

Advocate's Toolkit

FOR MAKING
EPILEPSY A PRIORITY
IN AFRICA





“This is the most important work that we should be doing, fighting epilepsy stigma at all levels, from the highest office to the very remote village in Africa.”

– Dr. Joyce Banda, former President of Malawi and champion of epilepsy advocacy

THIS PUBLICATION IS THE RESULT OF A PARTNERSHIP BETWEEN:

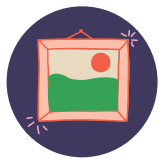


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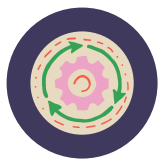
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I was at a wedding when I experienced my first seizure.

My parents were home and only heard about what had happened after the fact. No one was able to help. People from church and our community made a lot of assumptions about what caused the seizure, such as bewitchment, a curse, or demonic possession. Everyone communicated what they assumed. Everyone prescribed solutions, ranging from traditional healing to prayers. The conviction in my family was that it was a curse and needed prayers, as well as hidden visits to some traditional healers. I tasted all sorts of concoctions prescribed to stop me from “falling;” some required me to perform ritual-like acts. I drank the “muti” facing the east so that when the sun set, it set with my “falling.” I bathed with a concoction in a river so that the flowing water washed away my “falling.” I stopped eating chicken wings (their flapping causes seizure), eggs (which cause you to be confused), and okra (the foam that comes out of your mouth when you have a seizure). Even looking at the moon was seen as something that would trigger my seizures. This is a brief glimpse of what it’s like to be the so-called “bewitched son,” the “demon possessed child” in a so-called “normal” family or society.

It took us six years to get a proper diagnosis of epilepsy. However, my clinic visits allowed me to start meeting other boys and girls like me and start discussing our issues. That was a key difference! We formed a group as peers, and everyone wanted to be included. That was the birth of the advocate in me, where I learned to talk and push for our rights.

Personal advocacy is important, yet you also need others to advocate with you and for you! My experience and stories made me want to fight for the rights of persons with epilepsy. The facts of exclusion also convinced me. Here are a few:

- Many children with epilepsy in developing countries don’t attend school.
- There is high exclusion of persons with epilepsy due to stigmatisation and discrimination.
- The mortality ratio for persons with epilepsy is three times higher than average.
- Very few persons with epilepsy in developing countries have access to basic health services.

I realised that in the wider development and health community, we couldn’t be true to our vision if we didn’t advocate for the inclusion of epilepsy as a PRIORITY. That’s where this idea of an advocacy toolkit came in. Developed by the International Bureau for Epilepsy (IBE) and BAND Foundation during my tenure as Vice President of the IBE Africa, this toolkit includes tips, strategies, and resources to enable you to confidently take action and make advocacy part of your work. This kit will help you to become more comfortable with basic advocacy tools that will prepare you to ensure epilepsy is put on the agenda at the community, national, and regional levels. In your role as an epilepsy organisation, a nonprofit organisation, or people working around issues related to epilepsy, this toolkit will help you to construct a successful advocacy strategy.

This toolkit aims to assist you and your staff at the 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 some tools to help you and your team work your way logically through the different stages of an advocacy planning cycle. In each part, previous examples of successful advocacy are used to illustrate the different areas in which advocacy can have an impact.

Making epilepsy a priority is now or never!

Action Amos
Vice President Africa
International Bureau for Epilepsy



Introduction

WHO THIS TOOLKIT IS FOR AND HOW TO USE IT

This toolkit is for organisations looking for guidance, ideas, or inspiration as they develop advocacy projects around epilepsy. Generally, the toolkit is aimed at civil society organisations working across Africa and has been heavily influenced by the needs and experiences of such organisations.

The various modules and topics addressed in this toolkit can be used both as a step-by-step guide to lead you through a brand new advocacy planning process, or as a reference or set of stand-alone resources that can be used when encountering a problem or opportunity in the context of existing epilepsy advocacy work. It is meant to be versatile and useful to a variety of audiences.



HOW THE TOOLKIT WAS DEVELOPED

This toolkit was developed with input from key stakeholders, including persons with epilepsy and their families, IBE chapters across Africa and headquarters representatives, and input from others with a connection to epilepsy either personally or through an organisation. Through an initial needs assessment, stakeholders provided their perspectives on resources that were currently available to them, best practices they wanted to share, areas where they were seeking support, and opportunities for additional support or collaboration. This toolkit was developed based on that input as well as on feedback on initial drafts. We did not want to reinvent the wheel, and as such have provided links to other useful general advocacy resources available at the end of this toolkit.

ad·vo·ca·cy

['ad-və-kə-sē] noun

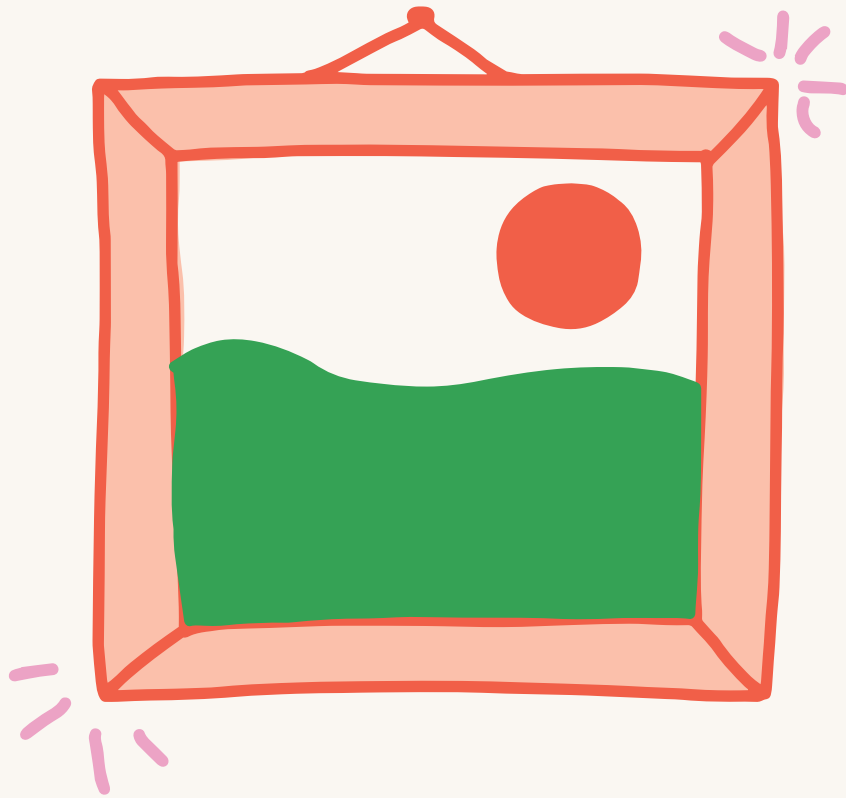
the act or process of supporting a cause or proposal¹

WHAT IS ADVOCACY?

So 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 or not the effort is aimed specifically at changing behaviour and/or policy. The table below describes various types of influencing actions, how they differ from one another, 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. ²	Key characteristics: Action taken to inform or educate people about a topic or issue but not necessarily aimed at specific behavioural 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 behaviour or policy.	Key characteristics: Actions that attempt to influence policymakers and stakeholders by increasing both public attention and private pressure/incentives on a certain issue.	Key audiences: Policymakers and duty bearers (e.g., government or other leaders) or other key stakeholders (e.g., hospital administrators, the media, or teachers' unions).
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: Policymakers, duty bearers, policy custodians, government officials.
CAMPAIGNING	Definition: Actions, events and activities conducted by people working together who seek to achieve a change and/or raise awareness on a defined issue.	Key characteristics: A number or series of organised advocacy and communication activities that builds 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.

The main difference is what you are asking for. With awareness raising, you are often asking people to pay attention, to think about something, to consider someone's situation, or to contribute to a conversation about something. Advocacy is moving your audience toward a desired behaviour or policy change. Policy advocacy is focusing on a specific policy or law that you want to change and developing 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?



MODULE 1:

The Big Picture

So you want to work toward change. There are many areas you can focus on as an advocate for persons with epilepsy: decreasing stigma and discrimination; reducing the treatment gap; and creating access to education, employment, and other basic services, to name a few. 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?

The good news is there has been significant progress on epilepsy in the last few years with an increasing number of international resolutions and commitments, a greater number of resources available, and a growing network of advocates that you can learn from and connect with to amplify your voice. This toolkit leverages this progress and gives you the tools you need to improve the quality of lives of persons with epilepsy.

Whether you are a small community group or a large organisation, **the first place to start is to understand the big picture of epilepsy and 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.

EPILEPSY IN AFRICA—KEY FACTS

WHAT IS EPILEPSY?



Epilepsy is a **noncommunicable, chronic brain condition*** that affects people of all ages.³

25% of epilepsy cases are preventable

These are caused by pre- and perinatal complications, stroke, central nervous system infections (such as malaria, neurocysticercosis, and river blindness), and traumatic brain injury from accidents. The burden of preventable epilepsy is higher in Africa than on other continents.⁴

WHO HAS EPILEPSY?



50 million people worldwide have epilepsy

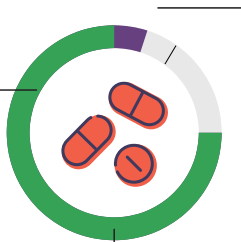
10 million people in Africa have epilepsy⁵



This makes epilepsy one of the most common neurological conditions worldwide.

EPILEPSY IS TREATABLE

80% of persons with epilepsy in Africa do not receive the care they need.



Yet **70%** could live seizure-free with proper treatment!⁶

For the 20% of persons with epilepsy who do receive treatment in Africa, **over 75%** are unable to properly manage it due to inconsistent access to antiseizure medications and high costs.⁷



The cost of medication can be as little as **US\$5/year**

94% of African countries have at least one antiseizure drug at the primary healthcare level, but it is often out of stock.⁸



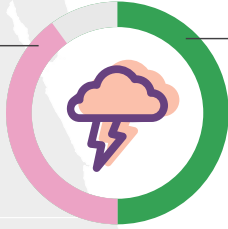
There are very few neurologists in the African region—slightly above 400 for all of Sub-Saharan Africa. Because of this, most persons with epilepsy are treated through traditional healers or mental health clinics.⁹

A CONDITION OR A DISEASE?

Epilepsy is defined as a noncommunicable disease of the brain (see glossary for full definition). However, throughout this toolkit, we refer to epilepsy as a condition, recognizing that the word disease has different connotations across languages and cultures. For example, in some African countries, the word disease leads to the misconception that epilepsy is infectious and can be spread from person to person. We encourage readers of this toolkit to use whatever term is most relevant and appropriate in their own community.

IMPACTS OF EPILEPSY

Up to **30%-40%** of children with epilepsy will have an intellectual disability.



Up to **50%** of persons with epilepsy can experience co-occurring conditions, such as anxiety and depression.¹⁰



An average African family, where one member is a person with epilepsy, **spends almost 50% of its income on epilepsy treatment** and care due to lack of affordable and effective care.¹²

In many African countries, epilepsy care is not covered by medical insurance. Persons with epilepsy **must pay mostly or entirely out of pocket for health services** in 83% of African countries.¹³



Persons with epilepsy have **up to three times higher risk of premature death**, including from fires, accidents, suicide, and sudden death, than the general population.¹¹



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

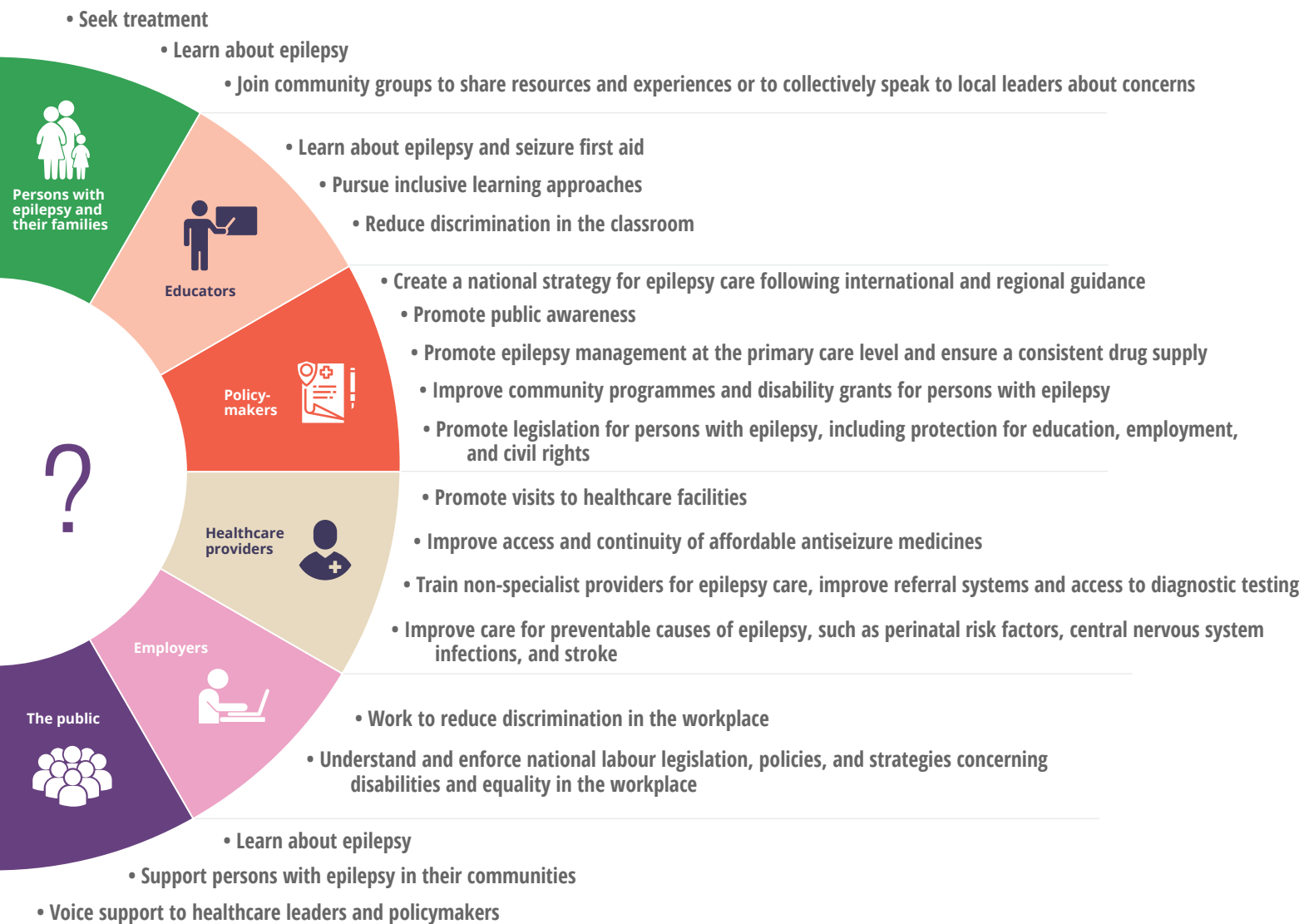
KEY ACTIONS WE SHOULD URGENTLY TAKE¹⁴

- 1** Promote epilepsy as a public health priority to reduce its burden.
- 2** Improve public attitudes, reduce stigma, and promote the rights of persons with epilepsy.
- 3** Invest in health and social care systems to improve access to care.
- 4** Enhance access to seizure medications.
- 5** Prevent acquired epilepsy by reducing brain infections, traumatic brain injuries, stroke, and perinatal injuries.

MENTAL HEALTH OR NEUROLOGICAL CONDITION?

The epilepsy-mental health connection is a complex issue. In many African countries, epilepsy is classified as a mental disorder within the Ministry of Health, placing epilepsy budgets within those of mental health and making epilepsy treatment the responsibility of mental health facilities and care providers. Identifying where decision makers place epilepsy will help you plan your advocacy. However, reclassifying epilepsy as a brain or neurological condition, and noting it is a noncommunicable disease (NCD), creates space to advocate for greater and more specific epilepsy funding. In addition, divorcing the concepts relieves persons with epilepsy from the additional stigma associated with mental health conditions. That said, there remain ways in which this link is useful, such as the resources in WHO's mhGAP. It is up to you to determine whether to link or separate the two issues in your specific situation.

WHO CAN DO WHAT?



THE UNIQUE ROLE OF NONGOVERNMENTAL ORGANISATIONS

Nongovernmental organisations (NGOs) can help bring different stakeholders together to advocate for changes in laws, practices, and perceptions. NGOs can advocate for the above stakeholders to take the highlighted actions and create greater political will to put epilepsy on the public health agenda. They can also monitor government commitments to international resolutions and agreements, and track progress. Organisations can play a key role in bringing persons with epilepsy, their families, the public, teachers, employers, policymakers, and health professionals together to advocate around key messages. They can play a role in providing information, collecting data, analysing problems, and suggesting solutions.

NGOs can provide critical support in their communities to persons with epilepsy and their families. They can, for example, help empower persons with epilepsy to seek out appropriate care, find their voice, tell their story, and help to advance change.

advocacy in action



In Malawi...

Ruthⁱ was working as a hotel manager and faced discrimination due to her repeated seizures. This led to her being fired. She reported her case to the National Epilepsy Association of Malawi. A letter was written to the hotel threatening litigation. The hotel reinstated her and sought advice on how to handle the issue. Educational awareness materials were printed at the hotel's cost and shared with all staff members. Though Ruth left the hotel months later, an impact was made at the hotel, which is now a model of mainstreaming diversity.

In Cameroon...

Boris' teachers wanted to dismiss him from school. His frequent seizures were causing low self-esteem, low confidence, poor academic performance, and inconsistent attendance. The Community Development and Epilepsy Foundation of Cameroon worked with him through a support group to begin antiseizure medication and make sure he took it every single day. Because of this, his seizure frequency decreased, and he has been able to continue his studies. The school authorities were made aware of his condition and how to support him. He is now the school's flag boy, hoisting the flag every assembly day while his friends stand at attention, a job that he loves very much.

In Eswatini...

At age 49, Tony was living with epilepsy, HIV, and intellectual disabilities, which left him unemployed and homeless, forcing him to live on his cousin's homestead. Tony had been on the waiting list for a government disability grant since he was 12 years old. When the Eswatini Epilepsy Organisation met him, they immediately engaged with the Department of Social Welfare. Through this effort, Tony finally received his disability grant, which allowed him to contribute to his family. The organisation also engaged with local authorities who assigned him a Rural Health Motivator to serve as his guardian and provide more care. In a recent visit, Tony shared that he is now an active participant at local community meetings and is hoping to start a family.

In Kenya...

Due to an illness at age three, Eric began to experience seizures and was diagnosed with epilepsy. Luckily, a friend was able to connect him and his family to the Kenya Association for People Living with Epilepsy (KAWE), which has supported him ever since. When Eric was a child, KAWE enrolled him at a local health clinic and advocated for his access to medication. When Eric was older, the Association hosted a business management course and entrepreneurial workshops, in which both Eric and his mother enrolled. Today, Eric, who is seizure-free, runs a small business with his mother.

In Sierra Leone...

Abdul grew up in a boarding home for the blind in Kabala. In 2008, he experienced his first seizure and was kicked out of the residence because his peers feared it was a demonic attack. He returned home to his family. They did not understand his condition and took him to traditional healers, who provided him with ineffective and harmful treatments. One day, Abdul experienced a seizure while in town, and a friend of the Epilepsy Association of Sierra Leone happened to be nearby. Abdul connected with the Association and began to receive counselling and treatment. Today, he lives seizure-free and has returned to school.

ⁱ All names have been changed to protect the identity of individuals.

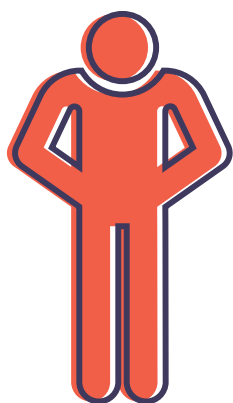
OVERARCHING MESSAGES

When assessing advocacy priorities for your community or country, it is important to focus on the work of the World Health Organization (WHO), which has been instrumental in making the case for epilepsy as a global health priority. The following messages and key actions are adapted for the African context from WHO's "Epilepsy: A Public Health Imperative," which is an essential resource for all epilepsy advocates. How can you help contribute to tackling these problems?¹⁵



BURDEN

In Africa, epilepsy is an enormous health and social burden. Worldwide, more than 50 million people live with epilepsy, 10 million of whom live in Africa. Epilepsy is a common but neglected neurological condition that has high physical, economic, and social consequences due to the physical and psychological suffering caused by seizures, the social exclusion faced by persons with epilepsy and their families, and the reduced opportunities in education, marriage, driving, and employment due to deeply ingrained stigma.



STIGMA AND DISCRIMINATION

In Africa and all over the world, persons with epilepsy are targets of discrimination and human rights violations. **In many communities, misconceptions about epilepsy have existed for centuries, and epilepsy is not considered a medical condition that can be treated but rather a spiritual or religious affliction.** From the belief that seizures are contagious (leading to isolation and an unwillingness to intervene in preventing seizure-related injury) to the perception that epilepsy is caused by witchcraft or supernatural forces (leading families to seek care from traditional healers rather than hospital or clinic-based providers), misunderstandings abound.

Because of these attitudes, seizures are met with fear, and persons with epilepsy are often prevented from attending school, marrying, driving, or seeking employment. Often traditional healing practices, such as dietary restrictions (e.g., avoiding chicken wings or okra), a prohibition against gazing at the moon, or special rituals, are recommended, which serve to delay treatment that might otherwise be received from healthcare providers at hospitals or clinics. The emotional impact of feeling socially excluded contributes to the burden of epilepsy and can delay or prevent people from seeking care and effective treatment.



TREATMENT GAP

Epilepsy is not a priority and is neglected in national public health agendas. **Over 80% of persons with epilepsy in Africa do not receive medical treatment for their seizures, even though antiseizure medications can cost as little as US\$5 per year and can control seizures for two-thirds of people with the condition.** This, coupled with weak healthcare systems and irregular drug supply chains in many countries, leaves healthcare providers without the skills and tools required to properly diagnose and treat epilepsy.



PREVENTION

Preventing epilepsy is an urgent and unmet need—an estimated 25% of global epilepsy cases are preventable. However, the burden of preventable epilepsy is greater in Africa due to higher rates of pre- and perinatal complications, central nervous system infections (such as malaria, neurocysticercosis, meningitis, river blindness, and encephalitis), and traumatic brain injury (resulting from road traffic accidents or falls). In some countries in Africa, nearly one-third of epilepsy cases have been attributed to neurocysticercosis, or pork tapeworm. Stroke is the main preventable cause when a person experiences their first epileptic seizure in adulthood.¹⁶ 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; ensuring all are immunised against measles, tetanus, meningitis, and other preventable diseases; and ensuring the prevention and prompt treatment of malaria and other febrile illnesses, especially in children.

There is evidence that the rates of epilepsy have decreased dramatically in high-income countries with the improvement of their healthcare systems. Rates of epilepsy can be seen as an indicator of the quality of a healthcare system.



THE TIME TO ACT IS NOW

Despite significant gaps in the recognition and treatment of epilepsy, **there is growing momentum to include epilepsy on global public health agendas.** WHO has called on all countries to make epilepsy a priority. This momentum has been inspired by advocates across Africa and an increasing number of persons with epilepsy willing to share their stories and demand change.

All African countries that have ratified WHO's landmark 2015 resolution on epilepsy now need to create country strategies for implementation, as well as seek partners and support to implement local and national plans. The unanimous passing of the WHO Resolution [Global Actions on Epilepsy and other Neurological Disorders](#) creates opportunities to advocate for implementation, as well as at the national level. Passed at the 73rd World Health Assembly (WHA73) in November 2020, this resolution calls on the Director General to: develop, in consultation with Member States, and in full collaboration with United Nations organisations and relevant non-State actors, a 10-year Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders. It also calls for the submission of a draft Intersectoral Global Action Plan for consideration by Member States, as well as to report on the progress achieved in implementing this resolution, with an intention to submit the plan to Member States for endorsement during the Seventy-fifth World Health Assembly. **What is your government doing about it?**

CONSIDER THIS

- What facts and figures do you have on epilepsy in your country?
- Has your organisation 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, whether religious or tribal leaders or local celebrities, who might help you convince others?
- Are there other organisations that support the epilepsy cause or can be supportive if mobilised? What about organisations working on noncommunicable or chronic diseases?
- Are there other approaches you can think of? What are they?



FURTHER INFORMATION

Developed in 2015 as part of the [WHO Programme on Reducing the Epilepsy Treatment Gap](#), [The Global Information Kit on Epilepsy](#) provides general information about epilepsy, an overview of some of the pilot projects, and actions that can be taken by specific stakeholder groups with reference to WHA68.20. It lays out the seven key objectives of the programme and notes training and reference materials that have been developed by WHO based on the [WHO mhGAP Intervention Guide for Mental, Neurological and Substance Use Disorders \(mhGAP-IG\)](#).

Another useful resource is "[Epilepsy: A Public Health Imperative](#)." Developed in 2019 by WHO in collaboration with the International League Against Epilepsy (ILAE) and the IBE, this global report on epilepsy summarises the available evidence on the burden of epilepsy and the public health response required at global, regional, and national levels.

MODULE 1: RECAP

While epilepsy is a challenging issue to address, the time has never been better for African advocates to raise their voices, work together, and demand solutions. Epilepsy is treatable for the majority of people with the condition. Medication can be made affordable and basic epilepsy care can be provided at the primary care level. All African countries have ratified WHO's landmark 2015 resolution on epilepsy, as well as the 2020 WHA73 resolution. Now is the time to raise awareness, hold governments accountable, and create meaningful national implementation plans.



MODULE 2:

Planning Your Advocacy

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

This module walks you through the steps needed to develop your ideas and plan your advocacy. In Part I, we look at how to understand the root of the problem and identify external and internal factors that will influence your plan. In Part II, now that you have a clear picture of the situation, you are ready to identify the goals, objectives, key messages, primary audience, key performance indicators, activities, and resources required to launch your work. In Part III, we look at developing a results framework and managing risks.



PART I: ASSESSING THE SITUATION

WHAT IS THE PROBLEM YOU ARE TRYING TO SOLVE?

It's hard to plan the best route, know when you have reached your destination, or when you might have taken a wrong turn, if you don't have a specific address.

The first thing you need to do is identify the problem you are trying to solve. WHO has helped articulate global norms around the key reform priorities associated with epilepsy in all countries (e.g., reducing stigma, closing the treatment gap, improved treatment, etc.). But those guideposts still leave significant space for an advocacy organisation to identify the most important and feasible reforms in their local and/or national context. For example, you may have noticed that many persons with epilepsy in your community aren't getting the medications they need, and may believe that barrier is the greatest short-term challenge facing the epilepsy community. But how can you make a difference in a reasonable amount of time? It's 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've decided will be at the heart of your advocacy work.

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

BASELINE DATA—WHERE ARE WE NOW?

What if you aren't 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 can help you to explain why communities and families need help. Conducting one-on-one key informant interviewsⁱⁱⁱ with those same persons with epilepsy and local healthcare providers, as well as larger focus group discussions with 6-12 of them at once, can help you and your organisation 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 programme. Baseline data might be 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. This is very useful for future advocacy, organisational 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.**

ii See [Annex 3](#) for more information on how to organise a successful advocacy planning workshop with your team or additional stakeholders.

iii See [Annex 1: Glossary](#) for more information on these terms and to understand how you can use them.



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 state the problem you have identified, and then ask why. You can do this five or seven times, however many you need to get at the root causes.

Persons with epilepsy aren’t getting the medications they need. **Why?**

- Because local clinics don’t have the medications needed. **Why?**
- Because healthcare facilities don’t see many persons with epilepsy and therefore don’t see the need to stock the drugs. **Why?**
 - Because persons with epilepsy often don’t visit local health clinics. **Why?**
 - Because healthcare providers often misdiagnose symptoms, and because of fear of discrimination or distrust, and because traditional healers are often visited. **Why?**
 - Because of a lack of knowledge about epilepsy among persons with epilepsy and their families, in local communities, among traditional healers, and among healthcare providers. **Why?**

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

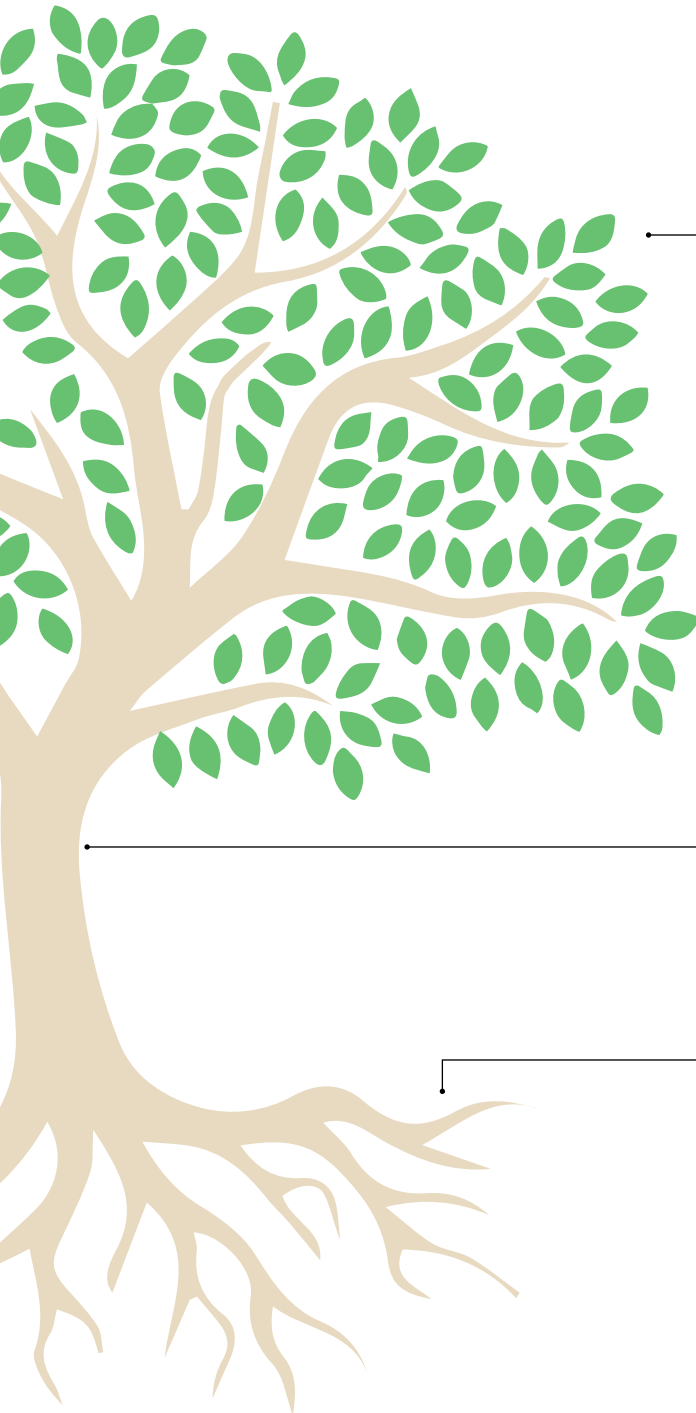
If you look at the above example, you can see how a lack of availability of medications is not just about the drug supply chain, but is more complicated. The deeper you go, the clearer your advocacy objectives become.

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



PROBLEM TREE

A Problem Tree is a visualisation 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 prioritise 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 its consequences, or branches.



EFFECTS

- Healthcare facilities don't have the medications they need
- Healthcare facilities don't see many persons with epilepsy and therefore don't see the need to stock the drugs
- Not many persons with epilepsy visit healthcare clinics
- Healthcare providers don't 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 aren't 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 don't prioritise prevention and treatment
- Significant stigma is attached to persons with epilepsy (belief in witchcraft or the supernatural as causes)

It's 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 whether it is accurate, what it reveals as the main causes, and what you see as the effects you want to influence the most.



ANALYSING YOUR SITUATION: PESTLE (POLITICAL, ECONOMIC, SOCIAL, TECHNOLOGICAL, LEGAL, ENVIRONMENTAL)

So you have an idea about 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 plan practical and achievable results.



POLITICAL

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



ECONOMIC

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



SOCIAL

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



TECHNOLOGICAL

Do most people in your community use technology, such as cell phones, radios, or computers?



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, programmes, and advocacy?



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 how problematic the lack of pre-disaster planning is for persons with epilepsy. Movement restrictions can lead to disruptions in medication and care access. 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, such as those that exist for other conditions (for example, ensuring the provision of dialysis for persons with diabetes). Regardless of the disaster—whether floods, pandemics, political unrest, or drought—advocating for the provision of care for persons with epilepsy in such situations 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 down with colleagues and writing these thoughts out on paper can help to identify important factors for your planning.



POLITICAL

- Elections are 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



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



ECONOMIC

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



LEGAL

- Current Disability Act is outdated and needs reform
- National government has publicly committed to WHA Resolution 73 and United Nations Sustainable Development Goal 3



SOCIETAL

- Strong stigma exists around epilepsy
- Traditional healers are main healthcare provider for majority of the community
- Famous actor/actress recently announced they are living with epilepsy



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 organisation's strengths and weaknesses as well as external opportunities and threats). SWOT is a widely used strategy tool; templates and guidance are easy to find on the internet.



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 effect.

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

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:

1. Lack of training by healthcare providers in hospitals and clinics → increase training for healthcare providers in hospitals and clinics.
2. A preference for and greater trust in traditional healthcare providers → increase work with traditional healthcare providers.
3. A large stigma around persons with epilepsy due to a lack of understanding → change knowledge and attitudes around persons with epilepsy.

However, let's be SMART about the objectives we identify!



“United we are
a rock, divided
we are sand.”

– AFRICAN PROVERB



SMART OBJECTIVES

Once you have an idea about what you want to do, it's important to make sure your objectives are SMART:



SPECIFIC

What is your target population?
A town? A hospital?
Women aged 19-30?



MEASURABLE

How will you know when you have achieved the objective?
Can you track progress?



ATTAINABLE

Will you be able to achieve this objective? Is it realistic?



RELEVANT

Does it respond to the greatest needs of the community?



TIME-BOUND

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 keep your advocacy programme manageable. It is also a good idea to use action words, such as “to develop, to create, to promote, to establish.” Remember, we aren't listing activities or outputs (e.g., 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 forums 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 traditional healers or tribal and community leaders, in a series of three meetings and sharing the outcomes through various media outlets by the end of the year.

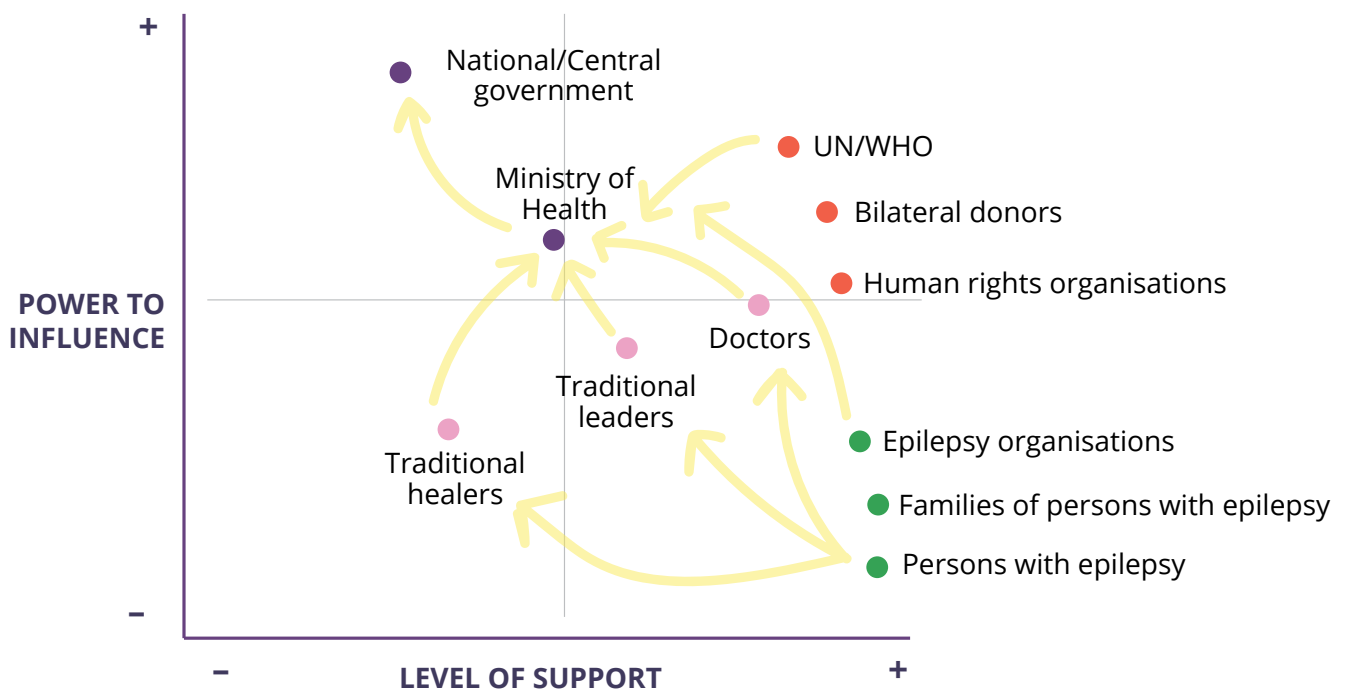


CONDUCTING A STAKEHOLDER ASSESSMENT: WHO ARE YOU GOING TO WORK WITH...AND WORK AROUND?

Now that you have your objectives, it's important to determine who might best support you and who might hinder you. You may want to engage local policymakers and traditional healers, 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 or 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 we're trying to convince a reluctant hospital director to make a change (your target decision maker), we might activate community activists and media (influencers) to generate pressure on the director to take action. While you are likely to need to account for many stakeholders in your advocacy 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 whereby third-party influencers (rather than your organisation) shape certain key stakeholders' behaviour indirectly.

The chart below shows an example of 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. The arrows within the diagram show where different actors might be able to influence others to create a larger impact.



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.

advocacy in action



PREVENTING EPILEPSY AND EXPANDING TREATMENT THROUGH AN ONCHOCERCIASIS CONTROL PROGRAMME

SOUTH SUDAN

ISSUE: Maridi County, South Sudan is one of a few onchocerciasis-endemic areas in South Sudan that has a high prevalence of epilepsy, or Nodding Syndrome—with some *bomas* (villages) recording an epilepsy prevalence as high as 11.9%.

E.F. is a six-year-old girl from the village of Araka, Maridi County, South Sudan. When she experienced recurrent fevers, seizures, and general body weakness, her father took her to a local traditional healer who recommended that E.F. eat alone, not eat chicken or goat's meat, and sleep separately from the other children to prevent her siblings from becoming sick. Unfortunately, E.F. did not get better and her health and nutritional status deteriorated. She became a concern to her father—emotionally, socially, and financially.

ACTION: Thankfully, Amref Health Africa and other nonprofit partners collaborated with the South Sudanese Ministry of Health to tackle the problem of epilepsy and Nodding Syndrome. This Nodding Syndrome Alliance launched an epilepsy clinic at Maridi County Hospital, where E.F. was diagnosed with epilepsy, enrolled for care, and initiated on free antiseizure treatment. Today, E.F. is improving and her family does not struggle financially to obtain treatment.

RESULT: Amref Health Africa's partnership with the Ministry of Health is improving the diagnosis and treatment of epilepsy at the primary care level. It is also enhancing the prevention of onchocerciasis, which can cause Nodding Syndrome and have grave impacts, especially on children.



Amref and partner organisations in South Sudan are actively advocating for greater treatment of epilepsy at the primary healthcare level.

WHEN WILL WE KNOW WE HAVE SUCCEEDED? KEY PERFORMANCE INDICATORS

As with any complex effort at social change, defining success is not always a simple process. In some cases, we know what we're trying to achieve and can somewhat easily track whether we've 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's 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're likely making progress. Ideally, the KPIs follow the SMART methodology of being specific, measurable, attainable, relevant, and time-bound, just as our objectives do.



SPECIFIC

Have you targeted a specific area for improvement?



MEASURABLE

How will you know when you have succeeded?



ATTAINABLE

Can the goal be accomplished? Is it realistic?



RELEVANT

Does this seem worthwhile? Is this the right time? Does this match our other efforts/needs?



TIME-BOUND

When will the result be achieved? (Your action may have a scope of anywhere from weeks to years.)

Here's an example of SMART KPIs:

GOAL: Improved access to antiseizure medicines in the region

SMART KPIs:

Medication stockouts are reduced by 20% at local primary healthcare facilities (**SPECIFIC**)

Working in cooperation with the regional health department, we will conduct inexpensive monthly surveys of select clinics to assess current drug stock levels (**MEASURABLE**)

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 (**ACHIEVABLE**)

Persons with epilepsy tell us that improved drug stocks would significantly improve their care (**RELEVANT**)

We are setting our goal to achieve our reduction in drug stockout rates in the next six months (**TIME-BOUND**)



FOCUS ON: WORKING WITH TRADITIONAL LEADERS AND HEALERS

Traditional leaders and healers often are gatekeepers of a community, and both are essential to have on your side in order to mobilise persons with epilepsy and to raise awareness within a community.

Traditional Leaders: When planning an advocacy campaign, it is important to check in with the local traditional leader ahead of time. Invite leaders to any event you are organising—ask if they would be willing to make opening remarks and if so, work with them to develop messaging that will emphasise your advocacy goals. Traditional leaders are deeply respected within their communities and beyond. Having their support can build the respect of their communities and draw the attention of other traditional leaders.

Traditional or Religious Healers: People have strong cultural beliefs and traditions. Advocacy cannot change these overnight. When engaging with traditional healers, the goal is not to convert them to conventional healthcare practices. Rather, a more realistic goal is to simply make them aware that alternative methods of treatment—such as antiseizure medication—exist. Because persons with epilepsy and their families often turn to traditional healers first, advocates should keep relationships with healers strong and seek creative ways to partner with them.



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 below table and begin to finalise our advocacy plan.

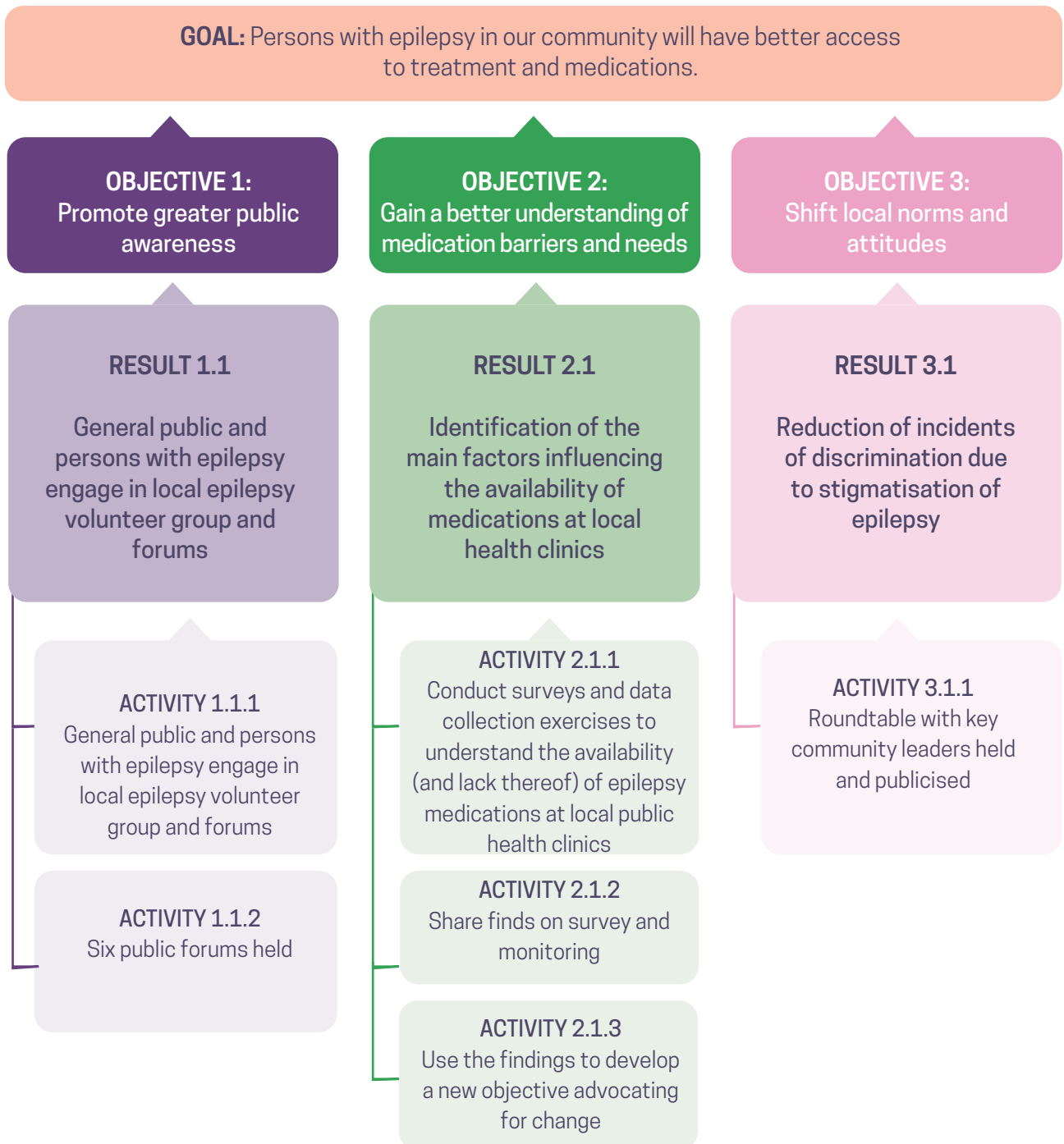
PERSONS WITH EPILEPSY IN OUR COMMUNITY WILL HAVE BETTER ACCESS TO TREATMENT AND MEDICATIONS.		
GOAL:		
OBJECTIVES	Improve availability of epilepsy medication.	Shift local norms and attitudes about the need for persons with epilepsy to be treated at public health clinics.
ACTIVITY (OUTPUT)	Conduct surveys 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	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	Survey questionnaire, staff to conduct the survey, staff to analyse data and write report on findings.	Location to hold roundtable, staff to engage and recruit community members and to organise and facilitate training, food and beverages for events.
KEY PERFORMANCE INDICATORS	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.

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





FOCUS ON: KEY FUNDING INVESTMENTS

Having enough funding is critical to every organisation. 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. There are three key investments you should make around funding:

INVESTMENT 1: 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 programme? 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 don’t forget to show your appreciation.

INVESTMENT 2: 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 your cause 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 organisation or cause that may not be direct asks for funding, such as in-kind donations (e.g., for transportation, office space for staff, etc.).

INVESTMENT 3: 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 organisation and, more importantly, on the people you serve. Collecting data at the start of your programme, 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.



HOW CAN YOU MANAGE RISKS?

When working in any situation, there is always the risk you won't 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, note the severity 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 programme	High	Low	Seek advice and lean on people in your network that are perceived favourably 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 programme timeline and local officials won't 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 programme 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 programme. Include ongoing engagement between medical staff and persons with epilepsy.

“Better a single decision than a thousand advisors.”

– AFRICAN PROVERB





FINDING NEW DRUG SUPPLY CHAINS

EPILEPSY SUPPORT ASSOCIATION UGANDA (ESAU)

ISSUE: In March 2020, the first case of COVID-19 was confirmed in Uganda. As cases increased, the Ministry of Health channelled most of its resources and personnel into fighting the pandemic and epilepsy was deprioritised. New cases of epilepsy were not being diagnosed and the drug supply collapsed. In addition, because everyone was quarantined at home, the association was having trouble reaching their members.

ACTION: In order to ensure that epilepsy patients were able to adhere to their medication, Epilepsy Support Association Uganda (ESAU) partnered with faith-based, nonprofit health centres that were able to bring antiseizure medication into the country.

RESULTS: Because of this collaboration, 1,240 persons with epilepsy were able to regain access to their medication from 25 partner faith-based health centres.



◀ ESAU's partnerships with a variety of actors ensured 1,240 persons with epilepsy had access to medication during the COVID-19 pandemic.



CONSIDER THIS

- Now it's your turn. In [Annex 2](#) are templates for each of the tools presented in this section. You can work through these yourself or refer to [Annex 3: Advocacy Planning Workshop](#) to help you work through these tools with your team and key stakeholders.
- Think about how you can leverage the impact of natural disasters or pandemics like COVID-19 to start a conversation with your local government, or Ministry of Health, to ensure that medical care of persons with epilepsy remains available during any emergency.

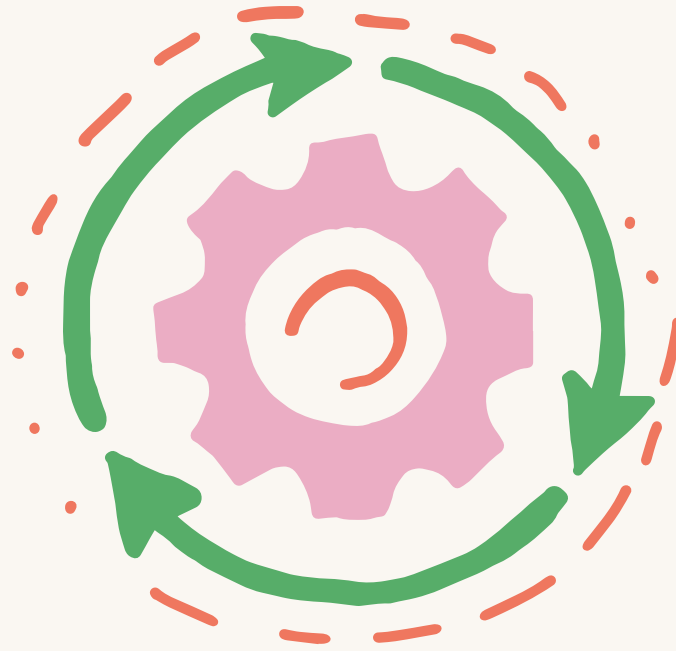


MODULE 2: RECAP

Planning your advocacy starts with understanding the problems faced by persons with epilepsy in your community. Taking a step back to have a look at the community you are working in can help you see connections and paths to change that you might not have seen before. There are many tools to help you:

1. Assess the specific situation in your community.
2. Define a goal and SMART objectives for addressing the situation.
3. Develop an advocacy plan to bring about change.





MODULE 3:

Taking Action

Once you have established your advocacy goal, objectives, and key stakeholders, you want to look at the specific activities you will take. There are many ways to advocate for change. Some are familiar for advocates, but there are always new and innovative ways to create change. Module 3 is a collection of ideas you may be familiar with, and if not, will hopefully bring inspiration.

TYPES OF ADVOCACY ACTIONS: WHAT ARE YOU GOING TO DO?



BUILDING COMMUNITY GROUPS

As an individual advocate, and especially as a person with epilepsy, **the first thing you can do is gather your friends, colleagues, and others in your local community to discuss the problems that you are facing and what can be done.** This can start by sharing recommendations, positive experiences with specific healthcare providers, resources you are aware of, and your own experiences to create a greater sense of community for you and others. From here, you may want to start thinking about small goals you can tackle and who you can involve to increase your credibility. Could you talk to a few sympathetic teachers at the local school about their policies around epilepsy and related disabilities? Might they then support you and even provide compelling information to take a message to the school board or Education Commission? These small goals can grow into larger ones. But creating a sense of community around your issues can be an immediate resource for everyone involved.



AWARENESS RAISING

Awareness raising is about getting your audience to see and understand the problem, the solution, and their role in both. Healthcare providers at your local hospital might tell you that your effort to establish a training programme is not needed because they do not currently serve many persons with epilepsy. However, you might know for a fact that there are many persons with epilepsy in your community who, for various reasons, don't 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. You could organise a walk around the hospital to demonstrate how many people do, in fact, need support, or you could invite healthcare providers and persons with epilepsy to a community forum or conduct a survey and share your findings.



MOBILISING

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

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UNIFYING VOICES OF PERSONS WITH EPILEPSY NATIONAL EPILEPSY ASSOCIATION OF MALAWI

ISSUE: In Malawi, there was no organisation that represented persons with epilepsy and that could advocate for their needs.

ACTION: In 2007, a group of persons with epilepsy formed a support group in Lilongwe. The intention was to voice their concerns about drug shortages and other social exclusion issues. The group grew and similar groups were formed across the country in six districts. This culminated into a full-fledged association in 2011.

RESULT: Persons with epilepsy now have a voice of their own and are advocating for their rights. They engaged with the Ministry of Health and (former) Ministry of Disabilities, pushing for epilepsy to be on the health and disability agenda. Since this engagement, there has been recognition of epilepsy by public health officials and antiseizure drugs are listed on the essential national drug list. The advocacy also helped to recruit new association members, and new groups formed in additional districts.



▲
The National Epilepsy Association of Malawi was formed in 2007 as a support and advocacy group, and has made progress toward getting epilepsy care and treatment on the public health agenda.



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 simultaneous activities designed around a clear message. For example, organising persons with epilepsy, the public, and educators to write letters to local government officials to ensure education rights are protected. Or organising a “walk for epilepsy” in which you engage stakeholders in helping you fundraise.

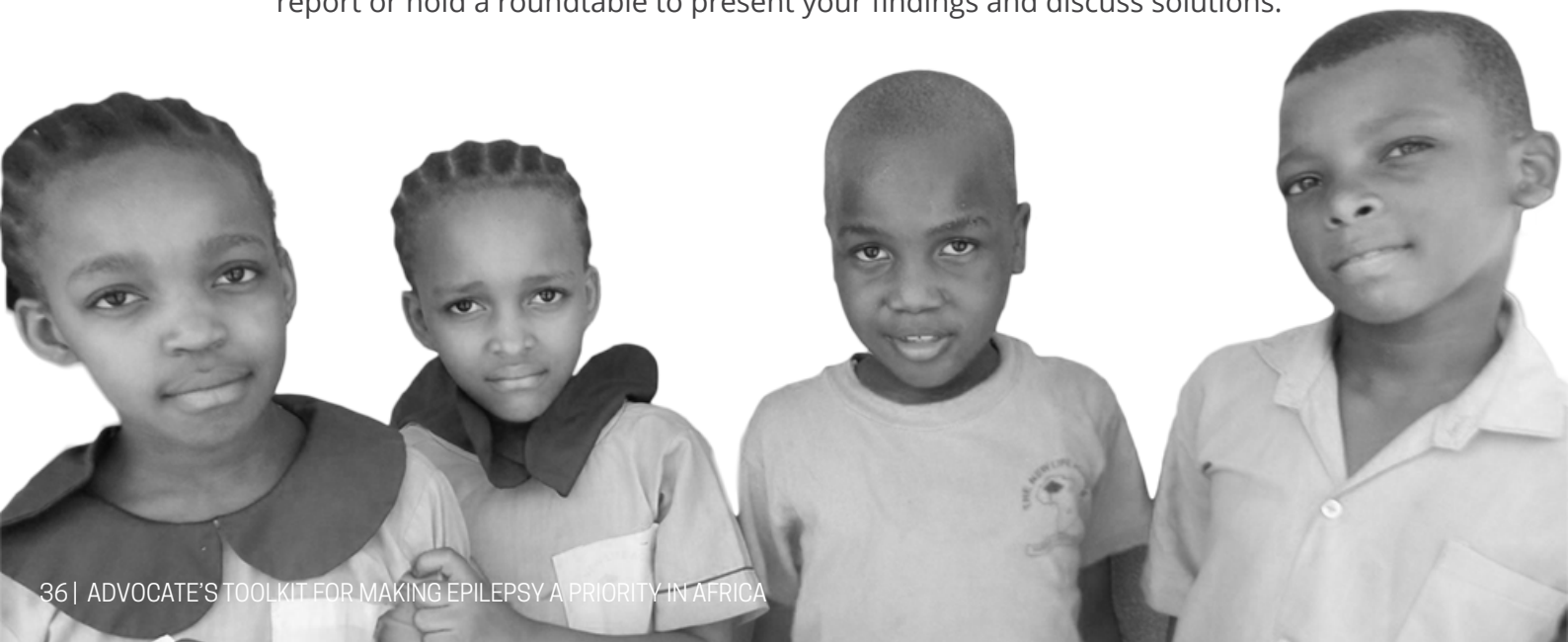
Campaigning often includes a communication aspect, such as posters, flyers, stickers, headbands, bracelets, short videos, or a collection of online stories. It can make use of social media platforms, such as Facebook or Twitter. It can be a video challenge asking people to post their videos on your Facebook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



ADVOCATING FOR POLICY CHANGE

Policy advocacy focuses on changing laws, practices, or public policies. Do you want an increased budget for government-subsidised antiseizure medications? To demand an existing law be upheld, like the right to education for all children, including children with epilepsy? When working with high-level officials, it's 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](#) or the UN Special Rapporteur's Report on Self-Representation.

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. Policymakers can be busy, so it's a good idea to bring both a problem and a solution. As always, interviewing government officials, educators, health professionals, persons with epilepsy, their families, and even other NGOs or funding agencies provides you with their perspectives and lays the foundation to engage them in your advocacy efforts early on. Invite them all to a launch event for the report or hold a roundtable to present your findings and discuss solutions.



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BRINGING EVERYONE'S VOICE INTO NEW POLICIES

EPILEPSY SOUTH AFRICA

ISSUE: In 2015, African countries committed to creating national strategies for implementing the World Health Assembly's Resolution on Epilepsy (WHA 68.20). South Africa was one of these countries. While it was a major milestone to have the government adopt this resolution, coordination and hard work are still needed to create and implement plans that respond to the needs of persons with epilepsy.

ACTION: In 2020, Epilepsy South Africa began to conduct a series of surveys to better understand the social, health, and economic factors impacting the lives of persons with epilepsy and their families in order to inform the new National Epilepsy Plan for South Africa. Aligned with the international disability slogan, "Nothing About Us Without Us," the work of Epilepsy South Africa is anchored in the concept of self-representation by persons with epilepsy. As such, persons with epilepsy are included in all planning, decision-making, and implementation processes of the organisation. The main target of its advocacy work is the National Department of Health, which is responsible for the implementation of Resolution 68.20 in South Africa. In order to liaise with this department successfully, the organisation works closely with the South African Chapter of the ILAE, which is made up of medical experts who can provide the technical expertise needed to inform conversations. In addition, the organisation also focuses its advocacy on the Department of Social Development, aiming to secure social protection for persons with epilepsy and to expand social development services in under- and unserved areas.

RESULT: At the time of publication, these surveys were still open for the public to complete. However, surveying a community or an entire country is an excellent way to make sure a wide range of voices is heard and integrated into public policy change.





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 prioritise 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 training and education plan. When you conduct your interviews again in the future, you should see improved results. You can then take these results to the next hospital, the local government, or at the national level to help you advocate for greater access to healthcare for persons with epilepsy.

Monitoring can also take the form of a report, which compares commitments to actual progress. Has your government committed to taking coordinated action under the World Health Assembly resolution on the Global Burden of Epilepsy? What have they done to make epilepsy a priority? Are there publicly available national strategies for achieving progress against those international commitments that you can track and monitor? How many commitments 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—highlight the problem and provide approaches to reduce the treatment gap.



OTHER ADVOCACY IDEAS

There are many ideas out there for how to create change. You can look for examples from peers in your network, from NGOs focused on issues other than epilepsy, and even look to what is generally considered commercial marketing. Here is a list of some additional tactics that you can embrace to help get your messages heard:

- **Host drawing, dance, or theatre competitions** with the theme of access to healthcare, or any other theme of your choosing.
- **Work with local companies to provide prizes** and support small events. You can keep costs low and still have impact without needing to secure major donors.
- **Get the help of a prominent figure.** Do you have any connections to anyone famous, even at the local level? Can you ask them to be a spokesperson or to share your message? People, especially youth, may be more likely to listen to someone they are familiar with. Look at your networks and see if there is anyone you can tap to share your message.

ESCALATION

Depending on your stakeholders—how open they are to listening and how willing they are to change—you may need to take different approaches. **Start friendly and only later escalate. Remember, it is always best to first start a conversation and listen so that you can understand the issue from their side.** If you ask the government for an informal discussion around its progress against commitments to Sustainable Development Goal 3 (on health) and they say no, what do you do? You might first have a local petition that asks for an open forum to discuss these issues. If officials don't agree to meet, you might get the media involved, publish a monitoring report, and so on. Facts, figures, and evidence are key in any discussion with officials that want to help make a change.

ENGAGING THE MEDIA

Ideally, an advocacy effort's media strategy amplifies and supports 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 summarise the vast amount of “media strategy” resources available to advocates; we, instead, 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's important to translate your complicated policy issues and advocacy “asks” into stories about the real-life impact on people. Be careful, however, to ensure that media outlets treat human stories with respect and dignity.
- » **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 isn't important to them, perhaps debates around universal healthcare 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?
- » **Nontraditional media are gaining influence.** Today, the media landscape is changing rapidly; instead of a 1,200-word piece in the newspaper, what might be more influential is a post to an influential WhatsApp or Facebook group. By using techniques such as PESTLE to analyse which forums are most important to the actors you seek to influence, you may discover that nontraditional media is 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.
- » **Targeting media houses.** What kind of language is used when talking about epilepsy, disabilities, and mental health issues? Going to media houses themselves and discussing their internal policies on these issues, and the principles under which they operate (i.e., respect for all, human rights, etc.), can help you open a dialogue and change the way epilepsy is presented in the media. You could also offer a seminar or training around these issues—which may be an effective way of gaining attention for your issues. Remember, the press likes a good story, so look at what major events are coming up, or develop your own human-interest stories that you can share when these topics are making the news. You can also ask to talk to journalists as training for your own staff. It may take time, but a good relationship with the media is always useful.

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INCREASING UNDERSTANDING OF EPILEPSY AND SAFE TREATMENT

EPILEPSY ASSOCIATION OF SIERRA LEONE

Issue: In Sierra Leone, there is still little understanding of epilepsy, especially in rural areas. Those with epilepsy often face devastating social exclusion, with profound educational and livelihood consequences, contributing significantly to poverty and ill health. The Epilepsy Association of Sierra Leone found that 74% of persons with epilepsy seek alternative treatments from traditional healers—which can include inappropriate, harmful, or dangerous practices—rather than go to a hospital or clinic.

Action: The Association wanted to increase knowledge of epilepsy by delivering persuasive, evidence-based, and solution-oriented messages through print, electronic, and TV advertisements. They also focused on capacity building and education of traditional healers, so when a person with epilepsy goes to them, they will be able to take care of them in an informed and safe manner or refer them for medical care.

Results: Through its work, the Association has observed a better understanding of epilepsy throughout the country, and the number of people who know about epilepsy clinics has increased—resulting in 11,500 new epilepsy patients seeking treatment in the past six years.



◀ The Epilepsy Association of Sierra Leone has raised mass awareness of epilepsy treatment through media engagement, widespread education initiatives, and capacity building of traditional healers.



FOCUS ON: RELATIONSHIP BUILDING

The messenger is often as important as the messaging

Advocacy strategies often centre on the idea that compelling evidence, arguments, and data will convince decision makers to embrace policy changes. 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, don't 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's particularly important not to forget that persons with epilepsy themselves may often be the most powerful and persuasive advocates and messengers.

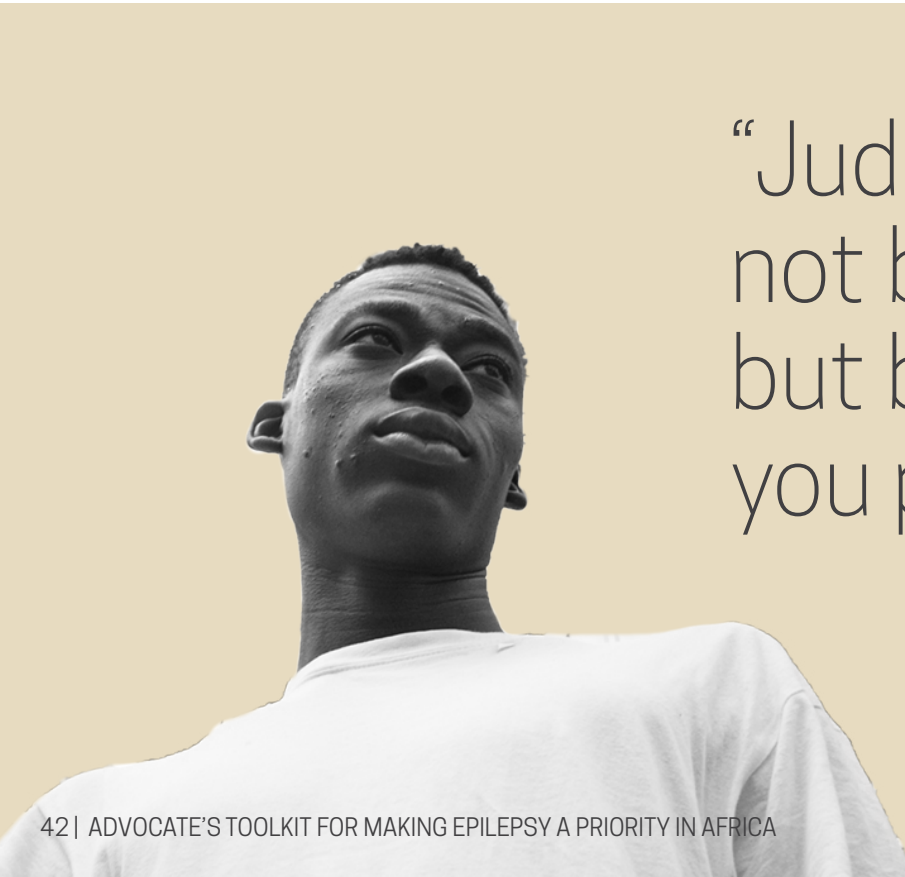
CONSIDER THIS

- What commitments have your local or national government made that you could monitor?
- Have you conducted a survey or interviews to generate data to demonstrate your progress? How could this help you to achieve your goal?



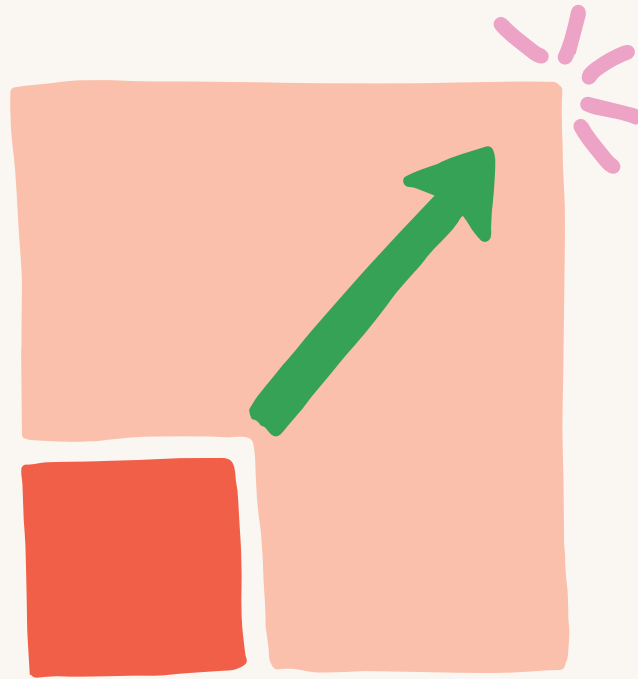
MODULE 3: RECAP

There are many ways to advocate for change, from building community groups and awareness raising, to mobilising, campaigning, and calling for policy change. The specific activities you decide to undertake will depend on your target audience and your goals. Whether working with the government, the media, or the community, building strong relationships and having a clear plan of engagement will help you achieve success.



“Judge each day
not by the harvest
but by the seeds
you planted.”

– AFRICAN PROVERB



MODULE 4:

Expanding Your Reach

WHAT ARE OTHERS DOING?

There are many organisations working on epilepsy across the globe (in particular, the IBE and the ILAE), and even more that advocate for improved healthcare. In some cases, partnering with organisations 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 healthcare 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:

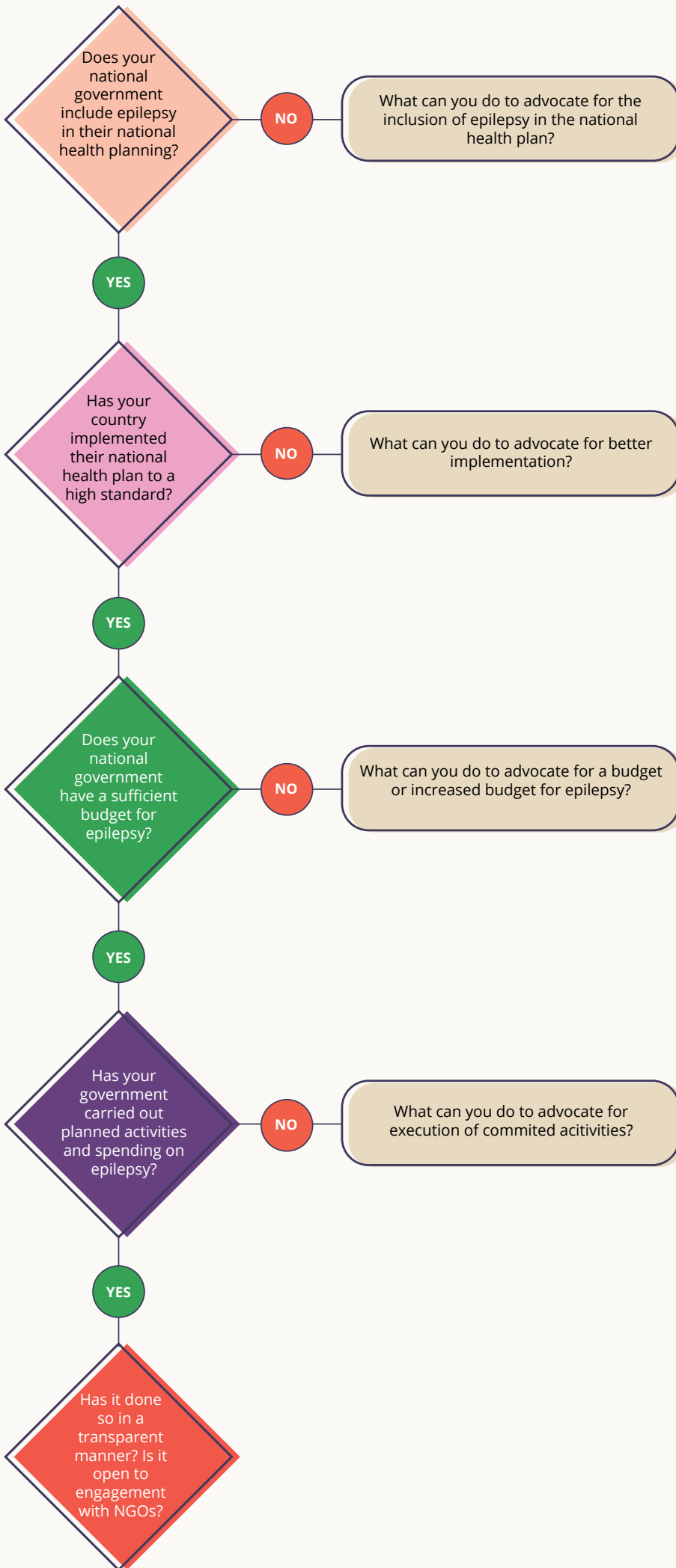
- Sharing information or best practices, increasing your connections, and learning from other experiences makes your organisation stronger.
- Having a network of like-minded individuals passionate about healthcare can build a sense of camaraderie and be a source of inspiration in what is often a difficult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

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.

There are several different approaches to take. One is to be loud and confrontational, especially if your government is set against engaging with you and you have a large amount of public support (this might take the form of a protest, a walk, or a demonstration). However, it is often easier to catch more bees with honey. Think about the people you are talking to. What are their jobs and priorities? Try to discover the real decision maker or obtain their latest budget, action plan, or strategy. Where might there be common interests that could make change mutually beneficial? Remember, a long-term positive relationship with governmental departments is likely to yield results as well as useful collaborative partnerships. Often, decision makers are simply too busy to come up with solutions themselves, so if you can provide realistic and implementable plans, they are going to be much more likely to hear you out.

An important strategy is to collaborate with decision makers on developing practical plans for implementing the often general and high-level international commitments that political leaders have made around epilepsy (for example, WHA Resolution 68.20). 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.



ADVOCACY ACTION FLOW CHART

Unsure of where to focus your advocacy efforts? There are so many places where you can focus your attention, it's sometimes hard to know. 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.

advocacy in action



COLLABORATING ON SHARED GOALS

ESWATINI EPILEPSY ORGANISATION

ISSUE: 70% of persons with epilepsy can live seizure-free with medication. Once a person with epilepsy begins treatment, they need to continue taking medication every day because a sudden stop in treatment can actually be fatal. When the COVID-19 pandemic reached Eswatini, antiseizure medication became increasingly hard to find. Eventually, the entire country was out of stock.

ACTION: The Eswatini Epilepsy Organisation brought this urgent issue to the public's attention through the national radio station and by publishing a column in the Sunday newspaper.

RESULTS: The Eswatini Epilepsy Organisation was overwhelmed by the responses to its public outreach and was invited to participate in the Civil Society Human Rights and Accountability Panel as a sitting member. This panel is in charge of tracking, reporting, monitoring, and advocating on human rights violations in the country. By collaborating with other groups focused on related but different interests, the organisation was able to have a louder and stronger voice to achieve its goals. Currently the pharmaceutical supply situation has improved.

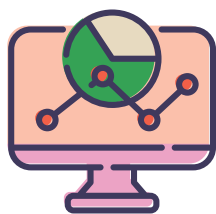


◀ The Eswatini Epilepsy Organisation raised awareness of the lack of antiseizure medications during the early days of the COVID-19 crisis and the danger that this posed to persons with epilepsy.

GOVERNMENT COMMITMENTS 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 epilepsy, or committing to achieving universal healthcare under the Sustainable Development Goals.^{iv} These public goals can be a great way to leverage and build on existing work. While most of these commitments are legally nonbinding, they do offer political leverage to advocates who can publicly question why their governments are failing to follow through on key reforms they approved. 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^v your government has made that will help to advance your agenda. The WHA resolution 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 organisations that house and support the commitment, and the press.**

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 an advocacy activity, such as a public report that notes progress and shortcomings related to 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 key data 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 their upcoming budget, and you have a contact who has helped you secure a meeting with someone relatively high up in the ministry, you might pitch 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.

iv See "Working with (and Through) Regional and International Bodies and Instruments" on page 50 for a more detailed look at these and other key actors on the international stage.

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



Ranking and rating (or naming and shaming), alongside monitoring and direct lobbying, can be a fraught yet highly effective method for influencing key decisions. **Ranking and rating can take many forms; some of the most notable are ranking governments, countries, or even specific decision makers against their peers.**

If your government has failed to live up to its WHA commitments, how does that performance compare to neighbouring countries and governments, or even globally? A simple infographic, chart, or “Top 10” list can be incredibly effective in focusing attention on the lack of progress; media, in particular, will often run stories touting these rankings. While care needs to be taken to use a defensible methodology for rating or ranking governments (for which there is abundant literature to consult), the upside can be significant. Bear in mind, however, that many officials inside government may feel particularly offended by a perceived poor ranking or rating, so factor that potential negative reaction into your decision-making and advocacy calculus.



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 long observed, budgets are where policymakers and politicians reveal their true agendas and priorities, regardless of campaign promises, speeches, and public pronouncements.

While effective epilepsy advocacy will naturally include asks around strengthening primary healthcare systems, 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 and a crucial tactic for matching increased political will for prioritising epilepsy treatment and stigmatisation efforts with the funds required to achieve those commitments. The International Budget Partnership, which works to enhance the budget advocacy skills of organisations around the world, offers tools and resources that are highly recommended for advocates. Other resources worth reviewing include specialised civil society advocacy networks that seek greater public spending in key human development sectors in low- and middle-income countries. In nutrition, Scaling Up Nutrition offers impactful approaches to pushing for greater government spending on the nutrition community’s key asks. In the Universal Healthcare (UHC) advocacy community, the African Collaborative for Health Financing Solutions’ Accountability Collaborative has experience across several African countries in efforts to mobilise greater public spending to reach UHC targets, despite resource-constrained budgets. These and other collective action efforts offer tactics and techniques that can serve epilepsy advocates well in ensuring that their priority issues receive the necessary piece of the [budget] pie.

advocacy in action



REPOSITIONING EPILEPSY IN THE MINISTRY OF HEALTH OF ZAMBIA

EPILEPSY ASSOCIATION OF ZAMBIA

ISSUE: In Zambia—and many other African countries—epilepsy treatment and care fall under the mental health programme within the Ministry of Health. Tying epilepsy to mental health reinforces its stigma and discrimination in the country. It also makes epilepsy the responsibility of mental health facilities and practitioners. Before the Epilepsy Association of Zambia began advocating for a separation of epilepsy and mental health, the Chainama College of Health Sciences,¹⁷ a mental health training institution in Lusaka, was the only health college with a comprehensive training curriculum on epilepsy. Because of this, clinical officers trained in psychiatry better understood epilepsy than general medical practitioners.

ACTION: The Association issued a questionnaire to health workers to figure out what they already knew about epilepsy; the answers they received helped to shape their goals and conversations. Advocates held meetings with Health Authorities, the WHO Country Office, persons with epilepsy, and care providers. These conversations led to the opportunity for the organisation to participate in the budget preparation for the Ministry of Health and to voice the need to move epilepsy out of the mental health programme.

RESULTS: Successful advocacy led the Zambian Ministry of Health to relocate epilepsy to the noncommunicable diseases programme. Because of this, patients with epilepsy are currently cared for by both general medical and psychiatry professionals. With the Ministry's support, eight new epilepsy clinics were established in Lusaka and the number of patients seeking care from these clinics is increasing. In other regions, mental health-focused clinics have designated special days specifically for epilepsy patients, prioritising their needs.



◀ The Epilepsy Association of Zambia helped broaden epilepsy care and advocated for additional budget support for epilepsy clinics.

WORKING WITH (AND THROUGH) REGIONAL AND INTERNATIONAL BODIES AND INSTRUMENTS

Epilepsy advocates should focus not only on their home turf of national, regional, and local governments but also explore whether and how engaging in global policymaking and advocacy forums can advance their work at home. Despite the costs and complexities of navigating global mechanisms, the benefits 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 forums is to advance government adoption of political and policy principles that align with the advocate's goals. Statements and resolutions signed by governments at these forums—even if legally nonbinding—help create political opportunity in home countries for advocates to leverage their government's public statements and declarations, holding them accountable and pushing for more ambitious reforms. Thus, while sometimes frustrating and time consuming to engage in the minutiae of international diplomacy, the rewards can be significant.

The below section gives a snapshot of the main conventions and organisations at the international level. Additional information on each is available through the links provided. Exploring which of these organisations and conventions has the most influence on your national and local policymakers will help you to amplify your message and generate increased advocacy leverage.



World Health Organization

THE WORLD HEALTH ORGANIZATION

As an advocate for epilepsy, you probably know that WHO is the largest global health organisation. But did you know that it's also a great resource for epilepsy advocates? There are a number of useful publications worth checking out, such as the [WHO Information Kit on Epilepsy](#) and the 2019 report "[Epilepsy: A Public Health Imperative](#)," both of which outline roles for persons with epilepsy, their families, the general public, healthcare institutions, and governments. It also provides numerous tools from a programme it developed called "Reducing the Epilepsy Treatment Gap." Many of these tools are free and shareable upon request.

One of the most useful things WHO can provide advocates with is standard language and focus for advocacy messaging. Those key messages can be found in the "[Epilepsy: A Public Health Imperative](#)" report, and they can help guide your communications and focus for change.

AFRICAN UNION

In 2018, the African Union adopted the [Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa](#), a historic milestone for the protection of universal human

rights for the 84 million Africans with disabilities. All African Union member states have signed up for the Charter and are now being called upon to ratify this protocol. By holding governments accountable to their human rights obligations and by creating space for greater inclusion of the concerns of persons with disabilities in laws, policies, and budgets, the lives of persons with disabilities in Africa have an opportunity to be considerably improved.





THE WORLD HEALTH ASSEMBLY RESOLUTION ON THE GLOBAL BURDEN OF EPILEPSY

The World Health Assembly (WHA) is the decision-making body of WHO and convenes representatives from all WHO member states annually in Geneva, Switzerland. The 68th WHA passed the resolution on the global burden of epilepsy and the need for coordinated action at the country level to address its health, social, and public knowledge implications in January 2015.¹⁸ The resolution urges member states to take a series of actions around leadership, implementation, integration, promoting public awareness and prevention, as well as engaging with civil society on the topic of epilepsy. Like other WHO resources highlighted above, it is recommended that advocates review the WHA resolution in detail for potential advocacy entry points at the national and local levels in their respective country contexts.

THE UNITED NATIONS SUSTAINABLE DEVELOPMENT GOALS

“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 recognise that ending poverty must go hand-in-hand 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.”¹⁹



Developed by the United Nations, the SDGs are the universally agreed roadmap 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 54 African nations. Used as a basis for the majority of government and donor development strategies, the SDGs are important for you, as an epilepsy advocate, to be familiar with, especially Goal 3 focused on health (and 3.8 specifically on universal health coverage). It can be a way to engage policymakers on their current priorities, as well as to come together and connect with other advocates such as those focused on disabilities, mental health, or human rights, who are also basing their advocacy messages around these same SDG commitments.



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, 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 in order to exercise their rights and areas where their rights have been violated, as well as where protection of rights must be reinforced. Only a handful of African countries have failed to sign or ratify the convention.²⁰

CONSIDER THIS

- Is your government one of the WHO member states that has not committed to implementing the coordinated action outline in the [World Health Assembly resolution](#) on the Global Burden of Epilepsy and the Need for Coordinated Action at the Country Level to Address its Health, Social and Public Knowledge Implications?
- What about the other conventions noted above? If so, how could you leverage these international agreements to encourage your government to act?

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, fundamental human rights to be universally protected and it has been translated into over 500 languages.

Be sure as well to follow the WHA73 resolution and find out what your government is doing. For more information [see this document](#).

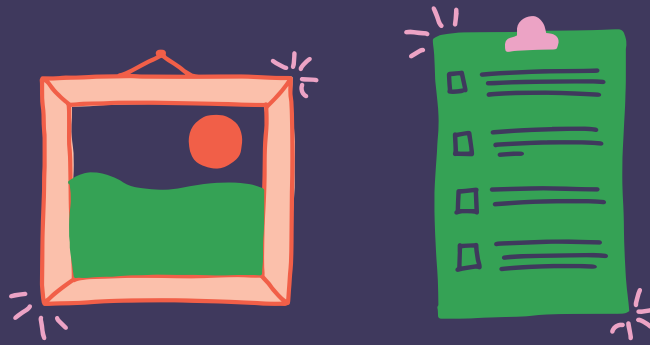
MODULE 4: RECAP

While there are many activities you can do on your own, working with others to advocate for change will increase your reach and your impact. Partnerships bring like-minded people together to work toward a collaborative goal. When working with governments, it is important to understand who the key players are in the decision-making process. There are also many regional and international organisations with existing platforms that you can engage with to work toward collective change, or work to include your key messages in their advocacy to optimise impact and create additional pressure on local or national governments.

“Teamwork without coordination leads to confusion.”

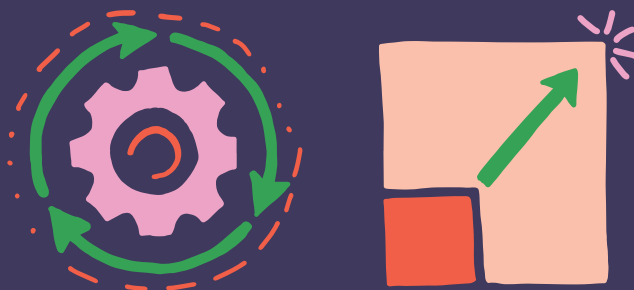
– AFRICAN PROVERB





You have now explored how to plan, take action, and expand the reach of your advocacy. 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 Annex 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 don't give up, don't 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 don't forget that progress has been made and that opportunities exist to make epilepsy a health priority.

The time is ripe. Good luck!





Annexes

ANNEX 1: GLOSSARY

ANNEX 2: TOOL TEMPLATES

ANNEX 3: ADVOCACY PLANNING WORKSHOP

ANNEX 1:

Glossary

Advocacy: The act or process of supporting a cause or proposal.

Campaigning: Actions, events and activities conducted by people working together who seek to achieve a change and/or raise awareness on a defined issue.

Chronic: A condition that persists for a long time or is constantly recurring.

Epilepsy: A disease of the brain defined by any of the following conditions:

1. At least two unprovoked (or reflex) seizures occurring greater than 24 hours apart.
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
3. Diagnosis of an epilepsy syndrome.

Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for 10 years, with no seizure medicines for the last five years.

Grassroots: Being, originating, or operating in or at the community level.

Noncommunicable condition: A medical condition that is not infectious and not transmissible among people.

Perinatal: The time, usually a number of weeks, immediately before and after birth.

Prenatal: Before birth; during or relating to pregnancy.

Seizure: Sometimes the neurons in the brain don't signal properly and cause a sudden burst of electrical energy, or what is known as a seizure. Seizure symptoms depend on where the abnormal bursts of electrical activity occur in the brain. Seizures may be observed as a transient change in sensation, movement, behaviour, or consciousness. Since the brain is responsible for a wide range of functions, there are many different types of seizures.

Stakeholders: Persons with an interest or concern in something (in this case, epilepsy).

Stigma: A mark of shame or discredit associated with a particular circumstance, quality, or person.

Subsidised: (Of an item) supported financially.

Treatment gap: The difference that exists between the number of people who need care and those who receive care.

Universal healthcare: All people have access to the health services they need, when and where they need them, without financial hardship. It includes the full range of essential health services, from health promotion to prevention, treatment, rehabilitation, and palliative care.



ANNEX 2:

Tool Templates

Here you'll find blank versions and instructions for the tools discussed in the body of the text. 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.

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?

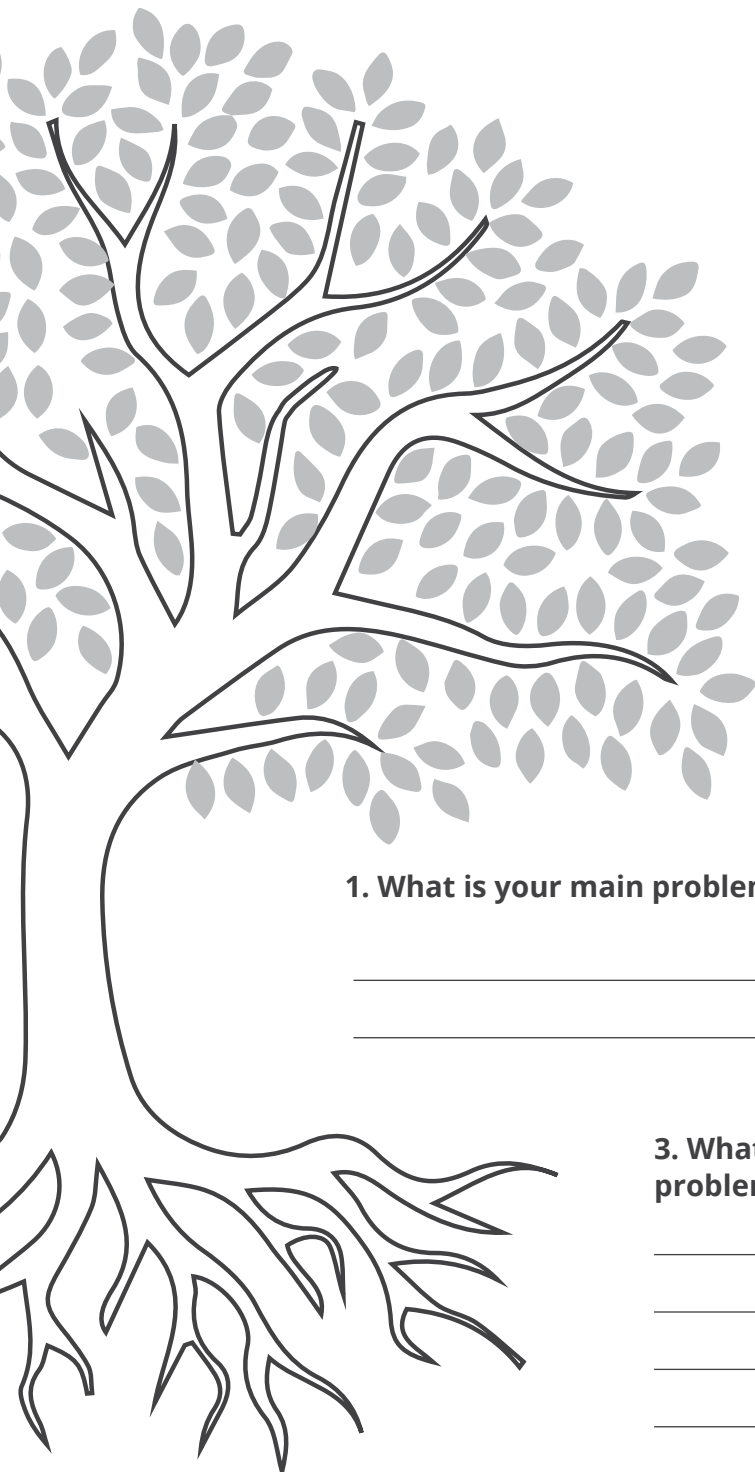
6. Why is that a problem?

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

PROBLEM TREE

**LEARN
MORE ON
PAGE 18**

Instructions: For the main problem you've identified, brainstorm the effects that 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

**LEARN
MORE ON
PAGE 19**

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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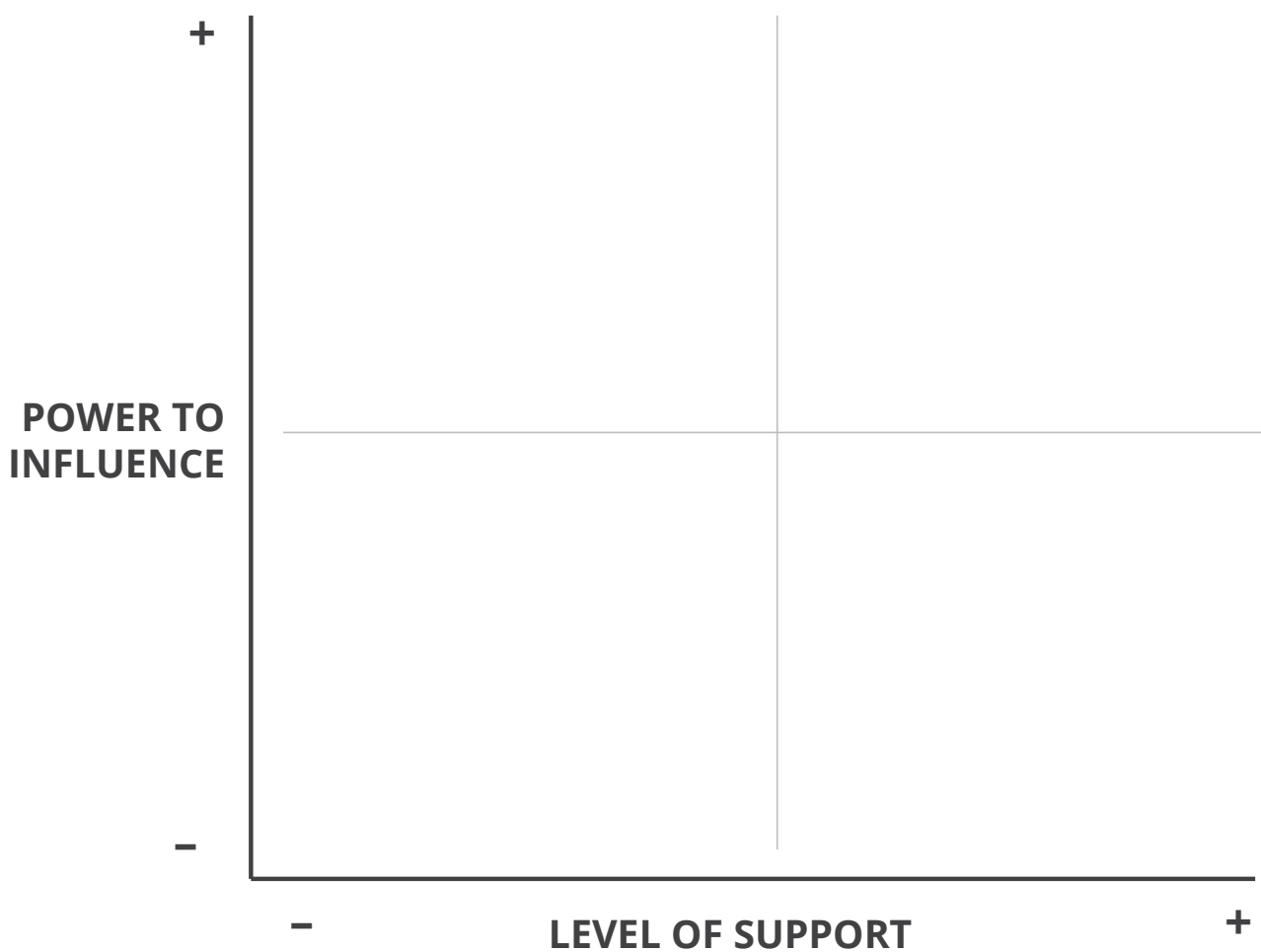
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STAKEHOLDER ASSESSMENT

LEARN
MORE ON
PAGE 23

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

**LEARN
MORE ON
PAGE 27**

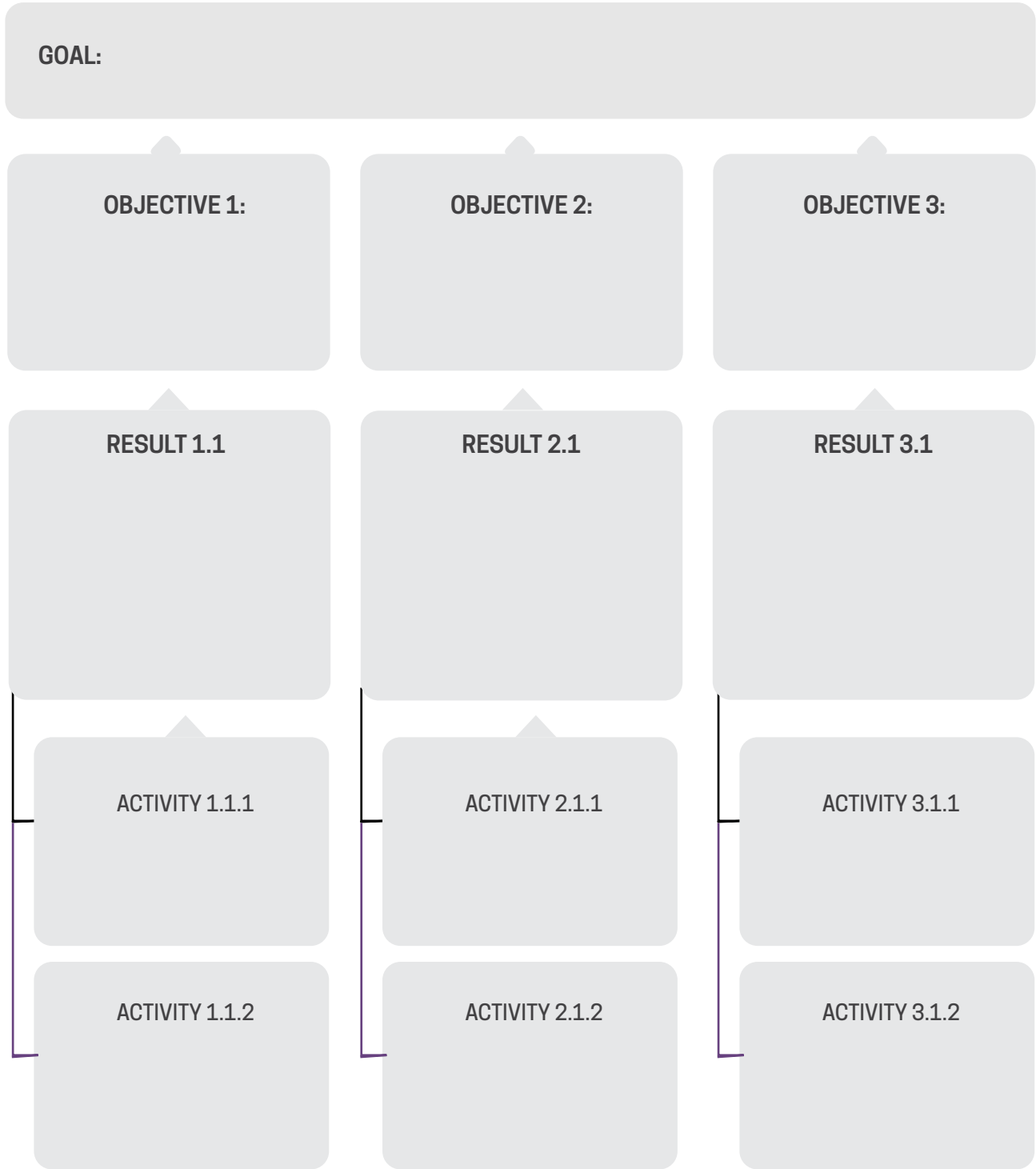
Instructions: Once you've defined a SMART goal, set objectives, and identified key stakeholders and KPIs, you can complete the table below. Note that you may need fewer or more objectives to reach your goal, but three is a good place to start.

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

RESULTS FRAMEWORK

**LEARN
MORE ON
PAGE 28**

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

LEARN
MORE ON
PAGE 29

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 doesn't 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's often best to hold a workshop with colleagues, stakeholders, and even beneficiaries, to gather ideas and work through solutions. So how do you organise 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 white board, 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 won't 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 programme? 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 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 don't 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

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	Tea 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

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

ENDNOTES

- 1 Merriam-Webster.com Dictionary, s.v. "advocacy," accessed November 12, 2020, <https://www.merriam-webster.com/dictionary/advocacy>.
- 2 "Raising Awareness through Public Outreach Campaigns," SDG Accountability Handbook, TAP Network, accessed November 11, 2020, <https://sdgaccountability.org/working-with-informal-processes/raising-awareness-through-public-outreach-campaigns/>.
- 3 "Epilepsy Fact Sheet," World Health Organization, July 20, 2019, <https://www.who.int/news-room/fact-sheets/detail/epilepsy>.
- 4 Baingana, Florence, "Epilepsy in Africa Today: WHO Perspective" (Webinar, IBE Africa Region Webinar: Making Epilepsy a Health Priority, September 23, 2020).
- 5 "Epilepsy in the WHO African Region: Bridging the Gap," The Global Campaign Against Epilepsy, World Health Organization (2004) https://www.who.int/mental_health/management/epilepsy_in_African-region.pdf.
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- 7 Ba-Diop, Awa et al., "Epidemiology, causes, and treatment of epilepsy in sub-Saharan Africa," *The Lancet, Neurology* vol. 13, 10 (2014): 1029-44 doi:[10.1016/S1474-4422\(14\)70114-0](https://doi.org/10.1016/S1474-4422(14)70114-0).
- 8 Baingana, 2020.
- 9 Baingana, 2020.
- 10 "Epilepsy: A Public Health Imperative," pp. xi-xii. For additional information and international messages, see: https://www.who.int/mental_health/neurology/epilepsy/report_2019/en/.
- 11 "Epilepsy Fact Sheet," 2019.
- 12 Fodjo, Joseph Nelson Sieww, et al., "Economic Burden of Epilepsy in Rural Ituri, Democratic Republic of Congo," *EClinicalMedicine* vol. 9 (2019): 60-66 doi: [10.1016/j.eclinm.2019.03.010](https://doi.org/10.1016/j.eclinm.2019.03.010).
- 13 Baingana, 2020.
- 14 These key messages reference the key themes of WHO's report, "[Epilepsy: A Public Health Imperative](https://www.who.int/mental_health/neurology/epilepsy/report_2019/en/)."
- 15 "Epilepsy: A Public Health Imperative," pp. xi-xii. For additional information and international messages, see: https://www.who.int/mental_health/neurology/epilepsy/report_2019/en/.
- 16 Thurman, David et al., "The primary prevention of epilepsy: A report of the Prevention Task Force of the International League Against Epilepsy," *Epilepsia* vol. 59, 5 (2018): 905-914 doi:[10.1111/epi.14068](https://doi.org/10.1111/epi.14068).
- 17 The Chainama College of Health Sciences merged with the Levy Mwanawasa Medical University (LMMU) in August 2019 and now operates under the LMMU name.
- 18 "Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications," ([World Health Assembly, Resolution WHA68.2](https://www.who.int/news-room/fact-sheets/detail/epilepsy), eighth meeting, 29 January 2015), <https://www.ibe-epilepsy.org/wp-content/uploads/2015/05/NewResolutionText.pdf>.
- 19 Sustainable Development Goals, United Nations, accessed on November 12, 2020, <https://www.un.org/sustainabledevelopment/>.
- 20 Western Sahara, Eritrea, Somalia, South Sudan, Equatorial New Guinea, and Botswana. To find out more information about your country, see <https://www.un.org/disabilities/documents/maps/enablemap.jpg>.

“Having epilepsy can be a challenge for children, adolescents, and their families. It fundamentally alters relationships and life trajectories. Given the burden of epilepsy for sufferers and their carers, increased funding in all areas of epilepsy research, treatment, and care can promise to improve their lives and prognoses.”

– His Royal Highness
Prince Bandzile of Eswatini


ACKNOWLEDGEMENTS

This toolkit was developed in partnership with a variety of essential stakeholders who kindly provided their time and expertise. Thank you to the IBE representatives and chapters that thoughtfully filled out surveys and had follow up conversations about how this toolkit could be most informative and useful. Special thanks to Action Amos, whose visionary leadership and ongoing advocacy helps advance the rights of persons with epilepsy. Thank you to the WHO Regional Office for Africa and the IBE Africa Advocacy Committee for their input on this document and for bringing epilepsy out of the shadows. We also appreciate the BAND Foundation, whose generous support has made this toolkit possible. Most importantly, thank you to all of the persons with epilepsy and their families who so bravely shared their perspective and commitment to make epilepsy a healthcare priority in Africa and around the globe.

CONTENT DEVELOPMENT: Geneva Global | www.genevaglobal.com

IMAGES: IBE and its Africa chapters, AMREF

DESIGN: Jennifer Geib {communication design} | jennifergeib.com



“Education is the
most powerful
weapon which you
can use to change
the world.”

– NELSON MANDELA,
FORMER PRESIDENT OF SOUTH AFRICA

**For more information, visit
www.epilepsyafrika.org**