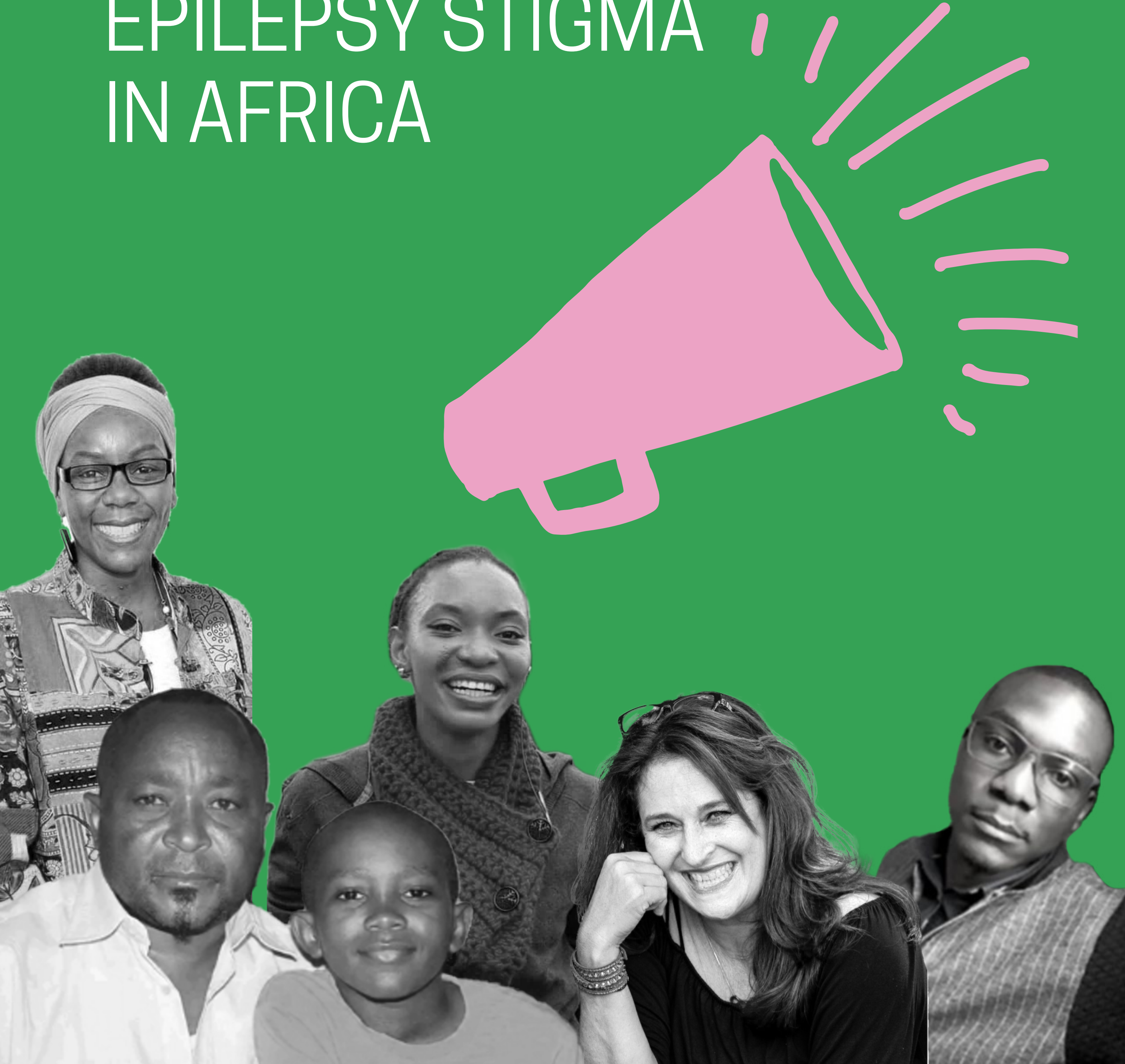
Advocate's Toolkit

FOR REDUCING EPILEPSY STIGMA IN AFRICA



IBE International Bureau for Epilepsy

Dear Friends,

This toolkit is a milestone in IBE's commitment to empower people with epilepsy. It recognises that stigma is a major barrier preventing social inclusion and access to health care and treatment for people with epilepsy.

The stigma surrounding epilepsy takes many forms and infects every aspect of the lives of people with epilepsy. Stigma is present in the family, community, school, clinic, and workplace. As a result, people with epilepsy tend to hide their condition and are precluded from a life of dignity.

This toolkit is full of resources, ideas, and guidance for addressing and dismantling stigma in the various communities on the African continent. The toolkit was developed to help advocates to be proactive in shaping communities that are inclusive of the needs of all people with epilepsy.

I am grateful to all who contributed to this project which brings us one step closer to a transformational social change so badly needed by people with epilepsy in Africa.

–Francesca Sofia, President IBE

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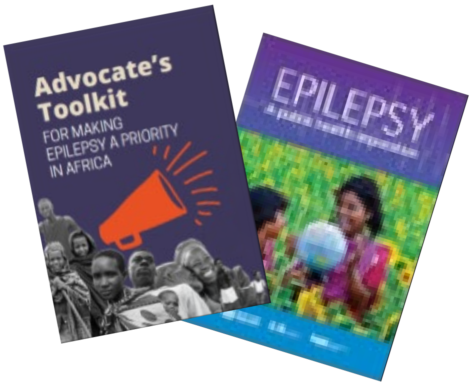


This toolkit is intended to be a 'how to' guide for recognising distinct types and forms of stigma. It contains practical information, best practice examples, case-studies and templates to enhance an advocate's capacity to engage in effective stigma reduction interventions. It is a companion to the *Advocate's Toolkit for Making Epilepsy a Health Priority in Africa* and *Epilepsy: A public health imperative*.

Throughout this toolkit you will also see references to the IGAP which is the *Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022-2031*. In May 2022, all 54 African member states endorsed this plan which includes the following global targets specifically for epilepsy:

GLOBAL TARGET 5.1

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

GLOBAL TARGET 5.2

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

Throughout this toolkit you will see the use of ***italics*** to indicate the words and experiences of people with epilepsy from Africa. IBE chose a community based participatory approach, inviting people with epilepsy and their families to identify the content for this toolkit. This approach underscores the importance of having people with epilepsy engaged in the development of stigma reduction interventions. People with epilepsy, their care providers and care partners can provide unique insight into the socio-cultural aspects of stigma and are best suited to identify the personal impact of social marginalisation and discrimination. People with lived experience understand the perspectives of the specific target audiences and can help determine the best mechanisms or platforms to reach them.

By endorsing this IGAP, member states acknowledge that people with epilepsy and other neurological disorders have the following rights:

» **Right to health care**

» **Right to safe and affordable medicines**

» **Right to be educated**

» **Right to paid work**

» **Right to fully participate without discrimination in their communities**

This toolkit has been designed to give people with epilepsy and other neurological conditions the guidance and tools to ensure these human rights are no longer denied.

ONLINE RESOURCE PORTAL

You can easily find all of the resources mentioned in this toolkit at **www.ibe-epilepsy.org/stigmatoolkitafrica**

advocacy in action

When **Sharlene (South Africa)** was diagnosed with epilepsy at the age of 8, her parents were told to put her in a special needs school but they outrightly refused. Sharlene believes her parents set out her future path as a person WITH Epilepsy and NOT a person whose life would be defined by Epilepsy. In April 2021, Sharlene was appointed as National Director for Epilepsy South Africa. Sharlene has a degree in psychology and education and is a role model for people with epilepsy. She challenges stigma by helping people with epilepsy to access information and supportive programs.

SECTION 1:

Understanding Stigma

LEARNING OBJECTIVES

1. Know the difference between felt and enacted stigma
2. Understand the impact of internalised, interpersonal and institutional stigma
3. Identify the misconceptions, labels and stereotypes that perpetuate epilepsy stigma in Africa

stig·ma

['ad-və-kə-sē] noun

an attribute, behavior or reputation which is socially discrediting in a particular way; it causes an individual to be mentally classified by others in an undesirable, rejected, stereotyped way.[1]

HEALTH-RELATED STIGMA

Health-related stigma is typically a social process characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group. The judgement is based on an enduring feature conferred by a health problem or health-related condition, and the judgement is in some essential way medically unwarranted.[2]

» **Felt stigma:** The shame, embarrassment or disgrace of having epilepsy or the fear of being discriminated against.

» **Enacted stigma:** the actual instances of discrimination because of the diagnosis of epilepsy.

» **Reflected stigma:** stigma by association, affects family members, care and health providers.

IN THE 18TH CENTURY BRITISH NEUROLOGIST HUGHLING JACKSON IDENTIFIED EPILEPSY AS A BRAIN DISORDER

The word "epilepsy" is from the Greek word 'epilambanein', meaning "to seize" or "to attack". It is described in many cultures, in ways that suggest mystical or supernatural origins. In ancient times, epilepsy was believed to be a sacred disease resulting from invasion of a body by a god; it was thought that only a god could deprive a healthy person of their senses, throw them to the ground, convulse them, and then rapidly restore them to consciousness.[3]

Epilepsy affects people of all ages, genders, races and income levels. Poor populations and those living in low- and middle-income countries bear a disproportionate burden, which poses a threat to public health and economic and social development.[4]

advocacy in action

In 2004, **Golden Chikaphonya (Malawi)** started having seizures. At school people would tease and isolate him. People associated his seizures with 'misala' (madness). In 2010 he heard about an awareness event offered by the National Epilepsy Association of Malawi. He attended the meeting and later formed a support group in his district. People in his community now call him 'Advokota' (doctor) because of the awareness he created around epilepsy.

THREE BROAD CLASSIFICATIONS OF STIGMA

INTERNALISED STIGMA
(person with epilepsy)
Internalised stigma is felt within the person with epilepsy and reflects their feelings, thoughts, beliefs and fears about being different.

For example:

"Epilepsy has caused me to feel low self-esteem, lack of confidence, abandonment, traumatisation and demoralisation."

INTERPERSONAL STIGMA
(family)
Interpersonal stigma is the negative actions and reactions of significant others (within and external to the family system) towards the person with epilepsy.

For example:

"As a family we were discriminated and ostracised by members of our community who believed that we bewitched our sister to acquire riches and wealth."

INSTITUTIONAL STIGMA
(society)
Institutional stigma is the societal position taken, as embedded in its laws and statutes.

For example:

"I had a seizure at work, and I was fired. I could not talk about it. I knew why I lost my job, but it was too difficult to go after my employer because there were no laws to protect me."

advocacy in action

Jessie (Zambia) experienced her first seizure at the age of 14 and nobody knew what was happening or what to do to help her. It took her 6 years to get a diagnosis and a treatment plan. Jessie joined the Epilepsy Association of Zambia where she is an advocate who fights stigma which she believes is a result of ignorance. To overcome stigma, she openly speaks to people in the community, on the radio and through social media, working to break the taboo.

HOW DOES EPILEPSY STIGMA AFFECT THE FAMILY?

This tool provides insight into the impact of internalised and institutionalised stigma. Using this same template, add content on how epilepsy stigma can affect members of the family (parents, grandparents, siblings, etc.).

INTERNALISED STIGMA (PERSON WITH EPILEPSY)
Causes the person to feel socially isolated, anxious, hopeless, depressed
Causes the person to conceal their diagnosis feeling shame and blame
Impacts their Relationships (family, marriage, school, work, church, community)
Causes poor physical and mental health
To avoid being labelled the person may avoid seeking medical care. This can cause a medical crisis (injury, status epilepticus, or worst-case scenario death)
INTERPERSONAL STIGMA (FAMILY MEMBERS)
INSTITUTIONAL STIGMA (SOCIETY)
Punitive laws (marriage, employment, housing, education)
Lack of protective legislation (employment, education, marriage)
Lack of training for healthcare workers and first responders
Lack of access to affordable, safe, anti-seizure medications
Insufficient budgets

MISCONCEPTIONS, LABELS AND CULTURAL STEREOTYPES THAT PERPETUATE STIGMA IN EPILEPSY IN AFRICA

To identify the misconceptions and labels that cause stigma, IBE held two focus groups of people with epilepsy and their caregivers. People in these focus groups spoke about community misconceptions related to the cause of epilepsy. They said it is not uncommon for people in both urban and rural communities to believe that people with epilepsy are demon possessed or bewitched, and that this possession was caused by their family members. In this next section – we 'NAME' these stigmatising beliefs and provide the facts to counter these misconceptions. We also provide examples of how these misconceptions burden people with epilepsy and their families.

MISCONCEPTION	THE FACTS	“ THE IMPACT OF STIGMA
People with epilepsy are demon possessed (bewitched).	Epilepsy is a chronic non-communicable disorder of the brain, characterised by recurrent unprovoked seizures. A seizure is caused by excess electrical activity in the brain – it is not caused by witchcraft or evil spirits.[5] Epilepsy has many causes. It may occur in people who have a past history of birth trauma, brain injury (including head trauma and strokes), or brain infections. It may be genetic.[6]	*“In most parts of Africa there is a belief that there is a traditional concoction that can make you rich. The secret is that you need to sacrifice someone so the witch doctor will cast evil spirits on the sacrificial person and that can cause epilepsy or madness.”* *“Even people with epilepsy may believe they are demon possessed. They may say that somebody was trying to pull my leg or pull my hand – the devil was reaching for me.”*

MISCONCEPTION	THE FACTS	“ THE IMPACT OF STIGMA
People with epilepsy and their family members are to blame.	10 million people in Africa have epilepsy. Epilepsy is a disease of the brain. 1 in every 10 people will have a single seizure in their lifetime. Epilepsy is a medical term that is given to a person who has had 2 unprovoked seizures or 1 seizure with a strong possibility that they will have another.	***“I have heard stories of children with epilepsy living in houses with chickens, tied and chained away from the family.”*** ***“Once the community knows – this is when the labelling comes in. They will blame it on your parents because they want to be rich.”*** ***“When you tell your partner that you have ‘epilepsy’ they may not want to marry you.”***

advocacy in action

It was a normal day at the grocery store until **Tholoana (Lesotho)** had a seizure at the till. She was told that people literally ran away except for one staff who unknowingly did all the wrong things to help her. At a later date the manager allowed her to speak to the staff and to explain what epilepsy is and what they can do to help. From that day forward, she chose to talk about her epilepsy and to educate others.

In the focus groups, the participants spoke about the common community misconception that people with epilepsy are mad, insane or crazy.

MISCONCEPTION	THE FACTS	“ THE IMPACT OF STIGMA
People with epilepsy are mad/insane/crazy	Epilepsy is a neurological condition. It is a non-communicable disease.	*“My mom would tell them – my daughter is not mad, why are you taking her there?”* *“Our healthcare system treats epilepsy like it is a mental health problem. People need to get their medication at the national psychiatry center. The word for this institution literally translates into ‘mad people’. He is going to get his ‘crazy’ medication.”*

NAME IT – REFRAME IT

For this tool, chose a misconception that perpetuates stigma. Use the questions in the 'Name it' category to guide you in finding ways you can correct the misconception or 'Reframe it'.

NAME IT	REFRAME IT
Name it…what is the belief? People with epilepsy are mad or insane	Epilepsy is a treatable brain disease that affects 10 million people in Africa. Epilepsy is a medical term that is given to a person who has recurrent seizures. A seizure is caused by excess electrical activity in the brain.
Who perpetuates the belief?	People who are ignorant of the facts and those who do not have scientific or biomedical knowledge about epilepsy (target audiences: individuals, families, Traditional and Faith Healers, etc.) Institutions and health ministries that treat people with epilepsy in psychiatric institutions.
Why do they perpetuate this belief?	
How does this belief stigmatise people with epilepsy?	
What can we do to reframe the belief?	
Who can assist to destigmatise this belief?	
What are the potential barriers to reframing the belief?	

IDENTIFYING CARE PATHWAYS

In many African communities, people with epilepsy are either treated by psychiatrists in the mental health system or traditional and faith healers in the community. When designing programs and materials to reduce stigma it is important to consider the local culture, language and community literacy levels. It is also important to identify the local care pathways.

> *“The lack of guidelines for care forces people with epilepsy to cycle from witch doctor to clinic back to witch doctor seeking remedies.”*

> *“The conviction in my family was that it was a curse and needed prayers, as well as hidden visits to some traditional healers. It took us six years to get a proper diagnosis of epilepsy.”*

> *“The first port of call is to go to a witch doctor or a faith healer. By going to the witch doctor, it is an indication of a certain belief that there is a certain cause, so they are looking for a remedy.”*

> *“At the clinic there are drugs that are expired on the counter, so people don’t buy them, and the costs of news ones is so high.”*

> *“My mother took me to an herbalist who would induce me to vomit so that I bring out the bad things I might have unknowingly consumed as a toddler, but herbalists didn’t work. I was taken to a number of men of God for deliverance, but the seizures would still occur. I got relief at a referral hospital that proved that my brain was fine, but I had to start anti-seizure medications, which have greatly reduced my seizures.”*

IDENTIFYING CARE PATHWAYS

Pastors and traditional healers in many African countries outnumber biomedical health professionals. They often provide high quality interaction, meeting people in their homes with treatments that address cultural explanations of illness with flexible payment options.[7]

Meeting with traditional and faith healers is commonplace and usually devoid of stigma within African communities making them the first port of call.[8]

Decisions about when to consult may relate more to barriers such a availability, access and cost of biomedical health services.[9,10]

The various help providers (biomedical, traditional and faith) must strive to collaborate despite their differences in beliefs, because service users do not perceive them to be mutually exclusive and prefer consulting them simultaneously.[11,12]

IDENTIFYING CARE PATHWAYS

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

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

CASE SCENARIO #1

Sally goes to the clinic and is told she has epilepsy and needs to take daily medication. Sally is told that she should go to the dispensary which is at the psychiatric hospital to buy the medicine. Sally leaves the clinic and goes home without stopping at the psychiatric hospital. The next day she goes to see the traditional healer in her community. List ways you can help Sally.

advocacy in action

Nine-year-old Eshetu and his mother Yeshi (Ethiopia) reached out for help from Care Epilepsy Ethiopia two years ago, because Eshetu was continuously having seizures, and his mother was struggling to make ends meet due to his illness which required her 24hr support. The family credits Care Epilepsy Ethiopia for controlling his epilepsy. His mother, Yeshi, has attended several epilepsy awareness training sessions and received individual counselling. As a result, she now understands what epilepsy is about and feels no shame that her family is affected. She is currently employed and likes to talk about epilepsy with her neighbours.

TEACHING SEIZURE FIRST AID

The focus group participants also identified that most people in their communities do not know how to provide seizure first aid and that they also believe that epilepsy is contagious. In this next section we dispel these myths and provide tips for advocates to use when they develop seizure first aid materials.

EPILEPSY IS NOT CONTAGIOUS

MISCONCEPTION	THE FACTS	“ THE IMPACT OF STIGMA
Epilepsy is contagious	Epilepsy is not contagious. You cannot catch epilepsy by touching or eating with a person who has epilepsy. There is no connection between epilepsy and saliva or ‘dirty blood’.	***“A pastor is called to pray over the student. They need to pray for the whole school because the spirit may jump to the next student.”*** ***“One person recently died. She fell on her face and the people who were watching did not do anything because they were afraid of being demon possessed by catching it.”***

HOW TO HELP SOMEONE WHO IS HAVING A SEIZURE

MISCONCEPTION	THE FACTS	“ THE IMPACT OF STIGMA
You should put something in the persons mouth during a seizure. You should hold or restrain their hands and legs during a seizure.	Never put anything in the mouth during a seizure because you can hurt the person or break their teeth. They will not swallow their tongue.	***“They will put a spoon in the mouth, and they pour water on the face to wake the person because they don’t know how to assist.”*** ***“People believe that putting a spoon in the mouth stops the person from swallowing their tongue and stops the teeth from chattering.”*** ***“I woke up at school and found myself having injuries from pens and a ruler in my mouth. People thought they were helping me - but they were hurting me.”***
Eating the following foods: okra, chicken wings and snails will provoke a seizure.	Eating these foods does not cause a seizure.	***“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 did this for my family. My seizures stopped when I went to the clinic and was given anti-seizure medication.”*** ***“I stopped eating chicken wings (their flapping causes seizures), egg (which cause you to be confused), and okra (the foam comes out of your mouth when you have a seizure).”***

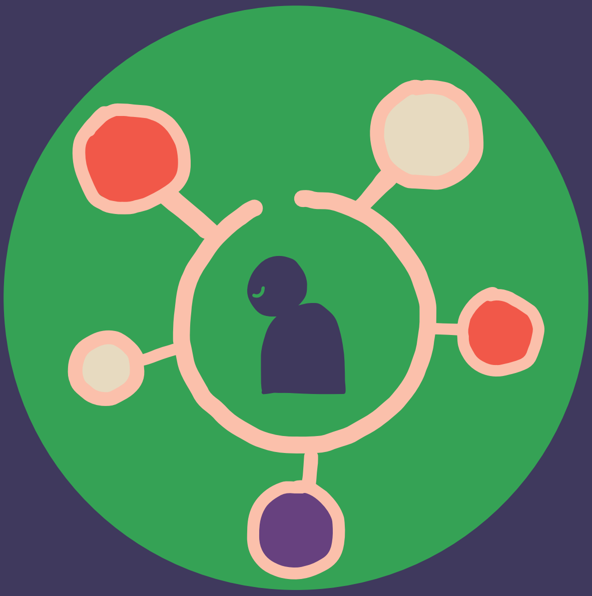
SEIZURE FIRST AID

- Remain Calm
- Stay with the Person
- Cushion their head and protect them from further injury (move them away from danger - fire, water, oil, traffic)
- Gently Roll them onto their side into the recovery position
- Never put anything in their mouth
- Do not restrain their hands or legs
- Time the seizure (a seizure is a medical emergency if it lasts longer than 5 minutes)

DEVELOPING SEIZURE FIRST AID MATERIALS

Review the materials that your organisation currently uses to teach seizure first aid.

- Are they targeted to a certain audience?
- Are they available in local languages?
- Do they use graphics to show 'what to do'?
- Do they clearly identify that providing seizure first aid is a skill that everyone can learn?
- Do your materials identify that you can touch someone having a seizure (you cannot catch epilepsy) and that during a seizure you should remove the person from harmful or dangerous objects (fire, water, traffic)?
- Have you checked to see that the materials are effective (focus group or pre and post knowledge survey)?
- How do you describe seizures that are medical emergencies?
- Have you developed different types of first aid materials (flyers, brochures, posters for clinics or dispensaries)?
- Do you provide seizure first aid training to people with epilepsy, their families, teachers, employers?
- Have you developed a list of places to distribute your materials?



SECTION 2:

Components of a Multisectoral Approach to Reducing Stigma in Epilepsy

LEARNING OBJECTIVES

1. Understand the goal of stigma change
2. Identify the different tools that can be used in a multisectoral approach
3. Identify the key multisectoral stakeholders to engage in reducing stigma in epilepsy
4. Identify content for an epilepsy awareness campaign

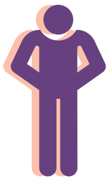
GOAL OF STIGMA CHANGE

The goal of stigma change efforts is to change behaviour. To reduce stigmatising beliefs, we can provide facts about epilepsy to dispel common myths, but this alone will not change a person's behaviour, nor will it change their attitudes. A persons' behaviour is motivated by social norms, cultural biases and strong emotions such as fear. To reduce stigma, advocates need to develop a multipronged approach with multiple messages to multiple audiences in different sectors.

advocacy in action

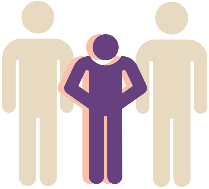
Sharon (Kenya) was diagnosed with epilepsy in 2018 after several episodes of unexplained seizure activity. Her struggle to get a prompt diagnosis motivates her to advocate for awareness in schools and clinics of the need for more information about epilepsy. Sharon also has certification in executive coaching and psychometric testing, as well as counselling and mediation. She uses these skills to lead the Mental Health Alliance of Kenya where she works to improve the quality of care for caregivers of and people who live with mental, intellectual and neurological disorders.

TOOLS FOR ADVOCATES TO USE TO DEVELOP A MULTISECTORAL APPROACH TO REDUCE STIGMA IN EPILEPSY



INTERNALISED STIGMA

- ✓ Provide Information
- ✓ Create awareness
- ✓ Disclosure – talk about it
- ✓ Teach seizure first aid
- ✓ Identify care pathways
- ✓ Provide psychosocial support- counselling
- ✓ Provide self-management programs
- ✓ Become Peer mentors
- ✓ Attend Support groups
- ✓ Share personal story (media, schools, clinics, churches, etc)



INTERPERSONAL STIGMA

- ✓ Provide Information
- ✓ Create awareness
- ✓ Disclosure – talk about it
- ✓ Teach seizure first aid
- ✓ Identify care pathways
- ✓ Provide psychosocial support - counselling
- ✓ Become Peer mentors
- ✓ Attend Support groups
- ✓ Share personal story (media, schools, clinics, churches, workplaces, etc)

INSTITUTIONAL STIGMA

- ✓ Targeted education: teachers, employers, healthcare providers, disability service providers, first responders, traditional and faith healers, media, community and policy makers
- ✓ Contact with People with Epilepsy
- ✓ Legislation and Policy Change
- ✓ Amend and Add Laws
- ✓ Advocacy
- ✓ Protest
- ✓ Public Campaigns

OVERARCHING MESSAGE

If people with epilepsy disclose their epilepsy status, they can get a proper diagnosis and a personalised treatment plan and they can benefit from community and peer support. If families with epilepsy 'talk about it' – policy makers, educators, employers and health care providers will begin to understand that epilepsy affects people in all communities and that when treated - people with epilepsy can live productive lives.

"I have realised that if we talk about it – not shy away – stand up for ourselves -before you know it people will tell you 'I live with it too'."

"People need to come out. I have a social media platform where I tell people I am a person with epilepsy."

"That was the birth of the advocate in me, where I learned to talk and push for our rights".

"When my daughter was first diagnosed, I decided to be her voice. I realised that the more I kept talking about epilepsy – people started looking up to me for help. I have kept my connection to our society, and we feel free."

"I have been on TV and agree that speaking out helps. Normalising the conversation and engaging people of influence and having more people talking about epilepsy ends up helping people who are not fully aware."

"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."

advocacy in action

Jesynta (Cameroon) acknowledges that she was broken when her daughter was diagnosed with a rare epilepsy syndrome but found the courage to look for ways to overcome her own despair to help her daughter. She learned about epilepsy - the different types, causes, first aid and treatments. She resolved not to be alone and reached out to the Community Development and Epilepsy Foundation in Cameroon (CODEF). She offered to be a community spokesperson and to share her family story on social media, Facebook, radio and with live audiences at schools, churches and workplaces. She acknowledges that talking to people about epilepsy has helped her family to feel love and acceptance from her community.

CONTACT WITH PEOPLE WITH EPILEPSY

Stigma can be reduced when people who are stigmatised are given opportunities to tell others about their lives and explain how stigma has affected them. Strategies to reduce public stigma on a person-to-person basis have also been shown to boost self-esteem which can reduce self-stigma by creating a sense of empowerment.[13]

Types of contact-based interventions:

- Story telling
- Presenting personal testimonies
- Recorded events
- Interviews
- Public speaking
- Blogs

TIPS FOR EFFECTIVE CONTACT-BASED INTERVENTIONS:

- Provide the person with epilepsy with opportunities to share their lived experience (healthcare provider training courses, radio and television interviews)
- Tell the truth but stay positive (don't blame the audience)
- Provide the person with epilepsy with coaching on 'how to' tell their personal story in an engaging way
- Provide solutions of how people with epilepsy have overcome adversity
- The quality of the contact is more important than the duration
- Combine sharing of personal stories with educational content
- Recognise that the person with epilepsy needs to be supported emotionally if you are asking them to be your community spokesperson because talking about epilepsy can trigger emotions

advocacy in action

Abdoulie (The Gambia) had his first seizure in 2006. He was told by many people that it was an evil spirit attack that caused him to have seizures. He performed sacrifices of fowl, goat and sheep, drank herbs and met with marabouts but this did not help. He credits his uncle who worked as a security officer at the local hospital for getting him a doctor who then prescribed anti-seizure medication. He has not experienced any seizures since starting medications in 2019. Abdoulie wants people to know that epilepsy is real and that it is treatable.

CASE SCENARIO #2

Amos is invited by his church to talk about his epilepsy. He has been told to expect questions after he shares his personal story. For this exercise the purpose is for the person with epilepsy to anticipate audience questions when they prepare their talk. Write a list of questions that people may ask you about your epilepsy.

advocacy in action

When **Neo Esther (Lesotho)** was diagnosed with epilepsy in 2010 many people avoided associating with her, and others were afraid. She started to feel different and lonely. She chose to educate herself and people around her and has joined Epilepsy Lesotho where she is a peer mentor to other youths with epilepsy.

PSYCHOSOCIAL PROGRAMS FOR PEOPLE WITH EPILEPSY AND THEIR FAMILIES

Psychosocial interventions to improve coping, self-esteem, self-management and problem solving have all been shown to reduce felt stigma.

TYPES OF PSYCHOSOCIAL INTERVENTIONS:

- Self-management programs
- Peer programs (peers can help to identify solutions, reduce social isolation and share coping mechanisms)
- Support groups (parent, sibling, youth, men, women, elderly)
- Mobile applications that are low cost (WhatsApp) or other private online communities (Facebook)

TIPS FOR EFFECTIVE PSYCHOSOCIAL INTERVENTIONS

- Provide formal training to peer mentors (it can be psychologically draining and triggering to support others).
- Monitor chat rooms and private online social media groups to ensure conversations are accurate and respectful.
- Intervene if you feel a participant is at risk or needs individualised therapeutic support.
- Provide tools like a seizure log or diary for people to record what happens before, during and after a seizure. A seizure diary is a good tool to identify potential seizure triggers. It helps people to manage and to monitor their diet, sleep, stress and medication.

advocacy in action

Bright (Zambia) has developed a cell phone application for people with epilepsy to track and manage their seizure activity. He uses this 'mobile app' to document his own seizure activity and has been invited to the local health clinic to share self-management strategies. In his own words, "my passion for advocacy is fueled by the joy I see in those I have been able to help".

MEDIA

Public campaigns that use mass media to advance a social or public policy initiative are seeking to communicate a message to a wide general audience.

TYPES OF MEDIA

- Newspapers
- Magazine
- Movies and Films
- Music
- Documentaries
- Advertising
- Television
- Radio
- Web-delivered materials
- Social Networks: Facebook, Twitter, LinkedIn, Reddit
- Media Sharing Networks: Instagram, Snapchat, YouTube

PROS AND CONS – USING MEDIA

BENEFITS OF USING MEDIA	POTENTIAL NEGATIVES OF USING MEDIA
Increase general awareness	Not effective at changing attitudes or behaviours
Share factual information	Buying media can be $$$
Counter misinformation	Media may use language or stories that perpetuate stigma (epileptic, suffering, victim, afflicted, crazy, mad, fit, catastrophic, dangerous, possessed, etc.)
Reframe public debate	
Increase public support	Media may perpetuate health stigma stereotypes and harmful myths if they represent epilepsy in ways that are sensationalising, inaccurate or offensive (for example: person has a seizure driving a car and causes an accident, person with epilepsy injured at workplace, etc.)

advocacy in action

Praise (Cameroon) has taken part in epilepsy outreach programs spreading anti-stigmatisation information on stickers, flyers and posters. She has appeared on national radio and television programs to share her personal story. Praise is CODEF's 2021 Advocacy Ambassador.

TIPS FOR WORKING WITH THE MEDIA

- Develop ‘fact sheets’ for media to ensure they have accurate information to counter stigma. Include recommended language, statistics, seizure first aid.
- Promote message repetition (using many types of media with the same message).
- Develop a media relations committee to monitor the media and immediately correct media misinformation.
- Develop relationships with media personalities and reporters.
- Provide media with stories and people to be interviewed.
- Write a Letter to the Editor (this is a good way to share facts, dispel myths and share your opinion).
- Develop a radio public service announcement.
- Ask to be a guest on a local talk show (prepare in advance – use accurate facts and statistics, plan how you will share your personal story).
- Write a blog.
- Post on social media.
- Use print media: billboards, flyers, posters.
- Develop messages that are positive (negative images may deepen stereotypes of hopelessness and despair).
- Offer solutions that are practical and achievable.

WORDS MATTER

In a study from Brazil, high school students received one of two versions of a questionnaire. The only difference in the two questionnaires was the reference to ‘persons with epilepsy’ in one and ‘epileptic’ in the other. The authors recommended that we ‘stop saying epileptic’ because it is stigmatising. They recommend using a ‘people first’ approach:[14]

- Do you think that persons with epilepsy are rejected by society? (41% said yes)
- Do you think that epileptics are rejected by society? (87% said yes).

In Malaysia and South Korea, the name ‘epilepsy’ was associated with insanity and animals such as goats and pigs. The name has been replaced with a neutral scientific term to reduce stigma.[15]

In the Kiswahili language – Pepo (evil spirit) is a term for epilepsy.

advocacy in action

Betty and Rose (Zambia): Rose encountered stigma from family members who believed it was better for her to live in their rural village and not move to Lusaka to attend college. While listening to an interview on the national radio, she heard a spokesperson from the IBE chapter in Zambia. Rose contacted the IBE chapter where she met Betty – a community epilepsy advocate. Betty invited Rose to live with her for two years allowing her to complete her college training at the Lusaka Technical Business College. Since then, Rose considers Betty as her second 'mother'.

ADVOCACY AND PROTEST

Advocacy is used to engage people who have some investment in health stigma change but lack the knowledge or motivation to translate their beliefs into action. A call to action can energise unengaged stakeholders by raising awareness about the cause and the harmful effects of stigma.

ADVOCACY AND PROTEST STRATEGIES:

- Letter writing
- Petitions
- Product boycotts
- Rallies
- Walks or marches
- Public demonstrations
- Meetings with opinion leaders, politicians, journalists, policy makers
- Local leaders who are socially well-connected play a pivotal role in reducing stigma

Influential leaders such as Her Excellency Dr. Joyce Banda, the former President of Malawi, and His Royal Highness Prince Bandzile of Eswatini are actively involved in bringing awareness to epilepsy and helping reduce stigma.

CASE SCENARIO #3

Protest is a good tool to increase public awareness and/or policy recognition of issues and concerns. Protest can also trigger a backlash or a rebound effect in which negative public opinion is heightened because of the protest.

What do you feel when you look at these images?

In what instances should protest be used to increase public support for people with epilepsy?

advocacy in action

Members of Shine Epilepsy Support Group (Kenya) organised a hike to Mount Kilimambogo to increase awareness of epilepsy and to raise funds to pay the annual National Hospital Insurance Fund (NHIF) for 2 people with epilepsy. Annastacia, the founder & CEO, knows that one way to reduce stigma is to increase community knowledge that epilepsy is treatable and that people with epilepsy need ongoing access to anti-seizure medicines.

TIPS FOR USING THE IGAP IN YOUR ADVOCACY

- The IGAP highlights the important role of advocacy to improve availability of anti-seizure medicines at affordable prices at all levels of the health care system.
- The IGAP encourages advocacy efforts and public education related to epilepsy for community health workers, community leaders and people with epilepsy and their families to correct misconceptions, counter negative stereotypes and provide knowledge on how to help a person having a seizure.
- The IGAP encourages non-state actors, like the IBE, to activate national networks and to lobby administrators, policy makers and other stakeholders to integrate care for the comorbidities as an integral part of epilepsy treatment and care services.
- One of the agreed upon global targets in the IGAP is 1.2: stating 100% of countries will have at least one functioning awareness campaign or advocacy programme for neurological disorders by 2031.

It is important that your advocacy message does not produce unintended consequences or reflect negatively on other people with epilepsy. For example, people who have drug refractory seizures or a dual diagnosis (for example: epilepsy and depression or psychosis, epilepsy and intellectual disability or epilepsy and HIV).

MULTIPLE STAKEHOLDERS

In a multipronged strategy, advocates should target the people and places where epilepsy stigma can be encountered. In this next section we have listed multiple stakeholders with information from the published literature related to their epilepsy knowledge and attitudes.

Targeted Education
Educational anti-stigma interventions present factual information about epilepsy with the goal of correcting misinformation or contradicting negative attitudes and beliefs. To be effective they need to be targeted to a specific audience:

- Teachers and school systems
- Healthcare providers
- Traditional and faith healers
- Employers
- People with epilepsy (children, youth, parents, men, women, elderly)

TIPS FOR COLLABORATING WITH TEACHERS AND SCHOOL SYSTEMS

- Consider adapting a program that has already been evaluated. Multiple IBE chapters have developed and evaluated programs and curricula for teachers and school aged children.
- Partner with other organisations that share the same goal of promoting safe and inclusive schools. There are a number of disability groups and organisations that represent children with learning and behavioural challenges that are also working to improve school inclusion and school success.
- Collaborate with other groups to develop standardised school safety plans for students with epilepsy or other medical conditions – for example: juvenile diabetes, asthma or anaphylaxis.
- Reach out to organisations that have a mandate to defend the rights of children and youth to fulfill their potential (for example, your local UNICEF office).
- Meet with the policy makers at the school board to co-develop a strategy to support students in your local community.
- Provide parents with the knowledge to understand epilepsy and with written materials for them to share with the child's school.

TEACHERS AND SCHOOL SYSTEMS

A systematic review of knowledge and attitudes towards epilepsy among teachers in 27 countries found deficits in teacher knowledge and negative attitudes were pervasive across all studies.[16]

Teachers do not receive formal training in epilepsy and have a lack of adequate knowledge about seizures and confidence working with a child with epilepsy.[17]

In a Nigerian study of school teachers knowledge and attitudes– 25% would object to having a child with epilepsy in their class.[18]

Healthcare Providers

The attitudes and beliefs of healthcare providers will influence the treatment they provide. This makes healthcare providers an important group for stigma reduction interventions.

> *"They give us drugs – tell us to the take the drugs – come for control in 3 months. This is not enough."*
>
> *"All that I have learned so far is through Google."*
>
> *"Our neurologist is only interested in medications. You come back and they give you another medication. "*
>
> *"Our neurologists don't give us an explanation. It is heart breaking. We need to learn how to manage on our own."*

TIPS FOR TARGETED EDUCATION TO HEALTHCARE PROVIDERS:

- Short programs work as well as long programs.
- Use standardised training like the WHO mhGAP (epilepsy).
- Physicians are the most difficult to engage. Consider targeted education to non-specialist health providers: nurses, clinical officers, community health workers, public health officials, midwives, pharmacists, mental health counsellors.
- Develop programs and training curricula to improve health literacy and empathy.
- One time only sessions do not work – boosters and repetition are always needed.
- Successful programs have incentives or expectations of participation of health care professionals, such as CME credits, being paid for their time, or receiving paid time off.
- Programs that include contact or are co-facilitated by a person with lived experience have the greatest impact on reducing stigma and improving healthcare provider empathy.

advocacy in action

Nina (Uganda) is the founder of the Purple Bench Initiative - a non-profit organisation that provides information and support to people with epilepsy in Uganda. Nina who had her first seizure at age 3 and was diagnosed at age 6 is an educator bridging the gap between people living with epilepsy and health care workers. Nina provides community awareness and targeted education to individuals, families and schools. Nina believes that through awareness there is increased participation and inclusion of people with epilepsy so that they live dignified, meaningful and highly impactful lives.

HEALTHCARE PROVIDERS

Surveys of medical students in Cameroon indicated they had an excellent knowledge of epilepsy but still maintain inappropriate attitudes towards people with epilepsy. For example, 46% would object to their own child marrying a person with epilepsy. Strong cultural values may be responsible for this attitude.[19]

Interventions directed at medical students have found attitudes are more amenable to change early in their education and training, and that these attitudes tend to solidify as they progress through medical school and residency.[20]

Traditional and Faith Healers
Advocates are encouraged to engage with traditional and faith healers to develop coordinated care models. Developing care pathways in partnership with traditional and faith healers creates an opportunity to provide holistic care; to identify stigmatising practices and to combine anti-seizure medicines with psychosocial interventions.

TIPS FOR WORKING WITH TRADITIONAL AND FAITH HEALERS:

- Invite the healer to work with you to co-develop coordinated care for people with epilepsy.
- Talk about the benefits of holistic care.
- Seek creative ways to raise awareness of epilepsy – co-host information sessions.

TRADITIONAL AND FAITH HEALERS

- Studies from Ghana and Kenya indicate traditional healers are open to referring people to biomedical facilities.[21,22]
- In HIV and TB, there is evidence of successful collaboration between biomedical services and traditional healers related to screening, referral and co-management.[23]
- Explanatory views held by people will determine the type of treatment they seek. If a person believes that they have a spiritual problem they will seek spiritual healing provided by traditional or faith healers.[24]

Employers
Stigma reduction interventions for employers can be implemented locally through targeted education, through health and safety departments, or nationally through enforcement of laws and protective legislation.

TIPS FOR REDUCING EMPLOYMENT RELATED STIGMA:

- Consider adapting an existing employment module. Many IBE chapters offer epilepsy employment modules and counselling to help job seekers to know when, if, and how to disclose to an employer.
- Collect employment forms to identify where employers disqualify the person who has epilepsy or another disability.
- Partner with other disability groups that want to see employment equity.
- Read the UN Convention on the Rights of Persons with Disabilities.
- Develop job seeking programs.
- Provide skill development and income generating programs for people with epilepsy.
- Contact UN Agencies or their regional and national offices like the International Federation of Labor (IFO) which promotes labor rights and employment standards.

CASE SCENARIO #4

David comes into your IBE chapter office and says that he doesn't have a job because he has epilepsy. You ask David if he lost his job after having a seizure at work? (Enacted stigma). He replies that he hasn't had a job in years because he knows people would never hire him because he has epilepsy (Felt stigma). List or role play ways you can help David.

Youth with Epilepsy
Young people are likely to turn to the internet as their first source of advice for both information gathering and social support.

TIPS FOR REDUCING STIGMA IN YOUTH WITH EPILEPSY:

- Use social media.
- Establish youth advisory groups to ensure that the message is engaging, relevant and developmentally appropriate.
- Social media can be used to tailor information, to increase peer interaction and social support.
- Monitor social media. Social media can also perpetuate negative stereotypes which can promote concealment which heightens internalised stigma.[25] [26]

advocacy in action

Fred (Kenya) is an activist that raises awareness about epilepsy by taking on challenges that will help bring attention to epilepsy issues. He has walked, cycled and climbed mountains attracting media attention to promote the message that epilepsy is treatable and manageable. Fred's passion is greatly inspired by his sister Mercy who was diagnosed with epilepsy when she was 2 years old.

Women with Epilepsy
Advocates seeking to champion the rights of women with epilepsy should consider partnering with other groups including UN Women and Women of Kulture. UN Women has country and regional offices in many African countries, and focuses exclusively on gender equality and women's empowerment.

WOMEN WITH EPILEPSY

In many African communities, women with epilepsy bear a disproportionate burden. Numerous studies indicate that African families would not want their sons to marry a woman with epilepsy. Often the belief is that women with epilepsy will have difficulty in childbirth and do not have the ability to contribute to household duties.[27]

In an Ethiopian study - 83% of men would not marry a woman with epilepsy and in Nigeria it was 88%.[28]

In a Zambian study the sexual assault rates for women with epilepsy were 20% versus 3% in women with other chronic conditions. [29]

For women with epilepsy in a Zambian study – the social and economic impact of epilepsy far outweighed the biomedical burden of disease.[30]

Fiscal abandonment and sexual rejection result in extreme poverty, food insecurity and great public humiliation for women with epilepsy.[31]

advocacy in action

EPILEPSY AND MARRIAGE

The **IBE chapter in Tanzania** have filed a case with the countries high court to challenge a marriage law that makes it legal to divorce someone who has epilepsy. Their goal is to have the courts repeal this discriminatory law.

Keji (South Sudan) had her first seizure in 2012 when she was expecting her first child. She was divorced by her husband after the family learned that she was living with epilepsy. When she joined IFEA-South Sudan in 2020, Keji began to share her story with others, and she is currently taking an active role as a community outreach coordinator to debunk myths and misconceptions about epilepsy in areas around Juba.

Awemung (Cameroon) had a fiancée to marry but his community objected to this union because he had epilepsy. He reached out to his local IBE chapter the Community Development and Epilepsy Foundation in Cameroon (CODEF). CODEF staff invited the two families to an information session where they reinforced that epilepsy is not transmissible. Today, Awemung is happily married and has 3 children.

CASE SCENARIO #5

The Chief has denied a man a farm input subsidy. He has told the man that he cannot grow a maize field because he has epilepsy. What can you do to end this discrimination?

advocacy in action

Anthony (Kenya) is a photographer by profession. He has faced a lot of discrimination in his life and has lost many jobs and opportunities due to the stigma in epilepsy. Accepting his condition is one of the major aspects that has helped him to shape his life and to be a peer mentor to others. Anthony is a father of three children and is proud that they are all on track to complete their secondary education.

IDENTIFYING CONTENT FOR AN EPILEPSY AWARENESS CAMPAIGN

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

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

PHOTO CREDIT: KAWE KENYA

> ***“My dream is the whole world to understand Epilepsy is a disease like any other; people living with it are not bewitched, demon-possessed or insane. They can achieve every one of their goals if they seek and adhere to their medication, stop pity-parties, work hard and believe in themselves like I do.”***
>
> **– SOPHIE, UGANDA**

LEGISLATORS AND POLICY MAKERS:

In legislative reform, the goal is often to enhance or enact protections of rights, increase access to social and health care resources, and reduce inequalities.

> *"To discredit his opponent, a politician shouted: "don't listen to the other guy; that one falls" [referring to epilepsy] - "there is nothing he can do", "don't listen to him". This is one of the worst labelling I have heard in the community since these were the words of people running for political office at the Presidential level."*

TIPS FOR CHANGING LEGISLATION AND LAWS

- In 2021, IBE Africa published a mapping report with details of 21 state epilepsy health laws. This report provides baseline data on the existence or lack of antidiscrimination health policies or laws (see Annex).
- Identify what laws currently exist and determine the level of domestic implementation.
- Advocates should check to see if a law that you oppose is active or inactive and whether the decision maker is even aware that it exists.
- To enact a change, legislators must first form an intent to act, which requires creation of a positive attitude toward the act of creating a new policy.
- Policymakers can reduce stigma by changing laws that are punitive to people with epilepsy or that disqualify people with epilepsy from receiving services (for example- health and insurance coverage, access to affordable medicines, access to housing).
- Policymakers can also add legislation to protect people with epilepsy (for example – employment standards, access to education, driving legislation, income security programs).

advocacy in action

Wimpie (South Africa) knew his epilepsy affected his concentration and memory and that he needed more time to complete his engineering degree. When his university made a decision that academically penalised him, he decided to take his case to court. He argued that the university did not provide proper accommodations for him to succeed in his engineering program. Wimpie launched a successful application to the Western Cape High Court who ruled that epilepsy is a disability and that the university council should re-consider his situation. Wimpie changed the law, and this new legislation will help other people with epilepsy to succeed in school and in the workplace.

Advocate Nkandu Nchindila (Zambia) is a lawyer, researcher, writer, and humanitarian worker. She supports the African Lawyers Network to monitor and engage with laws and policies affecting persons with epilepsy as well as to ensure the domestication of progressive legislation, regulations, and policies by duty-bound stakeholders in Africa. She is the author of the Report on the IBE Africa 21 State Epilepsy Health Laws Mapping Exercise.

IBE

AFRICA REGION

Report on the
IBE Africa 21 State
Epilepsy Health Laws
Mapping Exercise

Author
Adv. Nkandu Nchindila

May 2021

NAME IT – REFRAME IT – AGAIN!

As in the previous tool, note down the impacts of stigma and think about how you can reframe it to find ways you can help change the situation.

	THE IMPACT OF STIGMA	WHAT CAN YOU DO?
INTERNALISED **(person with epilepsy)**	• Concealment, low self-confidence, withdrawal, anxiety, depression, social isolation, shame, shunning, exclusion • Feeling undervalued in relationsips	• Make it ‘safe’ to disclose the diagnosis • Ensure that individuals have the information they need to understand their diagnosis of epilepsy – care pathways – seizure first aid. • Provide counselling
INTERPERSONAL **(family)**		
INSTITUTIONAL LEVEL **(society)**		

SECTION 3:

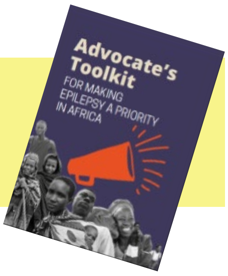
Planning a Stigma Reduction Intervention

LEARNING OBJECTIVES

1. Identify the 6 steps for planning a stigma reduction intervention
2. Identify ways to monitor and evaluate your intervention

STEP 1

IDENTIFY THE PROBLEM



Tip: Use the tools (5 why's and PESTLE) from the Advocates Toolkit for Making Epilepsy a Priority in Africa to define your problem.

STEP 2

IDENTIFY A TARGET GROUP AND TARGET AUDIENCE

Primary targets for stigma behaviour change could include:

- people with epilepsy (child, youth, man, woman, elderly)
- family members (parent, spouse, sibling, grandparents, people who have lost a loved one to epilepsy)
- healthcare workers – people who need to be equipped to provide non-judgmental, culturally competent healthcare. Be specific: carers, midwives, nurses, clinical officers, pharmacists, physicians, psychiatrists, neurologists, community health workers, public health workers, etc.
- teachers, school staff and school board personnel
- policy makers and politicians who have the ability to allocate budgets and create laws
- employers, employees and unions
- landlords
- traditional and religious leaders, faith healers, churches
- media (traditional and digital media)
- civil society and non-governmental organisations (NGO's)
- general public

Tip: Use the stakeholder analysis tool from the Advocates Toolkit for Making Epilepsy a Priority in Africa to identify the target groups and audiences.

STEP 3

REACHING YOUR TARGET AUDIENCE

The message needs to be well-tailored to the specific target audience. Target audiences whose personal values and priorities resonate with a message process the message more deeply, remember it better, and are more likely to act on the message than a general audience to whom the message is not so relevant.[32,33]

STEP 4

IDENTIFY THE MESSAGE

Once you have established a target group it is time to design a simple and unified message. A message typically contains one main idea that is specific, focused and limited in scope. The message should capture attention and hold the audience's memory for information. It should be co-developed with relevant partners. It should be developed to either increase knowledge or to change an attitude, behaviour or a belief. The message should be positive.[34]

Tip: Use the SMART Tool and Results Framework from the Advocates Toolkit for Making Epilepsy a Priority in Africa to develop your main idea.

REACHING YOUR TARGET AUDIENCE

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

TARGET GROUP	WHAT MESSAGE DOES THE TARGET GROUP NEED TO HEAR TO BE INFLUENCED TO CHANGE THEIR ATTITUDES AND BEHAVIOUR?
People with Epilepsy and their Family	70% of people get seizure control with the proper diagnosis and treatment. There are strategies for staying safe, reducing injuries, identifying triggers, improving quality of life, accommodating epilepsy at school or the workplace.
Health care Workers	
Teachers and School Staff	
Policy Makers	
Employers	
Traditional and Faith Healers	

STEP 5

IDENTIFY THE MESSAGE SOURCE

- The choice of messaging source needs to be made after the target audience is selected because the source needs to be someone whom the target audience finds relevant and worthy of trust and respect.
- The source that delivers the message has a strong impact on how messages are received.[35]
- People are most receptive to sources that are similar to themselves, and to people who embody positive characteristics and expertise.[36]
- A wide range of delivery methods can be used in stigma reduction interventions. These include contact based where a person with epilepsy shares their personal experience, in-person training workshops, webinars, videos, mass media, apps, posters, curriculum, policy and legislation, protests, letter writing, etc.

STEP 6

MONITORING AND EVALUATION

Data collection needs to happen at every stage of the stigma intervention. It begins at step one with identifying the problem through the collection of data to confirm the need. Advocates can identify the problem using a needs assessment, interviews, surveys or focus groups.

- Routine monitoring refers to the ongoing assessment of our progress. It is ongoing – weekly, monthly, quarterly, etc. Routine monitoring helps the team to know what is working well (and not so well). Monitoring compares the results to the original targets. Are we doing the work we planned? Are we on-track? It can alert us to problems early because we are continually reviewing the stigma intervention.
- Monitoring is the process of data collection and is used to measure your progress. It is important to document what is working well and what is not working well and what needs to be changed. This process data is collected during the development and the delivery of the intervention.
- Evaluation is intended to measure the extent to which change is happening because of the intervention. How effective is our program? Is our program showing any impact? Is our program changing knowledge, attitudes or behaviours? How can we prove that it is?
- An impact evaluation examines the success of the intervention based on the goal that was first identified when you developed your strategy to solve your problem.

Tips: Developing a Monitoring and Evaluation Plan

- **Advocates should develop a logic model for their intervention (goal, purpose, outputs, inputs)**
- **Advocates should develop a written monitoring and evaluation plan before implementing their stigma intervention.**
- **How will you share your progress (team meetings, progress reports, final report, newsletters, webinar)?**
- **Have you allocated a budget for monitoring and evaluation?**
- **Consider reaching out to researchers at local hospitals and universities to co-design and co-evaluate the intervention.**
- **The evaluation plan should include validated measures.**

advocacy in action

Youssouf (Mauritius), CEO of EDYCS Epilepsy Group, is providing epilepsy training to police officers as part of his country's IGAP domestication.

Abraham (Eswatini) is signing a Memorandum of Understanding for Cooperation between Eswatini Epilepsy Organization (EEO) and Autism Eswatini. This partnership is part of his country's IGAP domestication.

PLANNING A STIGMA REDUCTION INTERVENTION

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

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

Annexes

1. RECOMMENDED READING
2. BLANK TOOLS AND TEMPLATES

RECOMMENDED READING

- Report on the IBE Africa 21 State Epilepsy Health Laws Mapping Exercise
- Advocate's Toolkit for Making Epilepsy a Health Priority in Africa (IBE, 2020)
- Epilepsy A public health imperative (WHO, 2019)
- Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022-2031
- Epilepsy-related stigma and attitudes: Systematic review of screening instruments and interventions - Report by the International League Against Epilepsy Task Force on Stigma in Epilepsy
- Systematic review of frequency of felt and enacted stigma in epilepsy and determining factors and attitudes toward persons living with epilepsy—Report from the International League Against Epilepsy Task Force on Stigma in Epilepsy
- Development and validation of the Kilifi Stigma Scale for Epilepsy in Kenya

ONLINE RESOURCE PORTAL

You can easily find all of the resources mentioned in this toolkit at **www.ibe-epilepsy.org/stigmatoolkitafrica**

BLANK TOOLS AND TEMPLATES

Use the blank tools and templates on the following pages to work through the exercises on your own or with a team.

THE IMPACT OF EPILEPSY STIGMA

Use this template to describe how stigma in epilepsy affects the person, family and society.

INTERNALISED STIGMA (PERSON WITH EPILEPSY)
INTERPERSONAL STIGMA (FAMILY MEMBERS)
INSTITUTIONAL STIGMA (SOCIETY)

NAME IT – REFRAME IT

For this tool, chose a misconception that perpetuates stigma. Use the questions in the ‘Name it’ category to guide you in finding ways you can correct the misconception or ‘Reframe it’.

NAME IT	REFRAME IT
Name it…what is the belief?	
Who perpetuates the belief?	
Why do they perpetuate this belief?	
How does this belief stigmatise people with epilepsy?	
What can we do to reframe the belief?	
Who can assist to destigmatise this belief?	
What are the potential barriers to reframing the belief?	

IDENTIFYING CARE PATHWAYS

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

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

IDENTIFYING CONTENT FOR AN EPILEPSY AWARENESS CAMPAIGN

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

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

NAME IT – REFRAME IT – AGAIN!

As in the previous tool, note down the impacts of stigma and think about how you can reframe it to find ways you can help change the situation.

	THE IMPACT OF STIGMA	WHAT CAN YOU DO?
INTERNALISED **(person with epilepsy)**		
INTERPERSONAL **(family)**		
INSTITUTIONAL LEVEL **(society)**		

REACHING YOUR TARGET AUDIENCE

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

TARGET GROUP	WHAT MESSAGE DOES THE TARGET GROUP NEED TO HEAR TO BE INFLUENCED TO CHANGE THEIR ATTITUDES AND BEHAVIOUR?
People with Epilepsy and their Family	
Health care Workers	
Teachers and School Staff	
Policy Makers	
Employers	
Traditional and Faith Healers	

PLANNING A STIGMA REDUCTION INTERVENTION

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

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

CASE SCENARIO #1

Sally goes to the clinic and is told she has epilepsy and needs to take daily medication. Sally is told that she should go to the dispensary which is at the psychiatric hospital to buy the medicine. Sally leaves the clinic and goes home without stopping at the psychiatric hospital. The next day she goes to see the traditional healer in her community. List ways you can help Sally.

CASE SCENARIO #2

Amos is invited by his church to talk about his epilepsy. He has been told to expect questions after he shares his personal story. For this exercise the purpose is for the person with epilepsy to anticipate audience questions when they prepare their talk. Write a list of questions that people may ask you about your epilepsy.

CASE SCENARIO #3

Protest is a good tool to increase public awareness and/or policy recognition of issues and concerns. Protest can also trigger a backlash or a rebound effect in which negative public opinion is heightened because of the protest.

What do you feel when you look at these images?

In what instances should protest be used to increase public support for people with epilepsy?

CASE SCENARIO #4

David comes into your IBE chapter office and says that he doesn't have a job because he has epilepsy. You ask David if he lost his job after having a seizure at work? (Enacted stigma). He replies that he hasn't had a job in years because he knows people would never hire him because he has epilepsy (Felt stigma). List or role play ways you can help David.

CASE SCENARIO #5

The Chief has denied a man a farm input subsidy. He has told the man that he cannot grow a maize field because he has epilepsy. What can you do to end this discrimination?

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advocacy in action

Fides (Tanzania) is the CEO and Founder of Tanzania Epilepsy Organisation. She is celebrating International Epilepsy Day (2nd Monday of February each year) to promote awareness in her community.

> “You learn how to cut down trees by cutting them down.”
>
> – AFRICAN PROVERB

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