the module on epilepsy is always prioritized in the training with family doctors. Additionally, virtual courses in mhGAP are now available on the PAHO Virtual Campus for Public Health.

PAHO also has active technical cooperation to support Member States in the strengthening of legislation and regulatory frameworks that can be requested by civil society.

The United Nations Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) (A/RES/61/106) was ratified in 2006 and came into effect in 2008. One of the fastest conventions to be negotiated and quickest to be ratified, this convention lays out terms to ensure persons with disabilities are not viewed as “objects” of charity, medical treatment, and social protection, but rather as “subjects” with rights who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. It is meant to be used as a human rights instrument focused on social development. The convention reaffirms that all persons, regardless of disability, should enjoy all human rights and fundamental freedoms. It also helps to explain adaptations that should be made available to persons with disabilities to help them to exercise their rights and areas where their rights have been violated, as well as where protection of rights must be reinforced *(14)*.

advocacy in action

SDG 17 – A multistakeholder workshop on IGAP and the UN Sustainable Development Goals

Issue: Advocacy is a powerful lever to translate epilepsy needs into political action. Partnerships are critical for alignment on priorities, shared goals, and concerted action. However, advocacy efforts across the Americas remain fragmented, and globally ratified frameworks like IGAP and the SDGs are underutilized in epilepsy advocacy initiatives.

Actions: In 2023, the International Bureau for Epilepsy and the Chilean League Against Epilepsy PAHO/WHO Collaborating Center convened a multistakeholder workshop in Santiago, Chile, to discuss country-level opportunities for epilepsy advocacy in Chile and the wider region. The activity brought together people with epilepsy, their care providers and families, advocates, health professionals, and representatives of IBE, PAHO/WHO, International League Against Epilepsy (ILAE), and the Chilean Ministry of Health. In working groups, participants discussed (1) the status quo, (2) foreseeable impacts, (3) key challenges, (4) necessary measures, and (5) existing advocacy initiatives related to IGAP implementation. The direct relevance of several SDGs to epilepsy was mapped, and stakeholders discussed how to effectively leverage this framework for advocacy initiatives.

Results: Uniting epilepsy stakeholders is fundamental to identify key opportunities and challenges and develop partnerships around shared priority actions. As such, workshop participants identified that Chile's National Epilepsy Plan has improved epilepsy care yet needs more focus on integrated services for people with epilepsy, alignment with IGAP, and emphasis on multi-level education. Intersectoral policies should be co-created by people with lived experience and must reflect socio-economic epilepsy determinants, including SDGs on education, gender equity, and poverty reduction. Stakeholders agreed that IGAP and SDG-directed advocacy is critical but requires effective coordination mechanisms. In Chile, advocacy priorities include promoting service coverage (mental/social care, anti-seizure medicines, epilepsy surgery), and primary care training (technical, stigma, and social aspects; care giver and care provider support).

Finally, a direct result of this workshop was the creation of the Americas Toolkit Steering Group – the multistakeholder expert group whose inputs and guidance were instrumental to the co-creation of this toolkit.

FOCUS ON: Funding

Having enough funding is critical to every organization. While this can seem daunting, there are easy actions you can take that will help position you for success when the time comes to seek funding.

Take time to build relationships with potential and existing donors

Relationships are a critical part of securing funding, and there are many ways to build relationships. Are you about to start a new project or program? Try meeting with potential donors before kicking off the project to ask for their input and expertise. You can invite them to take part in a baseline survey or interview them for feedback on where they see the major problems in your community healthcare system. As the old fundraising adage goes, “When you’re asking for money, ask for advice. When you’re asking for advice, ask for money.” Then, as the project gets underway, share quick updates on how things are going and stories highlighting impact. Invite prospective donors to meetings and share resources that may be of interest to them. That way, when the time comes to make a concrete ask for funding, you will have already built relationships and trust with potential donors. As for current donors, make sure you communicate updates regularly and do not forget to show your appreciation.

Leverage the power of networks – both yours and others’

Your network is one of your most valuable assets for securing funding. Engage your board of directors, current funders, and other allies who are committed to improving health and social outcomes for people with epilepsy to broaden your pool of potential funders. There are also easy ways to expand your network. Strategic coffee meetings are not expensive but can be an opportunity to meet with someone and share your vision. If you can influence a person who can influence other key people, you can make change at the café. Look for opportunities like this and leverage them! Think creatively about other ways to gain support for your organization or cause that may not be direct asks for funding, such as in-kind donations (e.g., for transportation, office space for staff, etc.).

Sharpen your communications – have an advocacy strategy with clear objectives

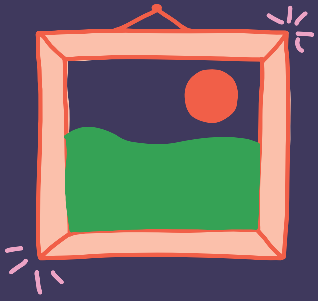
Define your objectives and hone your messaging to get the most out of your advocacy strategy. Your ability to tell your story – not just what you do but why it matters – in a compelling way increases your odds of raising money. Personal stories are one way of communicating impact, but you should also define metrics that you can track and report to donors, so they understand the impact their funding has on your organization and, more importantly, on the people you serve. Collecting data at the start of your program, the middle, and the end can help you generate real numbers to share. These can be used for advocacy messages as well as for providing concrete evidence that your advocacy is having an impact.

Consider this

- Is your government a member of WHO and has adopted IGAP in 2022 but not yet initiated the actions necessary to attain its 10 targets at the country level?
- What about the other conventions noted above? If so, how could you leverage these international agreements to encourage your government to act?
- Do you share your newsletter and links to your civil society website with other people and organizations? Sharing your programs with media, policy-makers, civil society, and elected officials is a good way to keep them informed of your priorities.

Further information

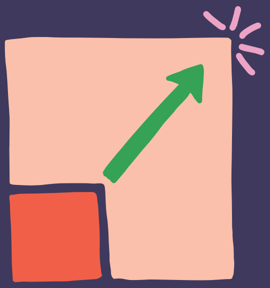
Additionally, you can take a look at the Universal Declaration of Human Rights, a common standard of achievements for all peoples and all nations. It sets out, for the first time, the fundamental human rights to be universally protected, and it has been translated into over 500 languages *(15)*.



TIME TO GET STARTED

You have now explored how to plan, act, and expand the reach of your advocacy for epilepsy. We have looked at examples from those who have come before and have looked at new strategies for you to pursue in the future. We have looked at how to find allies and overcome challenges. In the annexes of this toolkit, you will find additional information to support you and your advocacy along the way. Remember, at times advocacy can be very challenging on a professional and personal level, but do not give up, do not lose heart. Change is sometimes slow, but with a focused plan in place, a network of support, and a passion to make a difference in the lives of persons with epilepsy, you are ready for this challenge. Learn from and collaborate with others and do not forget that progress has been made and that opportunities exist to make epilepsy a health priority.

THE TIME IS RIPE. GOOD LUCK!



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Annexes

ANNEX 1

Recommended reading

Pan American Health Organization. Mental Health Atlas of the Americas. Washington, D.C.: PAHO; 2023. Available from: https://iris.paho.org/handle/10665.2/57879.

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ANNEX 2

Tool templates

Here you will find blank versions and instructions for the tools discussed in this toolkit. You can work through them at your own pace one by one, or spend time with your team in an advocacy planning workshop (Annex 3) working through them all together.

Identifying care pathways

This tool can be used by advocates to map out local care pathways and to identify the people that are currently providing care.

In your community, where do people seek help after having a seizure?	
Do they go to a traditional or faith healer?	
Do they have access to biomedical care?	
What is their level of knowledge on the causes of epilepsy, and their capacity to understand that epilepsy is a treatable neurological condition?	
How can biomedical care work with the alternative healthcare system (traditional and faith healers)?	
How does your health ministry classify epilepsy? (noncommunicable disease [NCD], mental health condition, neurological, disability, etc.)	
Are there locally developed materials or programs that help people with epilepsy to know where to find help after they have a seizure?	
Are there locally developed research or awareness initiatives?	
Are anti-seizure medicines affordable and available in your community?	

Identifying content for an epilepsy awareness campaign

This tool can be used to identify facts that can be used in your awareness campaign.

Epilepsy fact	Is this important to include? Why or why not?
Epilepsy is treatable: more than 70% of people with epilepsy could live seizure-free lives if they had access to appropriate treatment.	
Epilepsy can be diagnosed and treated at low cost in a primary care setting.	
Epilepsy is life-threatening if left undiagnosed, untreated, or unmanaged. The risk of premature death in epilepsy is three times higher than the general population.	
25% of epilepsy cases can be prevented.	
Epilepsy is not contagious. Everyone can learn how to help someone having a seizure.	
Epilepsy is a spectrum disorder. There are many different types of seizures.	
Some people with epilepsy have cognitive, psychological, and/or social consequences while others may not.	

Reaching your target audience

Use this template to identify the message for each target group. What do they need to hear? How can you change their attitudes and behavior?

Target group	What message does the target group need to hear to be influenced to change their attitudes and behavior?
People with epilepsy and their family	
Healthcare workers	
Teachers and school staff	
Policy-makers	
Employers	
Traditional and faith healers	

Planning a stigma reduction intervention

This tool can be used to help advocates to develop their stigma reduction intervention. Consider each question carefully before you begin to implement your program.

Identify the problem. What aspect of stigma do you want to address?	
What group(s) are perpetuating this problem?	
What is the stigma classification (internalized, interpersonal, or institutional)?	
How will you reach your target audience?	
How will you convey this message (message source)?	
List partners or collaborators that share your goal to solve this problem.	
What are the potential benefits of solving this stigma problem?	
How will you monitor your project?	
How will you evaluate your program?	

The Five Whys: getting to the root of the problem

Instructions: State the problem you have identified, then ask yourself “Why?” at least five times to drill down further and uncover the root causes of the problem. This will help you to better understand the various levels your advocacy actions should focus on to help resolve the problem.

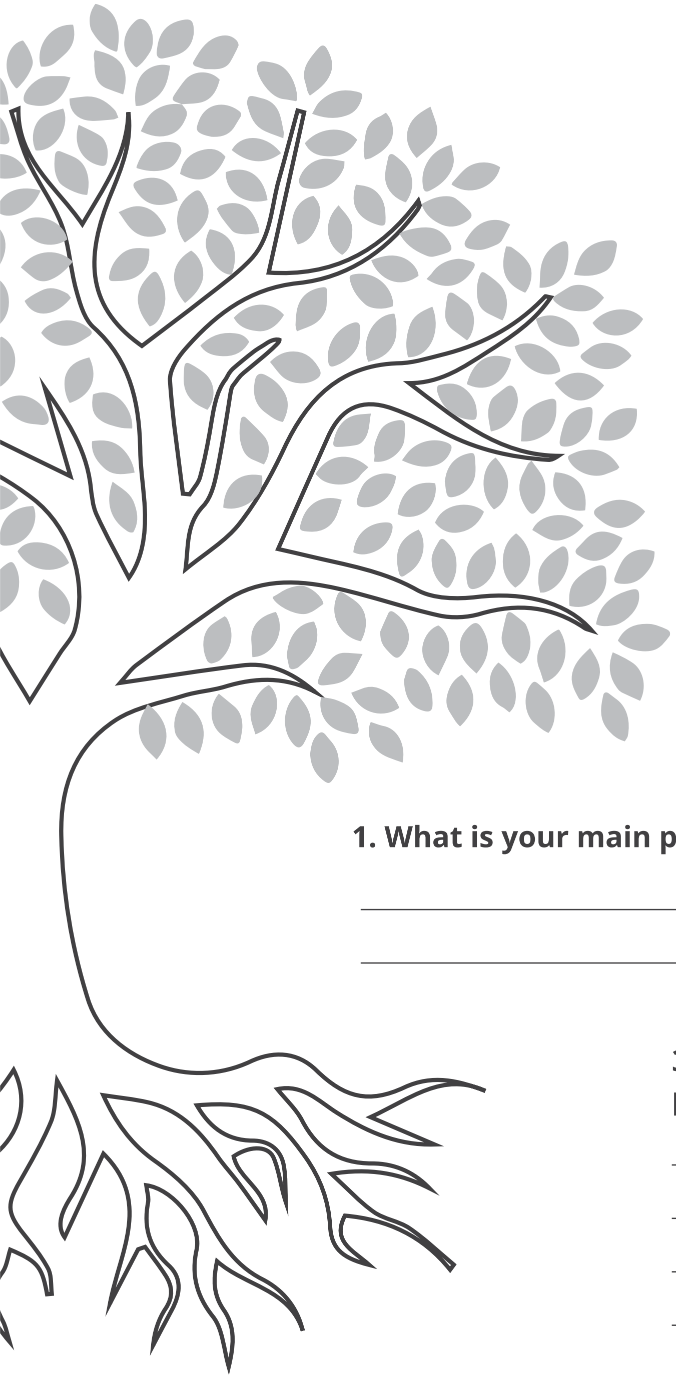
State the problem you have identified:

1. Why is that a problem?
2. Why is that a problem?
3. Why is that a problem?
4. Why is that a problem?
5. Why is that a problem?
6. Why is that a problem?

Continue this exercise until you feel you have sufficiently uncovered the root causes.

Problem tree

Instructions: For the main problem you have identified, brainstorm the effects that the problem has on persons with epilepsy, and what the root causes may be for that main problem.



2. What effects does the problem have?

____

____

____

____

1. What is your main problem?

____

____

3. What root causes can you identify for the main problem?

____

____

____

____

PESTLE assessment

Instructions: Fill out each of the six areas of the matrix to get a better sense of the multiple external factors that may impact the advocacy work that you want to do. Note which factors may be out of your control, and which factors you could harness for your purpose.

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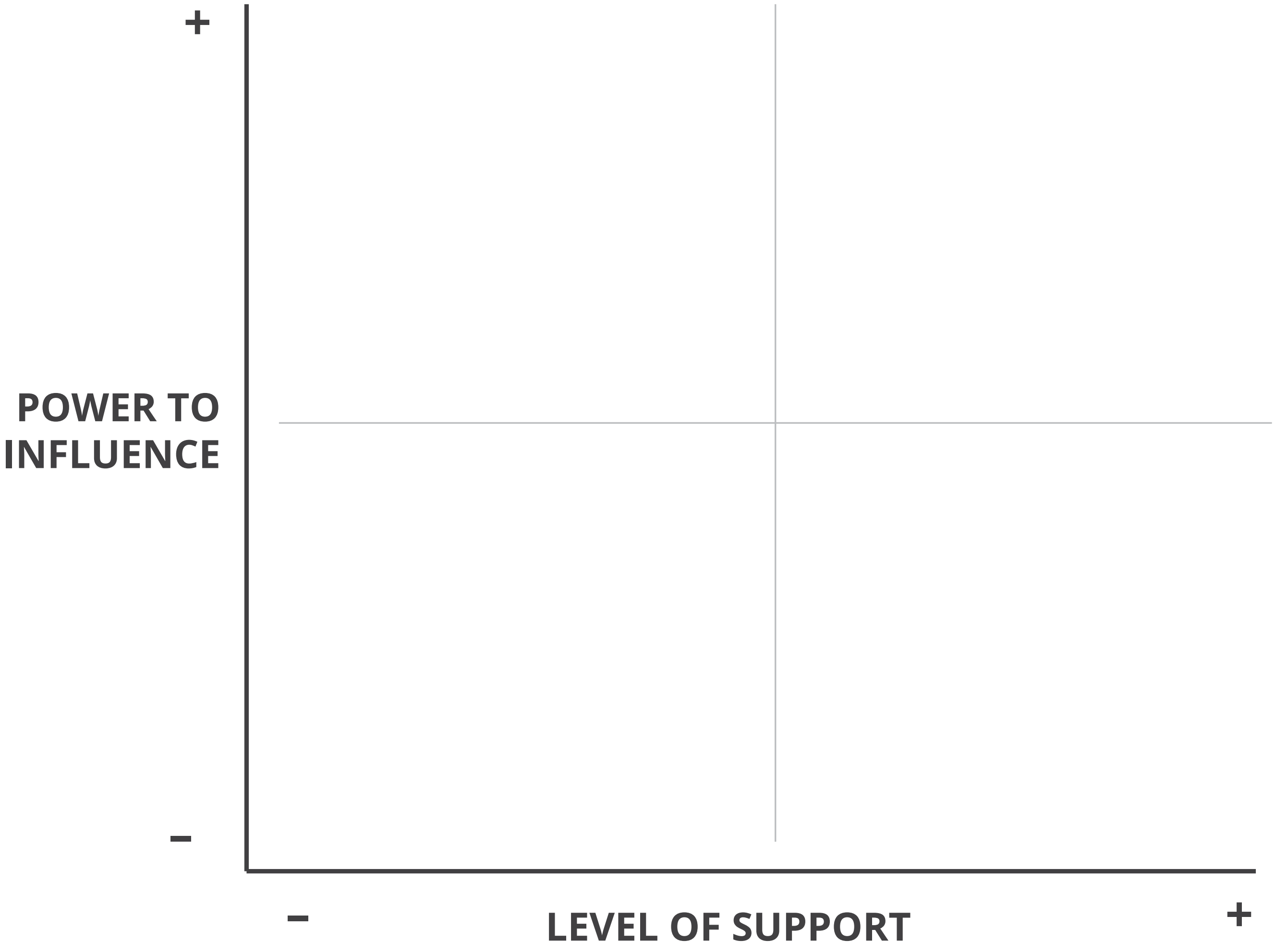
Stakeholder assessment

Instructions: Brainstorm a list of the stakeholders working in your context and add them to the stakeholder assessment matrix, placing them in the grid by their power and level of support for your advocacy agenda. Also take note of how different actors might pool their resources to influence other actors, and mark those with arrows on the graph.



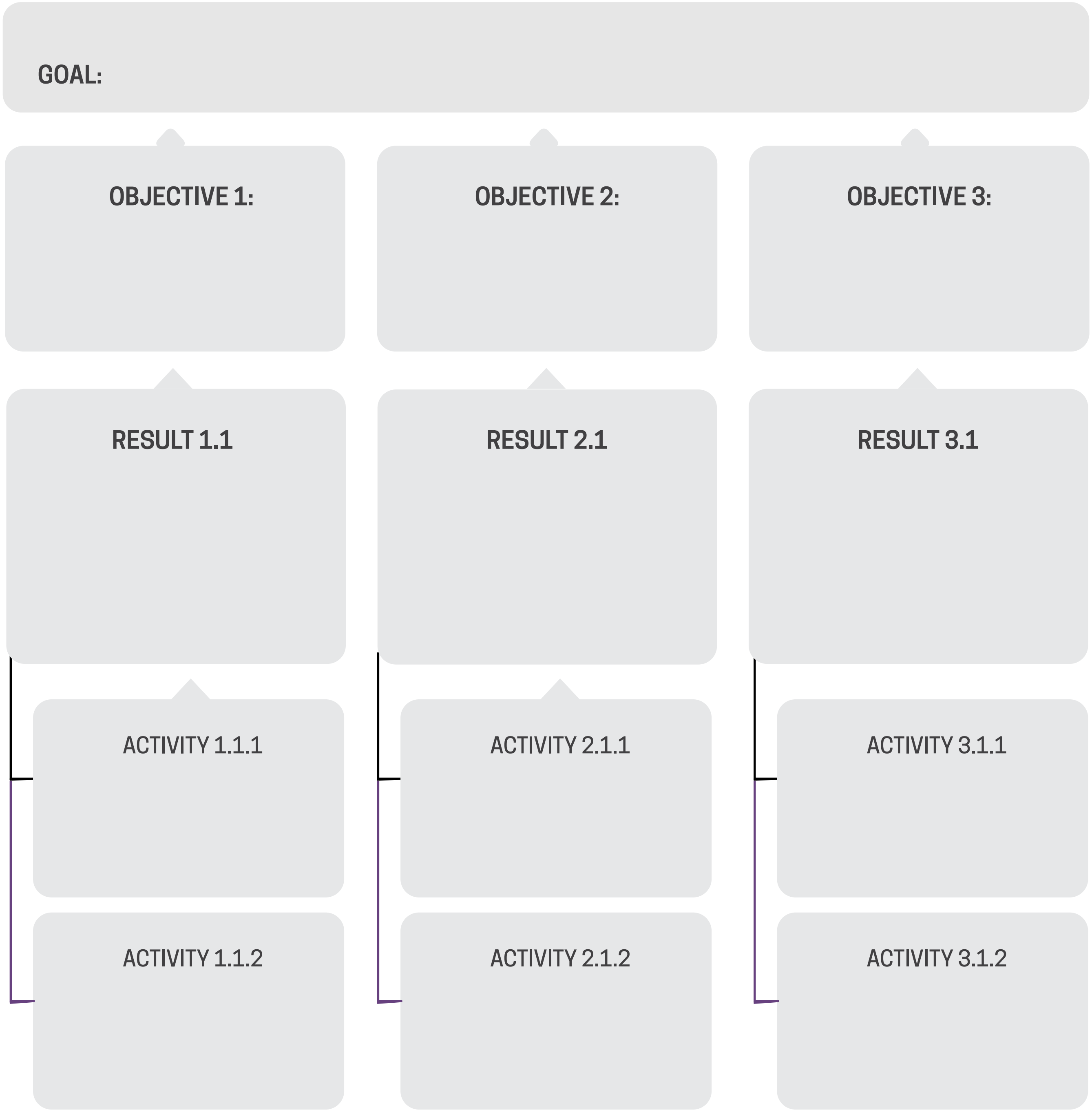
Advocacy plan

Instructions: Once you have defined a SMART goal, set objectives, and identified key stakeholders and key performance indicators, you can complete the table below. Note that you may need fewer or more objectives to reach your goal, but three is a good place to start.

GOAL:			
OBJECTIVES	Objective 1:	Objective 2:	Objective 3:
ACTIVITY (OUTPUT)	▪	▪	▪
KEY STAKEHOLDERS	▪	▪	▪
RESOURCES NEEDED	▪	▪	▪
KEY PERFORMANCE INDICATORS	▪	▪	▪

Results framework

Instructions: Placing your advocacy plan into a visual results framework helps everyone to easily see how all the different moving pieces fit together and get you closer to your end goal. You may need to alter this template to fit your specific results framework – adding or subtracting objectives, results, and activities as needed.



Risk assessment

Instructions: Brainstorm the possible risks that could affect your work, and rate the impact and likelihood of each. Enter ideas of how you could ensure that the risk does not derail your progress in the fourth column.

Risk	Impact level (high/med/low)	Likelihood (high/med/low)	How could we mitigate the risk?

ANNEX 3:

Advocacy planning workshop

You can work through the tool templates in Annex 2 on your own, but when planning for advocacy, it is often best to hold a workshop with colleagues, stakeholders, and even beneficiaries, to gather ideas and work through solutions. So how do you organize this?

Conducting an advocacy planning workshop:

Decide who you want to involve. Your first workshop might be just internal, and you then can share your results for feedback with key stakeholders, including donors to your work.

Decide where you want to hold the workshop and make sure there is space to spread out, as well as supplies like chalk boards or whiteboard, or flipcharts or large pieces of paper to brainstorm and share thoughts easily.

Choose a facilitator to lead the workshop. It is often useful to have someone external or neutral who will not be contributing to the ideas, so that they can focus on the process and moving the group along to the goal. You can also assign a different person for each session so that you can divide the preparation work.

Be sure to have a clear goal and allow enough time to get there. Are you collecting ideas and then planning to revise them and write a strategy later? Are you looking to identify specific results and objectives for a program? Are you looking to plan your advocacy work for the year? Do you want to create an advocacy strategy around a certain topic or for a specific project?

Create a simple agenda like the one below that lays out the process for everyone to understand.

Ask participants to set and agree on rules for the day; for example, turn off cell phones, raise your hand to speak and do not interrupt, return from breaks at the agreed time.

Make use of creative and engaging formats such as "Around the World." Write one topic or question at the top of each flipchart. Divide your team into groups of three to five people and provide each with a flipchart. Ask each group to begin noting their ideas about their chart's theme. After 5–10 minutes, ask each group to pass their flipchart to the right, read what the group before them has written, and add their ideas to the topic. They can also note where they might disagree. Once each group has had a turn with each topic, have each present the chart they ended with to the entire team. You should have a pretty good collection of thoughts and ideas that can be especially useful as a starting point for workshop discussion. This activity also allows people to get up and move if they need a break from presentations and sitting. You can use it to list resources, activities, and assumptions or to conduct the SWOT or PESTLE.

Switch between breakout groups and keeping everyone together to keep things interesting. You can also look up some useful ice breakers – simple games or questions that help participants get to know each other and relax for the day. “Two truths and a fib” is a good example, where everyone in turn tells the group three facts about themselves, but one is made up. The group then guesses which fact is the made-up one. Ice breakers can be good in the middle of the afternoon when energy is fading as well. Dance breaks or even “Simon Says” also works well just to break up the day and keep minds sharp.

Sample agenda
You can also include columns for resources needed, location, facilitator (if rotating), or anything else that might help you organize.

Time	Session	Purpose	Activities
9:00–9:45	Welcome	Participants get to know each other, understand the day, and set the rules.	Facilitator asks each participant to quickly introduce themselves in the circle Facilitator asks for suggestions for workshop rules, notes them on the board, asks for agreement from all Agenda is reviewed
9:45–11:00	Defining the problem	The key problem we will address is identified	Participants spend 30 minutes discussing the problems they see in their community while facilitator jots down ideas on the board Facilitator helps participants to narrow down and agree on the key problem Conduct the Five Whys exercise as a group to better understand the identified problem
11:00–11:15	Break		
11:15–12:30	PESTLE	External factors impacting the issue are identified	Participants break into four groups of three and sit behind one of the six pieces of paper/flipcharts, etc. Participants brainstorm factors that may influence the problem and move one place to the right every five minutes When the groups reach the last page, the group reflects on what has been written on the paper and agrees on the top two to three factors in each area

The Advocate's Toolkit for Making Epilepsy a Priority in the Americas Region was developed to help individuals and organizations identify opportunities to enable the full participation of people with epilepsy in the community. It was developed for organizations seeking guidance, ideas, or inspiration as they develop epilepsy advocacy projects. The toolkit is aimed at civil society organizations working throughout the Region of the Americas and has been inspired by the needs and experiences of people with epilepsy.

PAHO Pan American Health Organization
World Health Organization
Americas Region

IBE International Bureau for Epilepsy

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