Planning for Organizational Influence on Epilepsy Stigma

Vanderbilt University

Capstone White Paper

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Executive Summary:
Planning for Organizational Influence on
Epilepsy Stigma

Background Information

ROW Foundation is a funding-focused, United States 501(c)(3) private foundation, founded in 2014 and headquartered in Naperville, IL. The organization's name, ROW, stands for "Rest of World" and originates from the use of the acronym among pharmaceutical companies to denote sales in low- and middle- income countries (LMICs). Though these "ROW" countries contain approximately half of the world population, they are rarely identified as an important market for pharmaceutical sales. Recognizing this lack of investment in LMICs, ROW Foundation partners with ROW Global Health and OWP Pharmaceuticals to fund global partners that focus on training, diagnosis, treatment, and stigma reduction in under-resourced areas of the world.
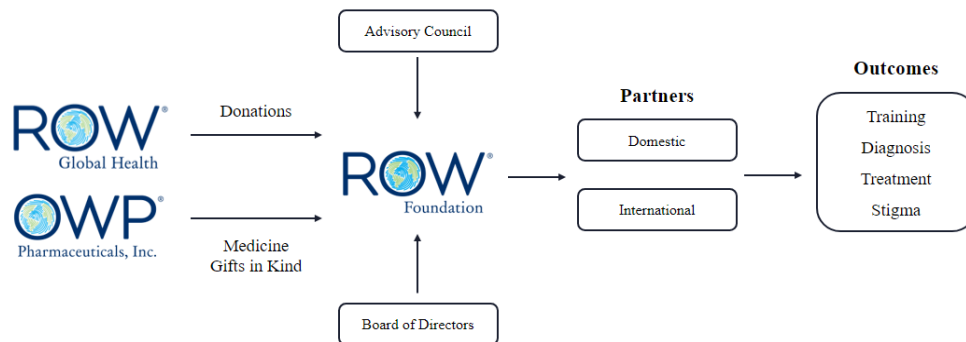
Area of Inquiry

ROW relies on successful domestic and international partnerships to reach people with epilepsy in LMICs. As those partners have identified stigma as a barrier to their projects, ROW recognizes an opportunity to help equip their partners to address stigma or to better identify potential partners with existing stigma strategies. To date, ROW has seen things like the successful management of epilepsy symptoms through medication encourage more people with epilepsy in the community to seek treatment. However, additional data on stigma and potential strategies to reduce it are scarce. Therefore, ROW anticipates that more inquiry into stigma mitigation could also help mitigate the detrimental impact of stigma on training, diagnosis, and treatment for epilepsy.

Additionally, ROW lacks a formal, systematic approach for evaluating the impact of its programs, especially regarding stigma mitigation. ROW suspects that a more robust system for gauging, collecting, and eventually sharing the impact and strategies of the programs it funds could increase the effectiveness of its partnerships in LMICs. Importantly, while ROW is currently limited in capacity from a human and financial resource perspective, they are expecting growth in their resources and operations over the next few years. ROW wants to plan for greater impact on epilepsy stigma as they grow.

Conceptual Framework

Building off the work of Thapa et al (2018), we developed a framework that conceptualizes stigma mitigation interventions according to components, mechanisms, and context of their targeted population. We used this conceptual framework to help determine how interventions worked and how funders could influence partners to modify or adopt intervention strategies.
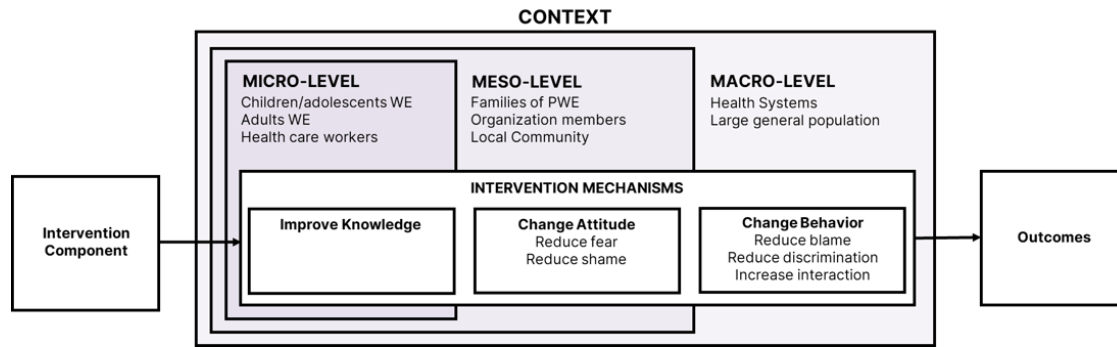
Project Questions Aligned with Project Design

Specifically, we approached ROW's aim to better address epilepsy stigma as they grow through three questions:

1. What interventions are partner organizations currently using to decrease epilepsy stigma in LMICs?
   a. What are the underlying mechanisms?
   b. What are the contextual factors?
2. What levers can funders use to encourage the practice of stigma reduction strategies?
3. What are the best evidence-based evaluation processes ROW can use to determine the efficacy of current and future partnerships?

To answer these questions, we explored three sources of data for analysis:

1. We conducted a document analysis of ROW's application and evaluation processes
2. We interviewed 10 individuals representing organizations working to reduce epilepsy stigma
3. We surveyed all ROW's current partners at the time of the project (78% response rate)

We used a deductive approach informed by our conceptual framework to code the surveys and interviews, and we inductively coded the interviews, surveys, and documents. Document analysis and interviews informed project questions 1-3, while the surveys informed project question 1 only.

Project Question (PQ) Findings

The coding of our surveys and interviews highlighted several major themes for each of our project questions:

PQ	Major themes
1	• The power of ambassadors as storytellers • Improving knowledge as a means to change perceptions, beliefs, or actions • The importance of building relationships with and access to authority holder
2	• Using calls for proposals to direct partners towards specific strategies, with partner input • Coordinating resources via networks that increase chances of success • Leveraging organizational longevity and reputation to connect to influential partners and drive lasting impact
3	• Analyzing existing partner organization's barriers as part of the evaluation • Creating systems of reporting that leverage known metrics

Recommendations

Based on the findings, we grouped recommendations into four major categories:

1. Listening to partners and influencing interventions
2. Collecting and organizing data
3. Leveraging reputation among funders
4. Implementing calls for proposals

Recognizing that ROW is currently limited in its operations but expecting to grow, we provided recommendations for both immediate and long-term implementation to best accommodate for ROW's current and future operational capacity. Importantly, the immediate recommendations are intended to prepare ROW for the more significant long-term recommendations in the future. Recommendations 1-3 have an immediate and long-term time horizon component, while recommendation 4 only has a long-term component, as it is best achieved after fully implementing recommendations 1-3.
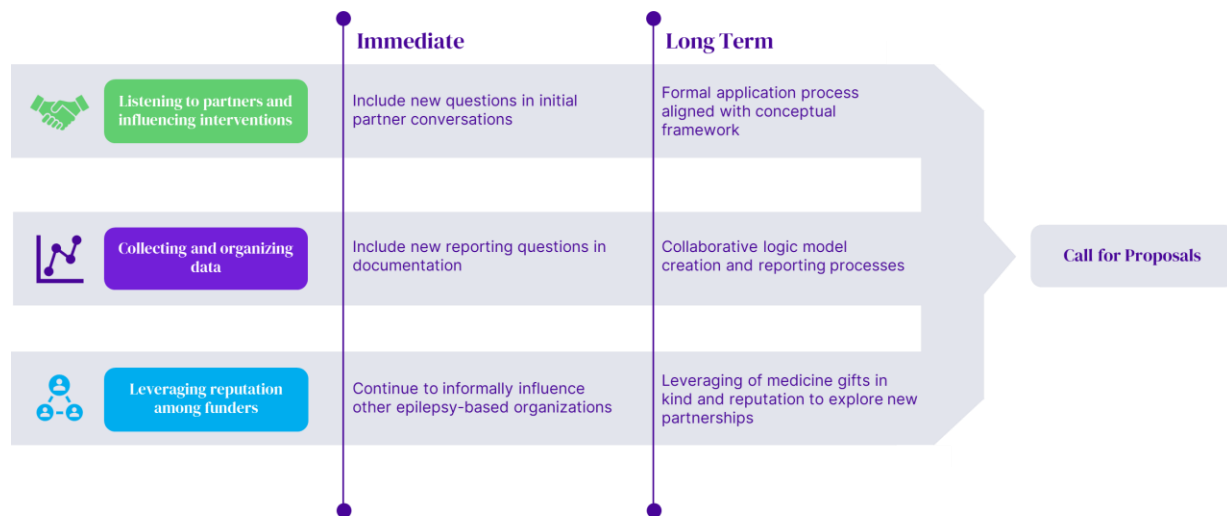
Implementing Recommendations

To best implement these recommendations, we suggest a general approach to process improvement using Lewin's three-step change model. This model suggests that organizations need to "unfreeze" current practices to make changes, then "freeze" in a new desired state. ROW can use the model when deciding when and how to implement changes recommended in this project. While examples are given for determining when and how to implement the formalized application and reporting process, we expect that ROW will best understand when to apply the recommendations provided here.

Unfreeze

Recognize the need for change as ROW's capacity grows

Change

Implement the new formal processes

Refreeze

Reinforce and stabilize the formal processes

Organization Context

ROW Foundation is a funding-focused, United States 501(c)(3) private foundation that has the goal to "transform the lives of people with epilepsy and associated psychiatric disorders in under resourced areas of the world" (ROW Foundation, n.d.). It was founded in 2014 and is headquartered in Naperville, IL. The organization's name, ROW, standing for "Rest of World", originates from pharmaceutical companies' use of the acronym to denote sales in low- and middle- income countries (LMICs). Though "ROW" consists of approximately half of the world population, sales there were substantially less than the first-world and emerging markets. Co-founder Scott Boyer named the foundation in honor of the people living in the rest of the world, often in poverty, with limited access to the standard of healthcare available in developed countries (ROW Foundation, n.d.).

ROW Foundation partners with ROW Global Health and OWP Pharmaceuticals to fund operations of their global partners (see Figure 1). These partners operate in under-resourced areas of the world and focus on training, diagnosis, treatment, and stigma reduction of epilepsy and associated psychiatric disorders. Importantly, OWP Pharmaceuticals provides ROW Foundation with pharmaceutical gifts in kind that have largely defined ROW Foundation's operations in LMICs. Since OWP is in the process of releasing new epilepsy medications, ROW anticipates an increase in its funding resources that will allow it to grow its operations.

Figure 1. *ROW Foundation partners with several organizations in LMICs.*
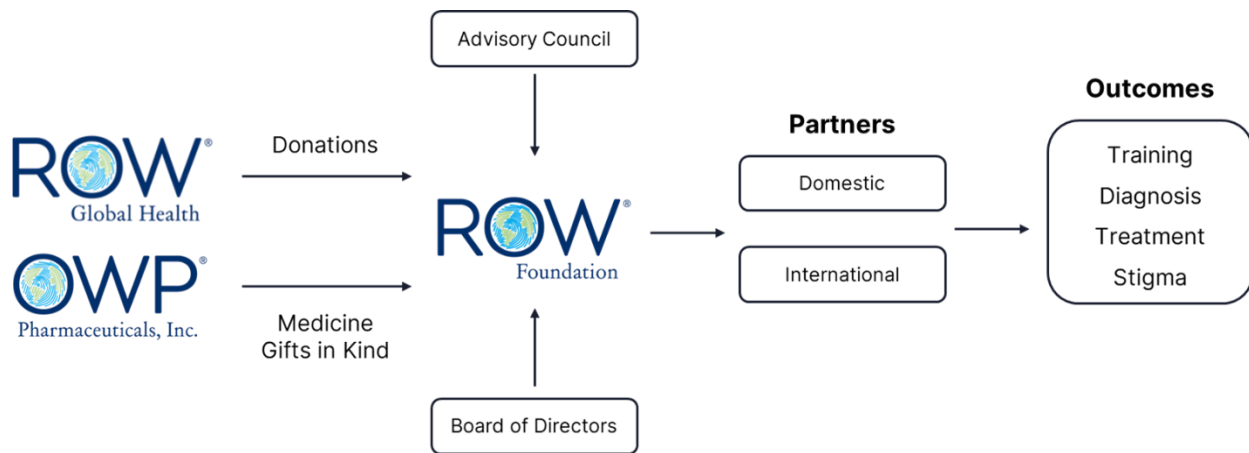
Problem of Practice

ROW currently relies on successful domestic and international partnerships to reach people with epilepsy in LMICs. The stigma surrounding epilepsy, however, complicates the processes of accessing information, finding local partners, providing medical care, and achieving holistic outcomes (von Gaudecker et al., 2022). Often, families of people with epilepsy consult traditional and faith-based healers who may not share the same explanatory model of epilepsy used by an international organization like ROW (von Gaudecker et al., 2022). Additionally, these families may hide members with epilepsy from other potential community partners - like schools - that could gather information on and help facilitate the treatment of the disease (Ali et al., 2014). The result is that potential partners may stigmatize epilepsy as a shameful, contagious, or demonic condition instead of a treatable neuropsychiatric one (Kaddumukasa, et al, 2018). The impact of stigma on the treatment of epilepsy is so significant that much current scholarship identifies the spread (Ali et al., 2014; Espinoza-Jovel et al., 2018; Kaddumukasa et al., 2018; von Gaudecker et al., 2022), quantification (Elafros et al., 2015), and mitigation of stigma (Bhwana et al., 2021, Kaddumukasa et al., 2018) as critical to the treatment of epilepsy in LMICs. ROW's experiences corroborate this research.

Identifying stigma as a barrier to epilepsy treatment, ROW recognizes an opportunity to help equip their partners to address stigma and better identify potential partners with existing stigma strategies as it grows its funding operations. However, clear recommendations on how to reduce stigma are scarce and highly contextual. ROW suspects that inquiry into best practices in the field could help them develop their own strategies to mitigate the impact of stigma on the effectiveness of their partnerships.

ROW currently collects mandated expenditure reports, project updates, and stories of program impact, but seeks to increase the effectiveness of its partnerships in LMICs with a more robust system for gauging, collecting, and eventually sharing the impact and strategies of the programs it funds. The foundation feels this is particularly important in the area of reducing stigma.

Review of the Literature

Epilepsy is a common neurological disorder, affecting an estimated 70 million people worldwide, 80% of which live in LMICs (Chakraborty et al, 2021). Due to the symptoms of epilepsy, stigma has emerged as a significant factor in the quality of life for people living with epilepsy (PWE) (Agbetou et al., 2022; Alkhotaini & Alkhotani, 2022; de Boer, 2010; Mogal & Aziz, 2020). Recognizing the impact that stigma has on PWE, the World Health Organization currently identifies reducing stigma as a major strategic initiative for the next ten years (2023).

To support ROW's contributions toward this effort, we reviewed the literature on epilepsy stigma in LMICs, stigma mitigation strategies for epilepsy, stigma mitigation strategies in general, and the role of non-profits in stigma mitigation in LMICs. We limited our review to six databases and repositories (ProQuest, Vanderbilt University, CINAHL, PubMed, Embase,

and PsychINFO). In each of those databases, we ran five searches limited to academic articles

published in English since 2000 with the following criteria:

- Search 1: title("epilepsy*") AND title("stigma*") AND abstract("LMICs")

- Search 2: title("epilepsy*") AND title("stigma*") AND title("treatment*" OR

  "intervention*")

- Search 3: abstract(LMICs) AND title("stigma reduction*") OR title("Stigma

  mitigation*")

- Search 4: title("epilepsy*") AND abstract("non profit*") AND abstract("LMICs")

- Search 5: abstract(LMICs) AND title("stigma reduction*") AND title("epilepsy*")

These searches resulted in 182 articles. After initially removing 111 duplicates, we screened the

remaining ones, removing articles that did not seem to address stigma (n=20), could not be fully

retrieved (n=5), or were either interviews or dissertations without peer-review (n=3). This

screening process ultimately yielded 43 articles in areas most likely to inform ROW's work with

its partner organizations (See Figure2).

Figure 2. *The identification and screening process resulted in 43 articles for review.*
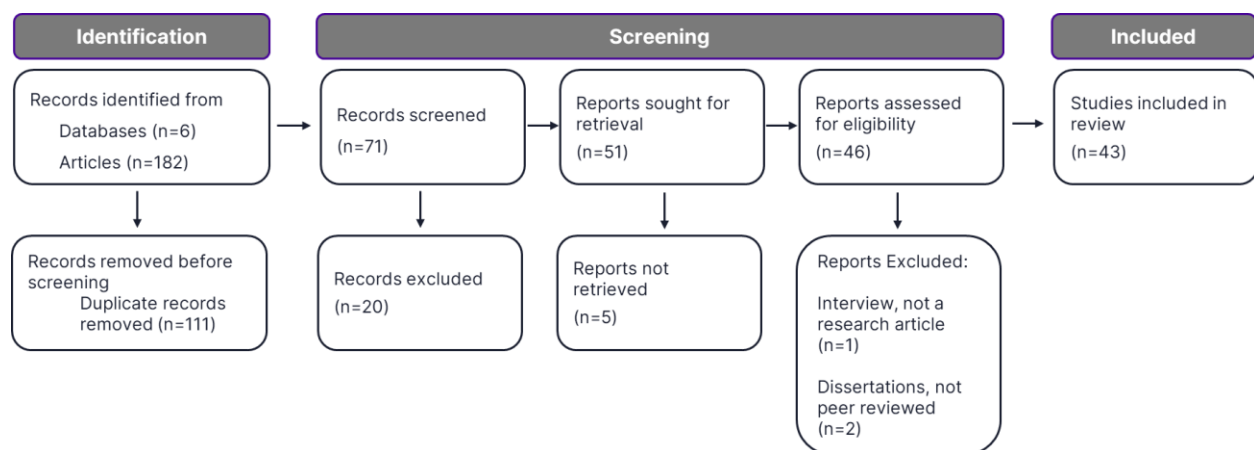
Our review of these articles suggests that, while the call to address epilepsy stigma is global, stigma itself is complex and contextual. People understand epilepsy differently across cultures, with some believing that it is either demonic, indicative of a failure to fit into community, or contagious (Keikelame & Swartz, 2016), and, as the understanding of epilepsy varies, so do the major ways in which people stigmatize community members living with it. For example, whether parents forbid their children to marry people with epilepsy seems to differ by location, as do teachers' hesitancy to include students with epilepsy in their classroom (Kaddumukasa et. al, 2018). In response to this complexity, researchers conceptualize stigma across several dimensions, including its target, context, operational level, and interactions with existing social systems (Cross et al., 2021; Kariuki et al., 2021). Even how stigma is measured seems to change across context, and researchers spend considerable time validating stigma measurement tools in new populations and locations (Bhalla et al., 2012; Elafros et al., 2015; Kirabira et al, 2020; Saadi et al, 2016; Turan et al, 2022; Viteva, 2016). There does not seem to be a single global approach to epilepsy stigma so much as a shared understanding that stigma presents differently across populations and locations.

The research on stigma strategies is similarly contextual, although it seems that these strategies often target a few common social systems. For example, many interventions target healthcare systems, since the prejudice, exclusion, and condemnation faced by people with epilepsy often leads to a treatment gap as people with epilepsy hide their symptoms (Von Gaudecker et al., 2017; Mogal & Aziz, 2020). Similarly, interventions are common in schools, since children with epilepsy are less likely to attend school, start school on time, avoid retaking courses, and graduate (Anguzu et al., 2021; Kirabira et al., 2020). Additionally, education can mitigate the effects of perceived epilepsy stigma in some contexts (Luna et al., 2017). People

with epilepsy tend to report difficulty engaging with the community, a sense of isolation and suffering, longing for a more fulfilling life (Von Gaudecker et al., 2017), and healthcare; education initiatives can help people with epilepsy engage with the community in new ways.

While these strategies might share common social and institutional targets, efforts to increase engagement with those systems take a variety of forms. Education initiatives range from acting and video dramas in grade schools in the Czech Republic (Brabcova et al., 2013; Brabcova et al., 2017) to government-sponsored education programs attached to treatment centers in Pakistan (Mogal & Aziz, 2020) and community interventions in Bolivia (Giuliano et al., 2019). Complicating the reality of these multiple possible strategies is the fact that, while a strategy like peer-support groups might fail to reduce stigma in Tanzania (Bhwana et al., 2021), a similar strategy might be effective with children – but not adults – in Zambia (Elafros et al., 2013).The research does not identify a set of key interventions that consistently mitigate stigma for all people with epilepsy so much as the need to identify tools by which individual strategies are coupled to specific contexts, targets, and populations.

Beyond the strategies directly addressing epilepsy stigma, our research also identifies several varied and context-dependent strategies associated with other conditions that could inform ROW's ability to identify successful partnerships (Clay et al., 2020). HIV research highlights several strategies that effectively mitigated stigma across different contexts and documents some of their long-term effects (Lyons et al., 2020; Rao et al., 2018; Thapa et al., 2018; Vijoen et al., 2021). Similarly, strategies around contraceptive use (Makenzius et al., 2023), mental health (Girma et al., 2022; Hasan et al., 2022; Javadi et al., 2017), and sexual gender-based violence (Logie et al., 2023) could provide additional insight into effective approaches to stigma for people living with epilepsy in similar contexts.

While these studies examine a range of strategies used to address stigma in epilepsy and other conditions, they underscore the importance of attaching the right strategy to any one particular context. Significantly, few address how an organization like ROW might identify and encourage successful strategies for its partners. Additional insight into how ROW might conceptualize, identify, encourage, and evaluate stigma strategies could provide the organization with tools to help connect strategies in the literature with its actual partners on the ground.

Conceptual Framing

ROW Foundation partners with organizations in low- and middle- income countries to improve the lives of people living with epilepsy. That work is negatively impacted by stigma. Stigma is multi-faceted, including both felt and experienced components that vary by context, and research on successful ways for organizations to mitigate stigma is similarly complex. Thapa et al. conceptualize anti-stigma strategies as intervention components that utilize mechanisms like improved knowledge and changed behavior in a context-mediated process that leads to measurable outcomes (2018). Kariuki et al. emphasize the importance of context and suggest that it works at mirco, meso, and macro levels (2021). Taking these two approaches together, we conceptualize stigma mitigation strategies as specific components that drive context-moderated mechanisms toward measurable outcomes (see Figure 3).

Figure 3. *Conceptualizing stigma mitigation strategies as intervention components that are driven by mechanisms and moderated by context.*
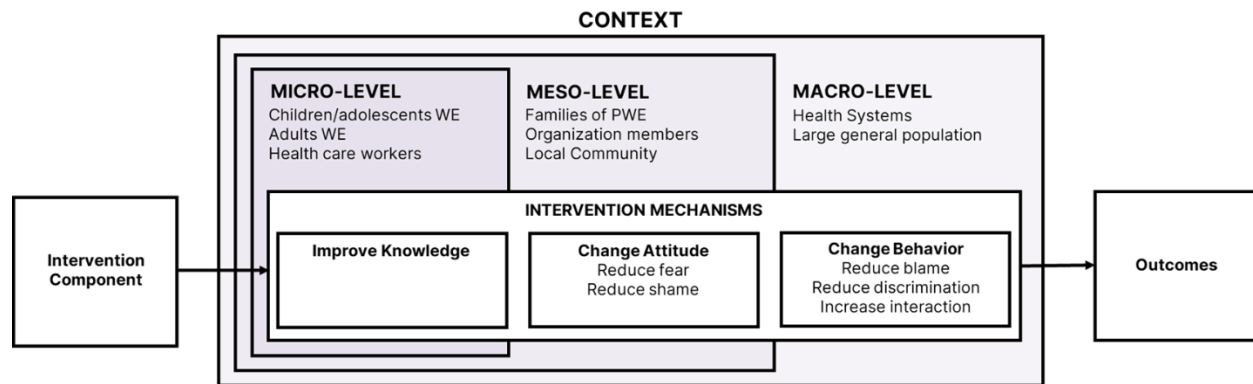
Our review of the literature supports the idea that conceptualizing target populations and interventions at micro, meso, and macro levels could help ROW in its work with partner organizations. Although there is variety in how organizations work with target populations, micro-level interventions (like therapy) tend to target populations that are conceptualized at the micro-level (like adults living with epilepsy) (see Table 1). Similarly, interventions that operate at the macro-level (like legislation) tend to target populations conceptualized at the macro-level (like the general population of an entire country). Other contextual factors seem similarly important. Reviews of stigma mitigation strategies often indicate the country in which the intervention took place, suggesting that these contexts are important in understanding the nature and impact of the intervention itself (Austin et al., 2022; Chakraborty et al., 2021; Kaddumukasa et al., 2018; Saadi et al., 2016).

Table 1. *A review of stigma mitigation strategies suggests possible interactions between types of target populations and strategies.*

			Intervention Component								
			Micro		Meso				Macro		
			Surgery	Therapy	AV Media	Print Media	Actin/ Storytelling	Group Intervention	Seminars	Campaign/ PSAs	Legislation
Target Population	Micro	Children/Adolescents WE			3	2	2		4	2	
		Adults WE	2	3					5		
	Meso	Health Care Workers			1				2		
		Families of PWE			1		1	4	2		
	Macro	Institution Members			4	2			13	2	
		General Population			1				3	7	1

These studies equip ROW with the framework that interventions and their mechanisms of action are context-dependent and can operate at different levels. They do not, however, help ROW understand what its partners are currently doing and how ROW might function as a more effective mediator in the stigma mitigation process.

Research Questions:

Three research questions set the foundation for determining how ROW Foundation might influence partner organizations in stigma mitigation:

1. What interventions are partner organizations currently using to decrease epilepsy stigma in LMIC's?

    a. What are the underlying mechanisms?

    b. What are the contextual factors?

2. What levers do funding organizations have to encourage practice of strategies to reduce stigma?

3. What best evidence-based evaluation processes can ROW Foundation use to determine the efficacy of current and future partnerships?

Question one highlights strategies that are most commonly used by partner organizations. Combining these with the strategies from the literature review will help us compare what is being used in practice with what is described in the research. Additionally, this question highlights underlying mechanisms for how these strategies work and how context-dependent factors might moderate the success of an intervention. Question two helps clarify the influence a funding organization might have over partner organizations and how that influence impacts their partnership. Question three informs how ROW Foundation can evaluate the efficacy of partner organizations enacting stigma strategies. Ultimately, all three questions can inform recommendations on effective stigma mitigation interventions and how ROW might encourage its partners' effective use of similar strategies.

Project Design

To answer our research questions, we used three sources of qualitative data: semi-structured interviews, online surveys, and document analysis. Table 2 outlines each research question with the corresponding method for data collection.

Table 2. *Research Questions and Corresponding Data Collection Instruments*

Research Question	Data Collection Instrument
What interventions are partner organizations currently using to decrease stigma around epilepsy in LMIC's?	Semi-structured interviews Partner surveys Document analysis
What are the levers funding organizations have to encourage the practice of strategies to reduce stigma?	Semi-structured interviews Document analysis
What are the best evidence-based evaluation processes that ROW can use to determine the efficacy of current and future partnerships?	Semi-structured interviews Document analysis

Semi-Structured Interviews:

To provide rich and contextual descriptions beyond what was found in the literature review, confidential interviews were conducted over Microsoft Teams in March and April 2024 (questions listed in Appendix A). The questions were designed to uncover information pertinent to ROW's interests and were informed by the literature review. Each interview lasted approximately one hour. Participants represented a variety of organizations suggested by ROW Foundation. Additionally, snowball sampling led to additional organizations suggested by interviewees. These organizations are all directly involved in epilepsy interventions and uniquely suited to inform ROW's operations (see Table 3).

Table 3. *Organizations represented in the interviews*

Organization Name
BAND Foundation
Espacio Epilepsia
Global Organization for Health Education
International Bureau for Epilepsy
ROW Foundation
Vanderbilt Institute for Global Health

Partner Surveys:

Current ROW partners were invited by email to participate in a brief survey via Google Forms in March. The email was then resent in April to those who did not initially respond. The survey consisted of five questions regarding the community and target populations each partner works with, the work they do to improve the lives of individuals with epilepsy, and how they specifically target epilepsy stigma. The primary purpose of this survey was to understand what is

currently being done to combat epilepsy stigma, including the communities and populations

ROW's partners are working in and with. Secondarily, it provided insight into how stigma

reduction is conceptualized in the field, since it is possible that partners may inadvertently

implement stigma reduction strategies without identifying them as such. This complete survey

can be found in Appendix B.

Document Analysis:

In addition to surveys and interviews, we conducted a brief document analysis of sources

that could provide additional insight into ROW's partners' current stigma mitigation strategies.

Specifically, we examined the following ROW Foundation documents from the previous year:

1. Grant applications

2. Annual reports

3. Documented stories of success or struggle in the treatment of epilepsy submitted by a
   partner organization.

In these documents, we looked at annual reports for partners' current reporting obligations to

ROW, grant proposals for insight into partner operations and stigma reduction strategies, and

documented stories of success for evidence of what works, for whom, and under what conditions

in the context of epilepsy treatment.

Timeline

The following timeline was utilized in collecting and analyzing the data:

Milestone	Date (2024)
• Create data collection tools and protocols • Request documents from ROW Foundation	February 1- 29
• Conduct organization interviews • Send out survey to partners	March 1 - 30
• Continue organization interviews • Send reminders to complete surveys and interviews three times, spaced out by 1 week per reminder	April 1 - 25
• Data collection concludes	April 26
• Conduct document analysis • Conduct analysis on data collected from interviews and surveys	April 1 – May 16
• Finalize recommendations	May 17 – June 30
• Present recommendations to ROW Foundation	August 6

Data Analysis

The study included seven semi-structured interviews, seven partner survey responses, and three documents. The data collected from these sources were analyzed in light of our three research questions, including 1) strategies ROW partners have used to address stigma, 2) partner comments on the level of success for those strategies, and 3) lenses to help assess how ROW could effectively enhance the work of its partners. Because our framework suggested that the outcomes of stigma interventions are influenced by the interaction of intervention component, intervention mechanism, target population, and context, the data we gathered were coded and analyzed to highlight possible interactions among those categories.

Coding Process

We coded the survey responses, interviews, and documents both deductively and inductively. Our conceptual framework informed the deductive analysis. Specifically, we coded according to intervention component (e.g. AV media, seminars, therapy, etc...), intervention

mechanism (improving knowledge, changing attitudes, and changing behaviors), intervention level (micro, meso, and macro), target population (children WE, adults WE, health care workers, families of PWE, institution members, and the general population), and target population level (micro, meso, and macro).

Inductive coding allowed additional categories to emerge from the data. Importantly, we only coded for topics related to stigma interventions. The criteria for stigma interventions included actions taken by organizations that reduce or aim to reduce experienced stigma at the self, community, or institutional level. Other interventions that did not meet these criteria were excluded from the analysis.

Trustworthiness

To support the trustworthiness of our findings, we triangulated themes among our three sources of data. Additionally, we wrote memos of our process and data coding to document our interpretations over time and kept an audit trail to ensure we followed our design, noting when and why changes were made. Lastly, we independently coded the interviews and surveys to enhance the accuracy of the coding.

Findings

Inductive and deductive coding of the interviews revealed several major themes related to the research questions. Three themes were found for research questions one and two, and two themes were found for research question three. Additionally, analysis of the documents provided insight into the data ROW currently collects data relative to those major themes.

Deductive Analysis and Matrix

The deductive coding process yielded several themes among the qualitative data sources (see Table 4). Of note, all interviewers referenced storytelling and medication as useful tools to combat epilepsy stigma. Additionally, while all three intervention mechanisms were present in our surveys and interviews, the most commonly referenced was improving knowledge, followed by changing attitudes, and lastly by changing behaviors. Interviewees focused on interventions applied to adults more than children, whereas the opposite was found in the surveys of partner organizations. Lastly, several interviewees highlighted the opportunity for smaller funding organizations like ROW to take on a coordinator role of resources between partners and other funding organizations.

Inductive analysis

While the deductive analysis highlighted themes consistent with the conceptual framework developed from the literature review, the inductive analysis of the surveys and interviews generated themes directly from the input of ROW's fellow funding organizations and its current partners. Arranging these themes by research question suggests how ROW might benefit from the insight provided in those sources. The themes relating to each of the research questions are addressed below Table 4.

Table 4. *Deductive analysis highlighted themes among qualitative data sources. Deductive codes are listed across the left with data sources (both interviews and surveys) listed across the top. Highlighted portions of the table indicate how often a code appeared in a specific data source.*

		I1	I2	I3	I4	I5	I6	I7	S1	S2	S3	S4	S5	S6	S7
Intervention Component	AV Media	1	6	7	0	4	9	0	1	2	0	1	0	3	0
	Acting/Storytelling	9	8	3	4	5	5	3	1	0	0	1	0	1	0
	Campains/PSAs	7	7	4	3	2	0	2	2	1	0	0	0	0	0
	Group Intervention	6	0	1	1	1	0	1	2	2	1	0	0	0	0
	Legislation	3	7	1	0	1	0	0	0	1	0	0	0	0	0
	Medication	2	4	1	2	2	1	9	1	4	0	0	1	1	0
	Print Media	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Seminars	2	0	0	3	3	2	3	2	0	0	0	0	4	2
	Surgery	0	0	0	0	0	0	0	0	0	0	0	0	0	0
	Therapy	0	0	0	0	0	0	0	1	0	0	0	0	1	0
Intervent. Level	Macro	13	15	19	4	3	2	4	0	2	0	1	1	2	0
	Meso	20	10	3	1	4	7	9	3	2	1	1	1	3	2
	Micro	12	3	0	7	0	0	14	1	0	0	0	2	0	0
Intervent. Mechanism	Changing Attitudes	7	4	5	11	4	1	2	0	1	1	0	0	0	0
	Changing Behaviors	7	5	0	5	4	5	3	3	1	0	0	0	4	2
	Improving Knowledge	10	11	7	18	6	4	18	9	3	5	3	1	5	3
Target Pop. Level	Macro	4	1	3	5	1	1	3	0	0	0	0	0	0	0
	Meso	18	3	1	7	5	5	17	2	4	0	0	0	5	2
	Micro	10	3	0	6	1	5	9	2	2	0	0	1	0	1
Target Population	Adults WE	6	8	1	6	3	8	4	8	5	3	1	2	2	0
	Children WE	0	0	4	4	0	0	15	6	3	3	1	2	1	1
	Families of PWE	2	0	4	1	0	4	4	5	2	3	2	2	2	2
	General Population	11	2	1	2	3	2	8	2	2	1	0	1	2	2
	Health Care Workers	3	8	4	2	6	5	5	4	6	2	2	1	7	2
	Institution Members	9	5	1	6	5	2	10	3	3	3	0	3	1	0

RQ 1: What interventions are partner organizations currently using to decrease stigma around epilepsy in LMIC's?

While ROW's partners address epilepsy stigma in different ways and in different contexts, three major themes emerged across the interviews of other funding organizations and surveys of current partners:

1. The power of using ambassadors as storytellers

2. Improving knowledge as a means to change perceptions, beliefs, or actions

3. The importance of building relationships with and access to authority holders

The power of using ambassadors as storytellers. First, multiple interviews and surveys stressed the impact of having people living with epilepsy function as storytelling ambassadors. Several people noted how ambassadors are more effective at providing context, increasing validity, and humanizing epilepsy than other educational interventions. Some interviews seemed to attribute this success to the fact that storytelling visibly attaches epilepsy to individuals in the community:

> Trying to encourage people with epilepsy, as difficult as it is to be active in the community, to be visible in the community, to talk about, you know, what epilepsy is and what it isn't and for people to see, you know, that this is a neurological disorder of the brain. (Partner #2)

Others highlighted the ability of community members with epilepsy to connect with community leaders:

> We have also come up recently with stigma benches where, in specific communities, chiefs, duty bearers, community leaders, opinion leaders are invited to a stigma bench to hear the stories of persons with epilepsy and the stigma that they face. (Partner #1)

Beyond targeting individuals and leaders in the community, leveraging ambassadors as storytellers was also identified by ROW's surveyed partners as a tool that could improve stigma strategies targeting healthcare workers:

> Stigma training is provided by clinicians, people with epilepsy and their caregivers. It is important that the stories and voices of people with epilepsy and their caregivers are heard. They have the lived-experience of stigma that clinicians will never have. To

eradicate stigma, it is important that clinicians learn from experts by experience. (Survey

#1)

Across contexts, partners described ambassadors as effective tools for combating stigma at the

individual and community level across several contexts and target populations.

Beyond these micro- and meso-level community interactions, some interviewees also

indicated storytellers can be effective through macro-level interventions like radio and film.

Interviewees specifically highlighted a film documenting the lives and stories of four people

living with epilepsy (Partner #5). This film aims to combat epilepsy stigma in LMICs by

showing community members, funders, and other stakeholders the impact of epilepsy stigma on

a community member's life. Similarly, others noted the potential impact of people with epilepsy

discussing their stories and the impact over the radio, due to the prevalence of radio in LMICs:

I think radio broadcasts, if they're done in local languages and respecting local cultures in

which local people provide their perspectives and then physician experts and ensure that

perspectives provided on the radio are also medically accurate, then radio broadcasts can

be a powerful tool. (Partner #3)

Whether the intervention targeted individuals, communities, or countries, having ambassadors

with epilepsy tell their stories was seen as a powerful tool against stigma.

In addition to stressing the importance of ambassadors, several partners highlighted the

potential role that initiatives like the International Bureau for Epilepsy (IBE)'s Advocate Toolkit

and the WHO's Intersectoral Global Action Plan (IGAP) could play in identifying and promoting

ambassador voice. One interviewee explicitly connected these plans when talking about the roles

of community ambassadors as storytellers:

You cannot talk about having an anti-stigma policy when you don't even have a national

epilepsy plan...now we're talking about the IGAP – Intersectional Global Action Plan of

May 22 by WHO, where we have a specific stigma pillar. If most countries were to

domesticate this pillar, it would be much easier for us to talk about policies, policies that I

would say are compatible or that speak to stigma. (Partner #1)

Although several interviewees discussed larger organizations like IBE and the WHO as potential

sources of information on how funding organizations can coordinate efforts (a point we discuss

in research question 2), they were often conceptualized in the discussions as a means to equip

communities with frameworks that make the critical work of ambassadors easier.

Improving knowledge as a means to change perceptions, beliefs, or actions. The

interviews suggested that most current interventions are primarily aimed at improving

knowledge. Several indicated that changing peoples' knowledge of epilepsy could lead to a

change in perception of epilepsy as demonic or contagious towards epilepsy as a medical

condition that is noncommunicable, highly treatable, and often connected to other comorbidities:

So, it's basic understanding, but the other things that people don't realize is that if you

have epilepsy, you're also going to have problems with your attention and concentration,

your memory, your ability to process information. There may be some language

disturbance as a consequence of that, and these comorbidities are actually part of the

same brain pathology that produces the seizures. So it's having an understanding that the

child in your class who may not be paying attention but has epilepsy may in fact be

having an absence seizure...If you get somebody to understand, they're going to be

much more benign in their attitudes and behavior. (Partner #4)

This change in understanding could then lead to a change in beliefs and actions. "Where you find an increase in knowledge you also have an increase in attitude, then an increase in practice. So, I would say the chain would be knowledge, attitude, then practice" (Partner #1). Partners consistently spoke of the need to address knowledge, attitudes, behaviors, and practices, but often identified addressing a lack of knowledge and understanding as the first task when addressing stigma.

Not all interviewees, however, agreed that a lack of knowledge was the first problem to address with epilepsy stigma. One partner suggested, in some context, it is not a lack of knowledge that inhibits progress on stigma, but a lack of tools for self-expression:

I saw that they were implementing strategies from the 90s, and it was 2010 and things were different. We had the same message, and we still have the same message: 'get epilepsy out of the shadows.' Epilepsy is not in the shadows. If I talk to a teenager, they speak openly about epilepsy. I think those messages are so old, so out of date. (Partner #6)

Instead of arguing for more information, Partner #6 identified the need for new behaviors and patterns of communication, suggesting that a lack of information might not be a primary concern in all contexts.

The importance of building relationships with and access to authority holders. The interviews and surveys suggested that partner organizations specifically target relationship building with and access to authority holders. These authority holders include duty bearers (community members with recognized influence), religious leaders, political figures, and members of culturally significant institutions. By focusing on creating relationships with authority holders and decision-makers, partners are able to better implement their educational

interventions. For example, partnerships with healthcare workers could be critical in some contexts, "In some communities the doctor's or the medical authority's opinion carries the most weight because of how the community values medical authority" (Partner #3).

While, in other contexts, that authority is assigned to family elders:

> In all the LMICs, local low middle income countries I've worked with in Asia, Africa, you know Central, South America, traditional family structure respects elders, and the authority for decision making is often given to grandparents, especially grandmothers when dealing with children. And so sometimes we fail because we can't get to the ultimate decision makers who are the grandparents. (Partner #3)

Regardless of whether authority resided with doctors or grandmothers, however, the interviews and surveys indicated that partnerships with cultural authorities were critical.

Importantly, all interviewers indicated the importance of understanding context and culture when delivering interventions. Prevalent contextual factors mentioned included poverty levels, language translation accuracy, trust between partner organizations and the funder and community, differences in rural and urban settings and policies, and the influence of authority holders. Additionally, interviewees underscored how important cultural factors such as the transparency of local relationships, the ability of educational programs to encourage knowledge change, the availability of medications that show communities that epilepsy can be treated, and staffing and funding of local organizations can impact stigma interventions.

RQ 2: What are the levers funding organizations have to encourage practice of strategies to reduce stigma?

The interviews and surveys also highlighted three major themes on the question of how funding organizations might encourage successful stigma mitigation strategies:

1. Using calls for proposals to direct partners toward specific strategies, with partner input

2. Coordinating resources via networks that increase chances of success

3. Leveraging organizational longevity and reputation to connect to influential partners and drive lasting impact

Using calls for proposals to direct partners toward specific strategies, with partner input. By creating calls for proposals, funding organizations can set parameters on the work to be completed and how that work should be done. For example, Partner #2 noted that "if we say this is the theme we want to pursue this year or you know this is what we'll be providing funds for this year, people will, I think, respond and you know adapt to whatever it might be that we're trying to do." By controlling resources, funding organizations have the power to shape stigma mitigation strategies.

The reality of this relationship, however, is more complicated. Partner organizations often require funding for their basic operations. "There are very basic needs that a lot of our chapters have as well. So sometimes it really is just around providing them funding so that they can exist, rather than really asking people to embark on a very specific piece of work" (Parter #2). Because of those needs, partners are incentivized to agree to calls to action that might not be successful in their communities:

> If [an organization] declares, 'we have the answer to this stigma problem, here's some money to implement this solution', then the people on the receiving end, who are poor, very often know that the solution will not likely work in their community. However,

they're not going to turn down the funding. They're going to try to do it, and the

program will not work very well. On the other hand, if [an organization] asks the local

community leaders, 'do you have a problem with stigma?... What else is it associated

with? How can we develop an intervention for your area, your community? Then they

partner with those local community leaders to develop a study or an intervention, taking

more time than declaring a solution, then this approach of community engagement can be

an extremely powerful tool for good. (Partner #3)

Calls for proposals, then, need to be informed by partners' needs and local communities. This

process of collaboration requires that both parties are "transparent on what you are willing and

not willing to do upfront" (Partner #6) but can lead to a "co-production of the work that we need

to work together on" (Partner #1).

Coordinating resources via networks that increase chances of success. Several

interviewees suggested that funders can drive impact by increasing collaboration as well as

access to authority holders, resources like money and education, and other funding and partner

organizations. The most frequently mentioned examples of this type of collaboration were the

WHO's IGAP and the IBE's Advocate Toolkit. The IGAP, in particular, was described as one of

the most important tools to "pull new funders into the space" (Partner #5). Another partner

stressed how this coordination focuses efforts toward a few agreed-upon goals:

It's only fairly recently that things have started to come together, and there's been some

coordination in some mutually agreed upon big goals that are part of IGAP. These WHO

IGAP goals to address the epilepsy diagnosis and treatment gaps have great potential to

bring together multiple funders and partners across the world to reach these goals, even if

the achievement of the goals takes decades and not years. (Partner #3)

This level of coordination requires interactions among funders. In fact, one partner stressed the

opportunity for funding organizations to attract more coordinated funders: "But [funding

organizations] should, I think, be looking towards how do we bring more [funders] in instead of

just funding one-off projects? How would you successfully attract funders?" (Partner #5).

Multiple interviewees also mentioned the coordination seen in HIV stigma mitigation or

other large-scale efforts as an example of how epilepsy organizations could work together:

> The [epilepsy] numbers are staggering, but if you want to address something on the scale,
>
> HIV, you've got to address co-morbid conditions and large scale governance issues,
>
> relationships, nutrition, public policy...You have to go multi-sector to deal with it, and
>
> that's one of the things I like about the WHO IGAP. (Partner #3)

ROWs current partners draw similar comparisons to previous HIV initiatives:

> We aim to improve quality of life for epilepsy-affected households through a community-
>
> based, districtwide stigma-reducing education initiative. Although seizure reduction can
>
> partially address epilepsy stigma, education is critical. Copying successes from
>
> HIV/AIDS education, [we] will hire, train, and mobilize an education team to launch an
>
> education initiative. (Survey #7)

These references to current and past international initiatives suggest there is potential to

coordinate efforts beyond the epilepsy community, including organizations that focus on

poverty, transportation, and language. This coordination across areas of need could benefit

people living with epilepsy:

> I don't think if we address [stigma] as a siloed issue and don't think about it in terms of in
>
> terms of education, economy, poverty, then we're just fooling ourselves. The stigma often

comes out of a place of severe extreme desperate poverty and people don't see other

options...Having an approach that's multifaceted is very important. (Partner #3)

Although epilepsy stigma is a serious issue on its own, its connection to other factors suggests

that it cannot be successfully addressed without teams of partners attending to those other factors

as well.

Leveraging organizational longevity and reputation to connect to influential

partners and drive lasting impact. A funder organization's reputation, as exemplified in their

sustained support of a specific mission and the projects they fund, can provide that funder's

partners with international credibility and access to valuable networks. Interviewees mentioned

there are finite amounts of time, money, and resources available to partner organizations and that

partners can struggle to fund their own operations. Because of this, sustained sources of support

are critical for the long-term impact of stigma mitigation strategies:

And that's why, for me, I think this WHO [IGAP] initiative that everybody can support

and work under is so helpful because this is not a ten-year project. This is a multi-

generational effort, and so we all have to be able to hand off to the next generation in

order to make this work. (Partner #3)

Similarly, this support seems most impactful when it goes to organizations with reach and

reputation in their communities:

[We need] to start showing people how their money is invested because it's an

investment for them too. And we need to give them access and tell other people how,

because we have a lot of organic reach in within the epilepsy community and I don't think

we're showing that enough. So when people get to know us, they say like 'oh, you really

have a lot of reach within the epilepsy community', but you have to sort of get to know

us. (Partner #6)

While relationships among influential organizations are opportunities for funders to commit to

long-term collaboration with others in the field, changes in leadership can undermine those

partnerships. Interviewees highlighted the opportunity for funders to prioritize systems of long-

term support and collaboration, so "when the leadership from [one] foundation moves to another

priority, sometimes a different condition or disease, it is critically important that the overall push

in the field is not lost. This is why a consortium of foundations and multiple government

partners, rather than a single dominant foundation, is a better long-term strategy." (Partner #3).

RQ 3: What are the best evidence-based evaluation processes that ROW can use to determine

efficacy of current and future partnerships?

Two major themes pertaining to this research question emerged from the surveys and interviews:

1. Analyzing existing partner organization's' barriers as part of the evaluation of a new

    partner organization.

2. Creating systems of reporting and evaluation that leverage known metrics

Analyzing existing partner organization's' barriers as part of the evaluation of a

new partner organization. First, many interviewees noted the importance of understanding

contextual barriers to the implementation of stigma interventions and the evaluation of potential

partners. Specifically, they suggested that identifying barriers during initial and annual

evaluation processes can be critical for identifying which partnerships and interventions are most

likely to be successful. Several interviews referred to the epilepsy stigma toolkit as an important

resource for analyzing the barriers associated with stigma. One interview detailed how useful it

is to inform partners and funders of the prevalence of epilepsy and associated stigma in

communities:

> As I have highlighted before, we did not have a systematic approach of gathering this
>
> information. Hence we came up with a Stigma toolkit. So our stigma toolkit has got a
>
> systematic information of gathering this information. So we are trained on how to do it
>
> through the toolkit, so they do understand what are the needs that we'll be looking for
>
> through that situational analysis. (Partner #1)

 Interviewees identified additional contextual barriers that could inform funders as well,

including available time, availability and reliability of technology, measurement tool

accessibility and usability, partner organization capacity and staffing, and partner organization

succession planning for leadership.

Creating systems of reporting and evaluation that leverage known metrics. Second,

interviewees mentioned the importance of reporting key metrics. Most, however, were quick to

express the known difficulties associated with the measurement of epilepsy stigma. Partner #4

stated "It's also extremely difficult to show in a positive way the impact of interventions that

address stigma." Potential measurement tools mentioned include pre- and post-tests following

training, measurements of engagement and attendance at key events, observed changes in

behavior such as return to activities for people living with epilepsy, counts of the number of

people with epilepsy engaged in storytelling, and observed changes in local and national policies.

Interviewees frequently mentioned the effective evaluation of interventions as an

important way for funders to support partners. For example, one partner commented on how

evaluation guided their support of partners:

And for those who weren't successful, we've actually decided to do a sort of capacity

building initiative where we're thinking, OK, look, you weren't successful this year, but

let's work with you on topics like policy, advocacy, fundraising, communications and

maybe get you guys to that place where you may be able to submit and deliver kind of a

piece of work longer term. (Partner #6)

Document Analysis

To provide context for how ROW might already be engaged in some of these processes,

we analyzed key documents, including the pre-grant inquiry, grant contract, and annual report on

expenditures. While there are various questions and reporting measures for financial

responsibility and legal terms and conditions, we focused on aspects of the documents related to

epilepsy stigma.

The pre-grant inquiry asks potential partners to disclose primary activities and practices

that would be funded. The grant contract has no mention of topics related to epilepsy stigma. The

expenditure report asks three questions that may uncover epilepsy stigma intervention and its

effectiveness. The first question asks how the funds were used, which may help determine what

type of interventions were prioritized by the organization. The second question asks if there has

been specific problems or challenges in using the grant to achieve the purpose of the funding,

which might shed light on the contextual mechanisms or barriers to implementing stigma

reduction strategies. The third question asks the partner to provide a narrative on the progress of

achieving the purpose of the grant, including the benefits patients have seen as a result of their

work. The last question provides a chance for organizations to give details on success stories.

Threats to Validity

Our project design potentially introduces several threats to the validity of our findings. First, the partners we surveyed are current recipients of ROW funding. Though we attempted to mitigate any potential misrepresentations of stigma reduction work being conducted by indicating the purpose of the survey is to ascertain what current strategies, if any, are being completed, there is an obvious power dynamic to consider. It is possible that in order to protect future funding opportunities, partners presented their current operations in a manner to be perceived more favorably by ROW or other funders.

Second, our project design utilized purposive and snowball sampling methods. These methods are subject to sampling bias due to relying on specific criteria and the professional networks of our interviewees for inclusion into our data collection protocol. Additionally, there were organizations we were unable to connect with, which is unfortunate considering the small number of organizations engaging in this type of work. Furthermore, the majority of organizations we were successful in connecting with predominately discussed stigma mitigation strategies in Africa, with only one organization solely focused on Latin America. Though there were similarities in terms of stigma reduction interventions being conducted, the position on epilepsy awareness was staunchly different. Partner #6, a Latin America-based interviewee suggested that "epilepsy is not in the shadows", while one interviewee based in Africa, Partner #1, highlighted the need to *"increase investment around capacity building... and also awareness around epilepsy"*. In addition to the continental differences, there are disparities within countries. Partner #2 stated that "even within countries, we see that there are big differences between like rural settings versus urban settings."

Due to the limited number of organizations we were able to connect with and the design of our study, the reasons behind these views were not sufficiently explored. This may, however, indicate a lack of representation among the various contexts where epilepsy stigma mitigation is being addressed and a potential threat to validity.

Findings Placed Within the Organizational Context

After analyzing the data, we conducted a root cause analysis with ROW Foundation to determine whether ROW was currently incorporating the practices identified in our data, what might be preventing them from incorporating those strategies, and how our findings could be applied to ROW's current operations (See Appendix C). This analysis suggested that, although ROW is anticipating growth in its current operations, it is currently operating near the capacity of its current resources and staffing. Because of these limitations, ROW had previously adopted a combination of informal approaches to working with its partners and fellow funders that, in addition to its reputation as a provider of medicinal gifts in kind, had effectively established its reputation among similar organizations in the field.

If ROW grows as anticipated, however, our data suggest that its current practices could create problems at scale. ROW anticipates this as well, although it is less clear that they have a roadmap for how, when, and with whom to modify their operations as capacity increases. Specifically, ROW could benefit from greater clarity on how to:

1. Improve its current operations considering limitations in staffing and resources

2. Implement best practices as additional staffing and resources become available

3. Conceptualize its current operations within a framework that identifies how and when to scale its processes with increasing resources

Recommendations

Based on ROW's current limitations, its anticipated growth, the review of the literature in the field, and the data from ROW's current partners and fellow funders, we developed four recommendations on how ROW can grow in its operations to more effectively address stigma as its capacity increases. Recommendations (1-3) that are implemented across two time horizons. The first horizon includes things that ROW can do right now. The second horizon includes things ROW can implement as their experience with the short-term recommendations, capacity, and financial resources build over time. Recommendation 4 does not have any immediate steps, as it is a culmination of the long-term implementation of recommendations 1-3.

Our recommendations address the following four areas:

1. Listening to partners and influencing interventions

2. Collecting and organizing data

3. Leveraging reputation among funders

4. Calls for proposals

Recommendation 1: Listening to partners and influencing interventions

ROW currently has limited capacity for influencing partners in their epilepsy stigma work, but they expect additional resources in the future. We anticipate that ROW's current informal process – including their initial conversations with potential partners – can be improved as tools to influence partner organizations and generate data at scale. Therefore, we propose an expansion of their initial conversation questions to include four additional items based on a conceptual framework for stigma mitigation:

1. What are the most important components of your plan?

2. Do you expect to see changes in what people who about epilepsy, how they feel about people with epilepsy, or how they behave around people with epilepsy?

3. Who will be most impacted by what you are doing?

4. How will you know your plan has worked?

These questions will help ROW determine what interventions are being used, the target population, and how they are measuring success. While ROW does not currently have the capacity to help shape or evaluate the implementation of stigma mitigation strategies with every one of their partners, they do have the ability to discuss the intervention with those partners and gain a deeper understanding of what exactly is being done to mitigate stigma.

By incorporating these questions in their initial conversations, ROW can start to systematically develop an understanding of what their partners are doing to mitigate stigma before attempting to influence those strategies. To build a systematic understanding of their partners' strategies, we suggest ROW use the conceptual framework shown in Figure 5 throughout the internal documentation. The conceptual framework for epilepsy stigma interventions helps conceptualize what their partners are doing and, eventually, analyze its impact. The conceptual framework shown in Figure 5 closely resembles our initial conceptual framework (figure 2). The framework was modified, however, to give ROW a simple approach to understanding a partner's interventions by breaking their partners' strategies down to their proposed mechanism, target population, and potential outcomes.

For example, a partner may want to tell kids a story around the medical nature of epilepsy in a school assembly. ROW would then think of this intervention as one that primarily uses storytelling (intervention component) to improve the knowledge (intervention mechanism) of kids (target population - individuals) in schools (target population - institutions). Conceptualizing

the work of their partners in this framework gives ROW a single tool to understand what its

partners are doing, even as the work varies across interventions, mechanisms, and contexts. Once

ROW has the financial and personnel capacity to help co-create interventions with partners

(medium term) and create calls for proposals (long term), ROW could use this conceptual

framework as a way to engage in conversations with potential partners. Additionally, the

framework helps ROW determine how proposed interventions compare to those that are reported

in the literature and by other partners in the field. Using the previous example of storytelling in a

school assembly, this framework would point ROW toward existing research in the areas of 1)

storytelling as an intervention, 2) improving knowledge as a mechanism, and 3) kids and schools

as target populations.

Figure 5. *The proposed conceptual framework for analyzing partners stigma interventions*
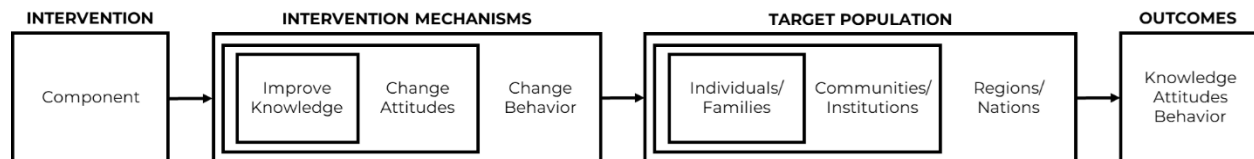
As ROW systematically builds a knowledge base about epilepsy stigma interventions

along with their capacity, we recommend they move to a formal application process aligned with

the conceptual framework. This application would replace the initial conversation questions and

could help ROW direct partners toward effective stigma mitigation work through the use of

specific application items. Additionally, it would serve as an initial touch point for ROW to

determine if more conversations with the potential partner are likely to be fruitful. ROW could

also reference strategies identified in the application to the literature review chart we have

developed for them (Appendix D) to determine if those interventions are currently supported in the literature.

Recommendation 2: Collecting and organizing data

Second, we recognize that ROW wants to be highly effective in the stigma mitigation space, but that they have limited ability to collect and organize the large data sets needed to track and report outcomes at that level. Therefore, we propose that ROW implement the following three questions into their annual expenditure report now to begin building more robust data collection systems:

1. Describe the epilepsy stigma reducing interventions you conducted (if any).

2. How did you measure the impact of your intervention during and/or after its implementation?

3. What barriers did you face in providing the intervention?

These questions will help ROW compare what was initially proposed by their partners to what was actually performed. Additionally, they will allow ROW to determine what type of metrics their partners are using to measure outcomes. The last question will guide ROW's understanding of barriers that may stifle successful outcomes. They may be able to use their knowledge of barriers in planning for future funded projects.

As ROW increases their understanding of interventions performed by partners, it will be important for ROW to understand how partners are implementing stigma reduction strategies and how those strategies relate to outcomes. This will not only help ROW support their partners more effectively but also help them understand what works, for whom, and under what conditions. This understanding, in turn, could equip ROW to better predict the success of future proposals and partnerships. Toward this end, we recommend ROW begin using the data gathered from

conversations and the annual reporting questions to develop a logic model for each of their

partners' stigma reduction interventions. Eventually, this model would be co-created by ROW

and their partner during their initial conversations and prior to any intervention taking place. By

understanding the intended inputs, outputs, and outcomes of each intervention, ROW will be

better equipped to identify key metrics and assess the efficacy of their partners' interventions.

Figure 4 provides an example of a logic model ROW could use to guide data collection as it

begins building toward more systematic data collection processes. Below each step in the model,

example metrics are provided that ROW or their partners could use to properly evaluate the

intervention.

Figure 4. *An example logic model that could help guide data collection and assessment for*

proposed stigma interventions.
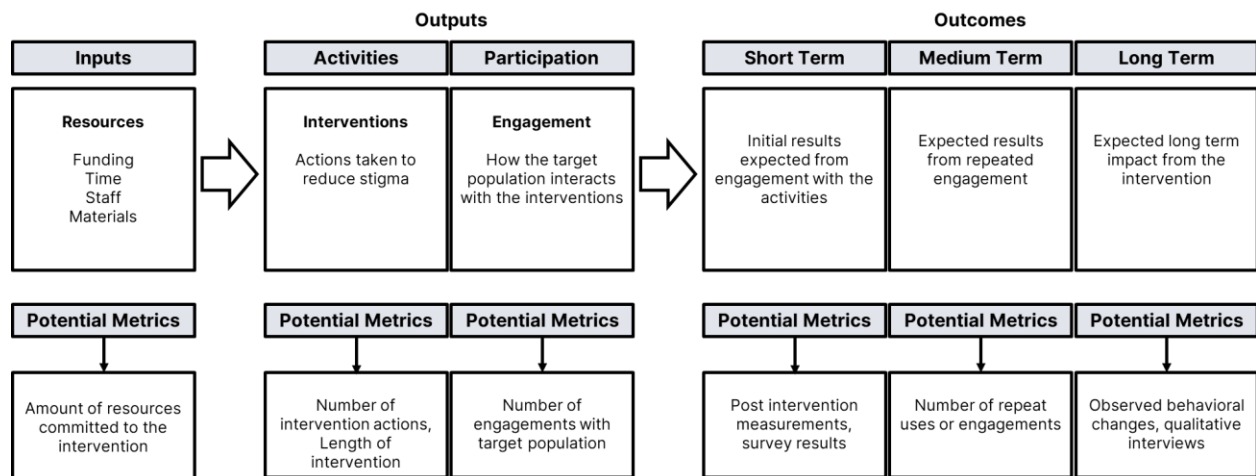
The implementation of the logic model will be key to creating a more robust reporting

process for ROW's partners. Since the model would eventually be co-created by ROW and its

partners, agreed-upon metrics could be integrated into the "Stima Reduction Outcomes' section

of the annual expenditure report. As ROW gathers increasing amounts of these data, patterns of

pairing interventions with metrics could inform how the organization tailors reporting for each

partner and more accurately gauges the effectiveness of their interventions. We foresee this

process bolstering ROW's efforts to support its partners as well as its reputation among potential

partners and contemporaries in the field.

Eventually, we recommend ROW strengthen the processes they use to create logic

models with their partners by including tools to help gauge contextual factors and potential

barriers in their communities. Research suggests that context can have significant influence over

the efficacy of an intervention, and both ROW and its partners will benefit from a more

systematic understanding of the context in which the partner will be performing the intervention.

Specifically, we recommend ROW implement a process that requires their partners to assess

their target community and identify any potential barriers that would inhibit the success of their

interventions as part of the "Stigma Reduction Intervention" section of the initial application.

This will not only help the partners be more successful with their interventions, but it will also

allow ROW to determine the feasibility of their partners' proposals. A tool to aide in this

process already exists and is publicly shared by the International Bureau of Epilepsy (IBE,

2022). We recommend ROW move toward adopting this Stigma Toolkit as part of the process

their partners engage in to receive funding. After a partner completes the stigma toolkit,

information gleamed from the context assessment could better inform the components of the

logic model and what data should be collected and tracked.

Recommendation 3: Leveraging reputation among funders

Third, we recommend ROW continue to partner with other epilepsy-based organizations

in funding projects to strengthen their organizational reputation within the industry. Because of

their relationship with OWP Pharmaceuticals, ROW is uniquely positioned to have a competitive advantage in partnering with other organizations through providing anti-seizure medication. This currently manifests through ROW providing medicinal gifts-in-kind when partnering with other funding organizations and through those organizations recognizing the impact ROW can have even at their current limited capacity. Though ROW seeks to expand their operations to include more directly-funded projects, their current position within the industry is advantageous. We recommend that, in the short term, ROW continue to partner with other funding organizations primarily as a provider of medicinal gifts-in-kind.

As ROW's operations and reputation grow, however, their long-term ability to explore new partnerships will increase, providing greater opportunity to positively affect the lived experiences of people with epilepsy in LMICs. Research into coordinated efforts to address HIV in LMICs suggests that organizations that provide medicine can have a critical role in coordinating across stakeholders:

> Expanding at-scale, sustainable, quality-assured, and afford-able supplies [requires]
> coordination among "originator pharmaceutical companies, generic manufacturers,
> funders, regulators, procurement and other global health agencies, access to medicines
> advocates, and, importantly, the communities of people living with, affected by,
> providing care for and/or at-risk of HIV. (Gaayeb et al., 2023)

By continuing to function as a provider of medicinal gifts-in-kind in the short term, ROW can foster relationships with the other types of agencies addressing epilepsy listed above. Because these kinds of relationships are important when addressing diseases other than epilepsy as well, the connections ROW develops in the treatment of epilepsy could also benefit organizations doing similar work in other areas. ROW currently notes that, although it is important to pair

epilepsy stigma interventions with interventions in other areas like housing, transportation, and nutrition, few organizations in those areas seem interested in partnering with ROW to address epilepsy. In the long-term, we recommend ROW offer the connections it has developed with regulators, procurement agents, and access to medicines advocates to organizations working outside epilepsy so that it can then draw those organizations into partnerships that do address epilepsy.

Recommendation 4: Implementing calls for proposals

Lastly, our fourth recommendation is a culmination of the previous three and is only viable on a long-term horizon. ROW's ability to effectively influence the interventions of its partners is only possible through the cultivation of authentic relationships. One avenue to initially structure these relationships is through the implementation of calls for proposals. Calls for proposals are used widely within the industry to communicate to potential partners the resources available for specific projects. Currently, ROW chooses new partners based on previous relationships or recommendations from current partners. Calls for proposals will allow ROW to communicate their objectives more broadly and attract new partners globally. This is of benefit to ROW as it will not only allow them to work with more partners but by doing so it will strengthen their reputation within the industry. Calls for proposals, similar to an application process, can clearly define the parameters of a partnership upfront including the desired outcomes of the project, the resources available, the type of interventions being utilized, and the required metrics to show the efficacy of those interventions. The process to implement calls for proposals, however, will require ROW to increase its organizational capacity and offer resources beyond medicinal gifts-in-kind. Until they have the capacity to issue those calls, the three recommendations above provide ROW with tools and frameworks that not only enhance their

work at their current funding and staffing levels, but prepare them to efficiently transition to more formal processes as capacity grows.

Conceptualizing and Implementing Recommendations

Including both immediate as well as long-term recommendations provides ROW with simple changes they could implement without additional resources as well as more complex processes that require specific organizational changes to implement. Knowing when to implement those long-term processes can be complicated, and we suspect that ROW is best positioned to recognize when it has the capacity to do so. To help with the transition from short-term changes to long-term processes, however, we recommend ROW follows a general approach to process improvement based on Lewin's three-step change model (Lewin, 1947). This model suggests that organizations need to "unfreeze" current practices, make changes, and then "refreeze" those changes in a new desired state. ROW can use the following three stages of Lewin's model when deciding when and how to implement the changes recommended above:

1. Unfreezing stage: ROW recognizes that they have the capacity and need to scale beyond their current practices in one area of the recommendations and stops current practices

2. Changing stage: ROW implements the long-term recommendation using knowledge and experience from the short-term recommendations

3. Refreezing stage: ROW commits to, reinforces, and stabilizes the new practices

For example, we recommend ROW use this approach when determining when and how to implement more formalized application and reporting processes. When ROW recognizes they now have the organizational capacity, resources, and need to use the formalized application and reporting processes, they would decide to replace the old process with the new ones. ROW would then implement and support those changes, highlighting the ways that the new processes

build on the knowledge and experience gained from the old ones while making a clean break with them. To highlight the break from the old processes, ROW would also officially integrate the logic model and Stigma Toolkit at this stage. During the refreezing stage, ROW would then reinforce the changes to stabilize the new application and reporting processes in place of the old ones.

Lewin's model is fairly simple, but we think it highlights some important considerations for ROW as it grows into an expanded funding role in the future. First, until current processes need to "unfreeze" to account for increased need and capacity, ROW should focus on making small, manageable improvements to the processes it is already using. Our short-term recommendations are intended both to provide ROW conceptual clarity as well as a foundation for future change without placing too great a burden on their current team and partners. When ROW is ready to scale the processes, however, we recommend completely "unfreezing" its current processes and changing to ones that generate a more systematic understanding of partner interventions, foster conversations around program logic, bolster partnerships with other funders, resulting in more rich and meaningful data. Specifically, we anticipate these recommendations eventually "refreezing" in specific calls for proposals and corresponding application processes in areas that both leverage ROW's strengths and meet the real needs of people living with epilepsy in LMICs.

Appendix A: Semi-Structured Interview Questions

1. How would you characterize the pool of suitable partners?

   a. Describe one of the most successful partnerships you've witnessed. Who was involved, how did it work, and how did you know it was successful?

   b. Describe partnerships that weren't successful. Who was involved, why didn't it work, and how did you know it wasn't successful?

2. How does stigma impact the work of your partner organizations?

   a. What strategies to mitigate epilepsy stigma have you used in your own work?

   b. What strategies to mitigate epilepsy stigma have you seen partner organizations use?

   c. How do you define successful outcomes in reducing epilepsy stigma?

      i. How are these measured? (Is there clear guidance from the literature?)

      ii. What is a good ROI for strategies used? (How do you account for context and target population?)

3. What information do you currently ask for from partners?

   a. What data have you been able to collect from partner organizations that would identify use of strategies or successful outcomes?

   b. What are the barriers to collecting useful information on epilepsy stigma strategies?

   c. What information would be helpful to know that you don't ask for:

      i. During initial proposals

      ii. During annual funding reporting times

4. Do you feel like you are able to influence partner organizations?

a. If "yes" - What mechanisms do you have available for that influence?

b. How about a time when you attempted to influence them, but they did not respond? What did you do and why was it not successful?

5. Based off the research, we've identified these strategies (team lists strategies):

a. What strategies hold the most promise either from what we mentioned, or others that were not outlined?

b. What mechanisms do you believe are at play for interventions noted?

c. How does context and target population affect the intervention's efficacy?

d. Could a funding organization effectively influence partner organizations to use these strategies?

6. Any questions for us?

Appendix B: Partner Survey Questions

LINK - https://forms.gle/hQ852t3n16KxWtUD8

Instructions: ROW Foundation is hoping to support organizations in addressing epilepsy stigma in the future. Defined, epilepsy stigma is a set of negative and often unfair beliefs that a society or group of people have about the symptoms and/or diagnosis of epilepsy. Most organizations have not been trained on this type of work yet, but we're hoping to learn if there is any current work being done. To the best of your ability, please answer the following questions related to your organization's efforts to reduce epilepsy stigma.

1. Please describe the community in which your work is based.

2. What population do you primarily work with? [please check all that apply]

    a. Children and Adolescents

    b. Adults with epilepsy

    c. Families of people with epilepsy

    d. Communities/community leaders

    e. Educators

    f. Healthcare workers

    g. Other: _____

3. Briefly describe the work your team or organization does to improve outcomes for people living with epilepsy.

4. Does your organization use stigma reduction programs?

    a. Yes

    b. No

    c. I don't know

For yes answers:

5. Briefly describe the stimga reduction programs your team uses to address epilepsy stigma.

6. In your opinion, how successful have stigma reduction programs been at addressing stigma?

7. What types of supports from outside your organization help you provide stigma reduction programs (if any).

For no answers:

8. What types of supports might help you start providing stigma reduction programs?

For I don't know answers:

9. What types of recourses would be helpful to understand epilepsy stigma reduction programs (check all that apply)

   a. Educational materials on epilepsy stigma

   b. Examples of interventions

   c. External help to design and/or implement stigma reduction programs

   d. Success stories of organizations who use stigma reduction programs

   e. Other: _____

Appendix C: Root Cause Analysis

RQ #	Major theme	Root Cause Analysis
1	Ambassadors as storytellers	ROW states they are already doing this in a limited capacity, but only in conjunction with community health workers. ROW notes they believe community health workers as more important than storytelling. ROW categorizes storytelling and plays/dramas as a similar intervention.
	Improving knowledge as a means to change perceptions, beliefs, or actions	ROW was unable to directly comment if their partners were using interventions aimed at improving knowledge, likely due to the lack of measurement and limited reporting measures collected for documentation. They do not have a process in place that would identify the mechanism of interventions.
	The importance of building relationships with and access to authority holders	ROW was unable to directly comment if their partners were focused on building relationships with authority holders, but noted they believed this was happening due to their experiences when visiting partners in country. They did not have a process in place that would help partners identify key authority holders.
2	Using calls for proposals to direct partners toward specific strategies, with partner input	At this time, ROW does not have the capacity to use calls for proposals.
	Coordinating resources via networks that increase chances of success	ROW coordinates with epilepsy-based organizations often. While they have tried to co-fund projects with organizations that help with improving living situations (such as poverty), they have not been successful. ROW believes their lack of success in creating partnerships with non-epilepsy-based organizations are due to a lack of interest in epilepsy work both from a local and global perspective.
	Leveraging organizational longevity and reputation to connect to influential partners and drive lasting impact	ROW's ability to distribute medication is their main asset, and this drives their reputation and ability to partner and co-fund projects.
3	Analyzing existing partner organization's' barriers as part of the evaluation of a new partner organization.	ROW's current method of finding partners is through word of mouth and referrals from other well-known epilepsy-based organizations. Due to this, ROW does not have a process in place that formally evaluates the partner's context dependent barriers to implement interventions.
	Creating systems of reporting and evaluation	ROW currently does not have a formalized system for reporting or evaluation. They do not know what should

	that leverage known metrics	be included in evaluation nor best processes for conducting evaluation within different contexts.

Appendix D: Literature Review Table

Our review of the literature highlighted the importance of a conceptual framework for making sense of the variety of possible stigma intervention strategies and how effective they are at reducing stigma. Below is an example of how a framework that highlights intervention components, target populations, and mechanisms of action could help an organization conceptualize the interventions presented in our literature review.

The point of this table, however, is not to highlight which interventions work. Ony a fraction of the literature on stigma is present here. Instead, this table serves as an illustration of how ROW might similarly conceptualize the work of its partners. Over time, an approach like this could give ROW greater clarity on how it might influence its partners in their own interventions.

Also, the categories used here are meant to be descriptive, not prescriptive. Although they helped make sense of the types of interventions we were seeing, ROW should feel free to substitute, replace, or add any categories that better capture the types of interventions their partners currently use.

Our categories include:

Intervention Component:

Audio/Visual Media:	Interventions that highlighted an audio (radio) or visual (tv, video) element a critical component
Acting:	Interventions that highlighted dramatization as a critical component
Group Intervention:	Interventions that incorporated a variety of elements tailored to a specific target audience (children WE, teachers)
Legislation:	Interventions that include laws, regulations, or campaigns that impact entire regions of people
Print Media:	Interventions that highlighted print material (brochures, fliers) as a critical component
Seminars:	Interventions that incorporate various elements to reach large heterogeneous groups at a few locations (web courses, conferences)
Surgery:	Interventions that highlight surgery as a critical component
Therapy:	Interventions that include medicine or counseling as a critical component

Target Population:

Adults WE:	Adults (18+) diagnosed as having epilepsy
Children WE:	Childre (<18) diagnosed as having epilepsy
Families of People WE	Families and primary caregivers for people with epilepsy
Communities:	Groups of people sharing a single important characteristic (members of the same rural area, elementary students)
Healthcare Workers:	People primarily identified as doctors, nurses, or other medical staff
Gov and Ed Workers	People primarily identified as government workers or school faculty/staff
General Population	Groups of people in an area who are not identified according to a single important characteristic

Mechanisms:

Knowledge:	Interventions primarily intended to increase knowledge about epilepsy
Attitudes:	Interventions primarily intended to change people's perceptions of epilepsy and people living with epilepsy. This includes self-perceptions of adults and children WE.
Behaviors:	Interventions primarily intended to change stigma-related behaviors. This does not include behaviors like taking medicine that could potentially impact stigma.

Reported Efficacy:

Low:	The study reported the intervention had no or little impact on stigma.
Mixed:	The study reported that the intervention had some or temporary impact, but often not in all the areas tested.
Clear:	The study reported that the intervention had clear impact in the areas and timeframes tested.

Importantly, this table highlights how much information is still lacking on which stigma interventions work, how they work, and with whom they work. We will provide this table in a form ROW can continue to fill out, including links to the research articles we've already included, so that ROW can continue to systematically develop an understanding of the stigma interventions its partners are currently using.

Literature Review Table: AV Media

Component	Intervention		Reported Efficacy			Countries
	Target Population	Mechanisms	Low	Mixed	Clear	
Audio/Visual Media	Adults WE	Knowledge				
		Attitudes				
		Behaviors				
	Children WE	Knowledge				
		Attitudes				
		Behaviors				
	Families of People WE	Knowledge				
		Attitudes				
		Behaviors				
	Communities	Knowledge		1	4	Australia[1], Canada[2], Czech Republic[3,4], Netherlands[5]
		Attitudes	1	1	5	Australia[1], Brazil[6], Canada[2,7], Czech Republic[4], Netherlands[5], UK[8]
		Behaviors				
	Healthcare Workers	Knowledge				
		Attitudes				
		Behaviors				
	Gov and Education Workers	Knowledge		1		Italy[9]
		Attitudes		1		Italy[9]
		Behaviors				
	General Population	Knowledge			3	Japan[10,11], Saudi Arabia[13]
		Attitudes	1	1	3	Japan[10,11,12], Saudi Arabia[13], USA[14]
		Behaviors				

[1] Roberts & Farhana, 2010; [2] Martiniuk et al., 2022; [3] Roberts & Farhana, 2010; [3] Brabcova et al., 2017; [4] Brabcova et al., 2013; [5] Gutteling et al., 1986; [6] Tedrus et al., 2007; [7] Martiniuk et al, 2010; [8] Noble & Marson, 2016; [9] Mecarelli et al., 2014; [10] Okumura et al., 2013; [11] Okumura et al., 2015; [12] Okumura et al., 2016; [13] Alaqeel et al., 2015; [14] Sajatovic et al., 2017

Literature Review Table: Acting

Intervention			Reported Efficacy			Countries
Component	Target Population	Mechanisms	Low	Mixed	Clear	
Acting	Adults WE	Knowledge				
		Attitudes				
		Behaviors				
	Children WE	Knowledge				
		Attitudes				
		Behaviors				
	Families of People WE	Knowledge				
		Attitudes				
		Behaviors				
	Communities	Knowledge			1	Czech Republic[4]
		Attitudes			1	Czech Republic[4]
		Behaviors				
	Healthcare Workers	Knowledge				
		Attitudes				
		Behaviors				
	Gov and Education Workers	Knowledge				
		Attitudes				
		Behaviors				
	General Population	Knowledge				
		Attitudes				
		Behaviors				

[4.]Brabcova et al., 2013

Literature Review Table: Group Intervention

Component	Intervention		Reported Efficacy			Countries
	Target Population	Mechanisms	Low	Mixed	Clear	
Group Intervention	Adults WE	Knowledge	1		1	Kenya[16], UK[17]
		Attitudes	4		3	Iran[15], Kenya[16], Tanzania[19], UK[17,18], USA[20], Zambia[22]
		Behaviors	1	1		UK[17], USA[21]
	Children WE	Knowledge			1	Australia[23]
		Attitudes	1	1	2	Australia[23], Germany[24], USA[25], Zambia[22]
		Behaviors				
	Families of People WE	Knowledge			1	Kenya[16]
		Attitudes	1	1	2	Germany[24], Kenya[16], Tanzania[19], USA[25]
		Behaviors				
	Communities	Knowledge			5	Bolivia[26], Brazil[33], India[29], Scotland[35], Turkey[30]
		Attitudes	4		5	Austria[31], Bolivia[26], Brazil[32], India[29,34], Korea[27], Scotand[35], Turkey[30], USA[28]
		Behaviors			1	India[29]
	Healthcare Workers	Knowledge				
		Attitudes				
		Behaviors				
	Gov and Education Workers	Knowledge		2	1	Germany[36], Turkey[41], USA[38]
		Attitudes	1	2	3	Germany[36], India[39,40], Italy[37], Turkey[41], USA[38]
		Behaviors				
	General Population	Knowledge				
		Attitudes				
		Behaviors				

[15.]Yadegary et al., 2015; [16.]Ibinda et al., 2014; [17.]Noble et al., 2014; [18.]Ridsdale et al., 2015; [19.]Bhwana et al., 2021; [20.]Fraser et al., 2015; [21.]Sung et al., 2017; [22.]Elafros et al., 2013; [23.]Frizzell et al., 2011; [24.]Pfafflin et al., 2012; [25.]Snead et al., 2004; [26.]Giuliano et al., 2019; [27.]Kim et al., 2003; [28.]Sands & Zalkind., 1972; [29.]Kolar Sridara Murthy et al., 2013; [30.]Bozkaya et al., 2010; [31.]Simon et al., 2016; [32.]Reno et al., 2007; [33.]Noronha et al., 2007; [34.]Eze et al., 2015; [35.]Mason et al., 1990; [36.]Dumeier et al., 2017; [37.]Mecarelli et al., 2015; [38.]Rassel et al., 1981; [39.]Goel et al., 2014; [40.]Aydin & Yildiz, 2007; [41.]Bekiroglu et al., 2004

Literature Review Table: Legislation

	Intervention		Reported Efficacy			
Component	Target Population	Mechanisms	Low	Mixed	Clear	Countries
Legislation	Adults WE	Knowledge				
		Attitudes				
		Behaviors				
	Children WE	Knowledge				
		Attitudes				
		Behaviors				
	Families of People WE	Knowledge				
		Attitudes				
		Behaviors				
	Communities	Knowledge				
		Attitudes				
		Behaviors		1		UK[42]
	Healthcare Workers	Knowledge				
		Attitudes				
		Behaviors				
	Gov and Education Workers	Knowledge				
		Attitudes				
		Behaviors				
	General Population	Knowledge			1	Pakistan[43]
		Attitudes			1	Pakistan[43]
		Behaviors			1	Pakistan[43]

[42.]Delany & Moody, 1999; [43.]Mogal & Aziz., 2020

Literature Review Table: Print Media

Component	Target Population	Mechanisms	Low	Mixed	Clear	Countries
			Intervention → Reported Efficacy			
Print Media	Adults WE	Knowledge				
		Attitudes				
		Behaviors				
	Children WE	Knowledge				
		Attitudes				
		Behaviors				
	Families of People WE	Knowledge				
		Attitudes				
		Behaviors				
	Communities	Knowledge		1	2	Canada[44], Ethiopia[45], Netherlands[5]
		Attitudes	1	2		Canada[44], Ethiopia[45], Netherlands[5]
		Behaviors				
	Healthcare Workers	Knowledge				
		Attitudes				
		Behaviors				
	Gov and Education Workers	Knowledge				
		Attitudes				
		Behaviors				
	General Population	Knowledge				
		Attitudes				
		Behaviors				

[5.]Gutteling et al., 1986; [44.]Young et al., 2002; [45.]Tekle-Haimanot et al., 2016

Literature Review Table: Seminars

Component	Intervention		Reported Efficacy			Countries
	Target Population	Mechanisms	Low	Mixed	Clear	
Seminars	Adults WE	Knowledge				
		Attitudes				
		Behaviors				
	Children WE	Knowledge				
		Attitudes				
		Behaviors				
	Families of People WE	Knowledge				
		Attitudes				
		Behaviors				
	Communities	Knowledge		1		Croatia[46]
		Attitudes		1		Croatia[46]
		Behaviors				
	Healthcare Workers	Knowledge			1	Brazil[47]
		Attitudes			1	Brazil[47]
		Behaviors				
	Gov and Education Workers	Knowledge			1	Brazil[47]
		Attitudes			1	Brazil[47]
		Behaviors				
	General Population	Knowledge				
		Attitudes			1	Saudi Arabia[13]
		Behaviors				

[46.]Bielen et al., 2012; [47.]Fernandes et al., 2007; [13.]Alaqeel et al., 2015

Literature Review Table: Storytelling

Component	Target Population	Mechanisms	Low	Mixed	Clear	Countries
			Intervention		Reported Efficacy	
Storytelling	Adults WE	Knowledge				
		Attitudes				
		Behaviors				
	Children WE	Knowledge				
		Attitudes				
		Behaviors				
	Families of People WE	Knowledge				
		Attitudes				
		Behaviors				
	Communities	Knowledge			1	Czech Republic[3]
		Attitudes				
		Behaviors				
	Healthcare Workers	Knowledge			1	Nepal[48]
		Attitudes	1			Nepal[48]
		Behaviors			1	Nepal[48]
	Gov and Education Workers	Knowledge				
		Attitudes				
		Behaviors				
	General Population	Knowledge				
		Attitudes				
		Behaviors				

[3]Brabcova et al., 2017; [48]Kaiser et al., 2022

Literature Review Table: Surgery

Component	Intervention Target Population	Mechanisms	Reported Efficacy Low	Mixed	Clear	Countries
Surgery	Adults WE	Knowledge				
		Attitudes			1	Canada[49]
		Behaviors			1	Korea[50]
	Children WE	Knowledge				
		Attitudes		1		India[51]
		Behaviors				
	Families of People WE	Knowledge				
		Attitudes			1	India[51]
		Behaviors				
	Communities	Knowledge				
		Attitudes				
		Behaviors				
	Healthcare Workers	Knowledge				
		Attitudes				
		Behaviors				
	Gov and Education Workers	Knowledge				
		Attitudes				
		Behaviors				
	General Population	Knowledge				
		Attitudes				
		Behaviors				

[49]Feist et al., 2014; [50.] Choi-Kwon et al., 2008; [51.] Bajaj et al., 2018

Literature Review Table: Therapy

Component	Intervention		Reported Efficacy			Countries
	Target Population	Mechanisms	Low	Mixed	Clear	
Therapy	Adults WE	Knowledge				
		Attitudes	1	2		Ecuador[52], India[53], Uganda[54]
		Behaviors				
	Children WE	Knowledge				
		Attitudes				
		Behaviors				
	Families of People WE	Knowledge				
		Attitudes				
		Behaviors				
	Communities	Knowledge				
		Attitudes				
		Behaviors				
	Healthcare Workers	Knowledge				
		Attitudes				
		Behaviors				
	Gov and Education Workers	Knowledge				
		Attitudes				
		Behaviors				
	General Population	Knowledge				
		Attitudes				
		Behaviors				

[52.]Placencia et al., 1995; [53.] Pimpalkhute et al., 2015; [54.] Nabukenya et al., 2014

Appendix E: Findings Associated with Research Questions

Research Question	Themes	Supporting Quotes & Sources	Overall Findings Summary
1: What **interventions are partner organizations** currently using to decrease epilepsy stigma in LMIC's?	Training	Stigma training is provided by clinicians, people with epilepsy and their carers. It is important that the stories and voices of people with epilepsy and their carers are heard. They have the lived experience of stigma that clinicians will never have. To eradicate stigma, it is important that clinicians learn from experts by experience. – Survey #6	Major theme 1: Ambassadors as storytellers (micro & meso) • Ambassadors • Storytelling • Medication Major theme 2: Improving knowledge to change perceptions, beliefs, or actions (micro, meso, & macro) • Education • Training • Perception • Medication Major theme 3: Building access to authority holders (micro, meso, & macro) • Relationship building
	Ambassadors	So trying to encourage people with epilepsy, as difficult as it is to be active in the community, to be visible in the community, to talk about, you know, what epilepsy is and what it isn't and for people to see, you know, that this is a neurological disorder of the brain. - Partner #2 I think radio broadcasts, if they're done in local languages and respecting local cultures in which local people provide their perspectives and then physician experts and ensure that perspectives provided on the radio are also medically accurate, then radio broadcasts can be a powerful tool. - Partner #3 So working at very various different levels rather than just a simple in and out approach where we've looked at trying to make people ambassadors for their own condition. So educating people with epilepsy who are like, who are more than able to communicate their condition to others and act as facilitators for knowledge at one level. - Partner #4	
	Medication	I think if you get people anti-seizure meds and they're not having seizures regularly, it reduces stigma hugely. - Partner #2	
	Education	And we've done looked at stigma reduction in in Vietnam and in China and looked at stigma reduction in countries in, in Europe. And the methodology that we've used is, is	

		basically education. That's the main approach. - Partner #4 Integrating the arts into education, including the use of drama and theater. -Survey #1	
	Storytelling	We have also come up recently with stigma benches where in specific communities' chiefs, duty bearers, community leaders, opinion leaders or are invited to a stigma bench to hear the stories of persons with epilepsy and the stigma that they face Partner #1 What they then did was kind of organized, you know, which is a very traditional African thing, people to come to sort of a place where they had a bench essentially and allowed people in that safe space to really share their experiences and their stories of epilepsy and how it has impacted on them and their families. - Partner #2 Like, I I need a tool so I can go to people who don't understand this issue and be like, watch this compelling thing.- Partner #5	
	Perception	So memes have been very, very, very useful tool to reduce stigma and epilepsy for us. - Partner #6 I think that it, you know, like like it's it's a hard conversation like right now it's people we don't have attention we our spread of attention is very, very little. And when you say with a joke, it's like, oh, it's easier to say. So if you say with a joke, it's sort of like, oh, it's nothing. So people say something with a meme, with a joke. And then that's the way you start the conversation. - Partner #6	
1A: What are the underlying mechanisms?	Relationships	mutual respect between the partners, transparency between the partners promoting equality and respect, - Partner #1 It's all about building partner relationships - Partner #5	2 options: 1. Keep our 3 mechanisms in the CF and detail these out as not as mechanism but "enabling" aspects for interventions
	Changing knowledge	What I would be what I'd want to do is probably do 3 lines of approach, Educate children, make sure they	

		understand. And these are not just children with epilepsy, but their peers. Educate, Make sure their families are educated as well so they understand about the epilepsy. - Partner #4 So I would say the chain would be knowledge, attitude, then practice. - Partner #1	2. UPGRADE the CF to include these mechanisms
	Staffing/Money	So sometimes it really is just around providing them funding so that they can exist, rather than really asking people to embark on a very specific piece of work. - Partner #2 We have a 90% treatment gap in The Gambia and the ratio of neurologists to the population is 0.2 per 100,000 with one EEG machine supported by TeleEEG (no EEG technicians in the country) – Survey #2	
1B: What are the contextual factors?	Poverty	I don't think if we address [stigma] as a siloed issue and don't think about it in terms of in terms of education, economy, poverty, then we're just fooling ourselves. The stigma often comes out of a place of severe extreme desperate poverty and people don't see other options. - Partner #3	
	Authority Holders	In some communities, the doctor's or the medical authority's opinion carries the most weight because of how the community values medical authority. - Partner #3 In all the LMICs, local low middle income countries I've worked with in Asia, Africa, you know Central, South America, traditional family structure respects elders, and the authority for decision making is often given to grandparents, especially grandmothers when dealing with children. And so sometimes we fail because we can't get to the ultimate decision-makers who are the grandparents. - Partner #3	
	Trust	that kind of building of trust and relationships over the years. - Partner #2	

		where there is a joint understanding of what the goals and missions are in relation to into what's trying to be achieved. - Partner #4	
		Experts have had challenges in the past where they were just being used as subjects but not as core producers. - Partner #1	
	Setting	even within countries, we see that there are big differences between like rural settings versus urban settings. - Partner #2	
		when you talk about access to treatment, you're not only talking about access to medication, you're also talking about distances to health centers. - Partner #1	
		it could be information around policies, anti-stigma policies because you know having an anti-stigma police or anti-stigma plans from duty bearers, it's a it's a big task because you cannot talk about an anti-stigma police when you don't even have a national epilepsy plan that these countries have or even a neurological plans that they have. - Partner #1	
		Epilepsy is not in the shadows. - Partner #6	
		There's no, you know, one kind of uniform approach that would work. - Partner #6	
		Another example that I can cite is partnerships that happen within at national level within countries where we have noted relationship between police makers as well as duty bearers. - Partner #1	
		And part of the reason for that was because our advocates and our chapters partners on the ground had actually done a lot of work in terms of raising awareness amongst their policymakers and decision-makers	

		about this, really trying to get them on board in in supporting this.- Partner #2	
	Funding	Stigma research is not and stigma interventions are not programs that have been historically well resourced, well-financed and that probably continues to be the case of the partnerships that you've witnessed in this work. - Partner #4	
2: What levers do funding organizations have to encourage practice of strategies to reduce stigma?	Education	we're just passing along information, you know, and I don't think we would tell them, hey, you have to use this. - ROW We're just passing along information we hope is helpful, but not trying to guide the direction of a particular program. - ROW So, for example, we have a toolkit for reducing stigma. We have a toolkit for helping people become ambassadors. We have a toolkit for lazy and communicating with local governments. Then we give them advice and information in respect to all aspects of epilepsy. So we have a Bank of information. - Partner #4	Major theme 1: Directing partners to do the work funders want via call for proposals (macro) • Wants of funders • Call for proposals • Identity/ownership • Money Major theme 2: Coordinated resources and funder networks can increase success due to increased access and longevity (meso, macro) • Team approach • Membership • Money • Education • Stepping back • Identity/ownership
	Money	I guess we do kind of we do kind of influence where our money goes – ROW the other thing is sometimes case of trial and error where we give some funding to one chapter and they really don't deliver or they report late or they don't report at all and you know that wasn't money well spent well, it's something we obviously then bear in mind for future years. - Partner #2	Major theme 3: Longevity & reputation can influence recognition of players in the game (micro, meso, & macro) • Identity/ownership • Longevity • Reputation
	10,000 foot view	It's more just kind of being on the lookout for what other organizations are doing that appears to be effective – ROW And I think ultimately, you know, if we still haven't found the answer to that question, I think we know that there are certain things that maybe work a little bit, but ultimately it has to be a	

		kind of multi-pronged, multi-agency sustained approach. - Partner #2	
	Call for proposal	I think where you influence partners more is when you fund via like a request for a proposal where Roe might say we think school campaign is what's needed. And so we put out a request for organizations to submit a proposal for some type of school campaign. – ROW if we say this is the theme we want to pursue this year or you know this is what we'll be providing funds for this year, people will I think respond and you know adapt to whatever it might be that we're trying to do. - Partner #2	
	Identity and ownership of the work	If they asked us directly, you know for some guidance, you know there might be some things we could refer them to, but we're certainly not the experts in that our role is to be supportive. - ROW But not only you know telling them what to they need to do but to do have what I'd call core production of the work that we need at work together on.- Partner #1	
	Team approach	a very successful partnership working with Bent Foundation because in this partnership we realize that the work was not kind of the agenda was not set by the partner that we work with, but it was sent by ourselves and only supported by the partner. - Partner #1 we've also tried to partner with groups that are like larger health and development organizations to integrate some of this epilepsy work into what they're already doing. - Partner #5	
	Wants of funders	We want to fund those things we think will be most effective. - ROW	
3: What best **evidence-based evaluation processes** can ROW	**Barriers** Measurement	it's tough for like ROW for example, to come up with measurable indicators on progress that we've made other than outputs things that we've done or things we've funded. - ROW	Major theme 1: Analysis of existing barriers as part of the evaluation of a partner • All barriers mentioned

Foundation use to determine the efficacy of current and future partnerships?		it's also extremely difficult to show in a positive way the impact of interventions that address stigma. - Partner #4	Major theme 2: Create a system of reporting and evaluation with known metrics
		=================	• All data collection methods mentioned
	============ Knowing what will work, where	even within countries, we see that there are big differences between like rural settings versus urban settings. - Partner #2	• Process vs outcome vs impact evaluations
		=================	
	============ Technology	in the communities where we work where access to Internet, it's quite a big challenge – Partner #1	
		there can be software issues, there can be hardware issues, there can be capacity issues. - Partner #2	
		============	
	============ Time	I think there has to be that sense of this is something that will take time and we're prepared to kind of stick with it and work this out together. - Partner #2	
		I think the important aspect of that is that you have to think about if you're going to try to change people's attitudes towards and behavior towards people, it's long term, it's multifaceted and it requires an incredible long-term intervention. - Partner #4	
		============	
	============ Capacity	And for those who weren't successful, we've actually decided to do a sort of capacity-building initiative where we're thinking, OK, look, you weren't successful this year, but let's work with you on topics like policy, advocacy, fundraising, communications and maybe get you guys to that place where you may be able to submit and deliver kind of a piece of work longer term.- Partner #2	
	Data collection

Testing knowledge pre/post | pre and post surveys to demonstrate that the people understand epilepsy when they, you know, when they didn't before it.- ROW

I would probably want to measure attitudes, beliefs and knowledge at the | |

		beginning of the program and then at the end of the program. - Partner #4 ==================== X amount of people saw and responded to our post. - Partner #2	
	============ Engagement or attendance at events	we measure how many people get in our workshops getting our educational programs and this year we are going to start doing with quality, with quality of life because we have around six WhatsApp groups with over 1500 peoples. - Partner #6 Number of medical and health professionals trained, Estimated total people trained, Number of training events- Survey #1 But the engagement that we have noted been done by duty bearers, by community leaders, by opinion leaders have actually been good indicators of the change that is happening within the when stigma campaigns are are done. - Partner #1 ==================== First, the adoption of the tools, secondly, by the change in behavior that happens in the communities where the work is done. - Partner #1	
	============ Observing for changes in behavior, return to life	the engagement that we have noted been done by duty bearers, by community leaders, by opinion leaders have actually been good indicators of the change that is happening within the when stigma campaigns are done. - Partner #1 a country like Malawi where community leaders have demonstrated a change in allowing persons with epilepsy, you know, to receive what we call farm subsidy inputs. - Partner #1 ==================== the open sharing of stories by persons with epilepsy are also a good outcome because most of them there were mainly in the shadows, they did not want to come out. - Partner #1	

		When we first started, it was 80 years ago and no one wanted to talk about epilepsy with us. I remember with one story, one person talking about epilepsy with us, and now we have so many stories that it's sort of impossible for us to share every story online. - Partner #6	
	============ Open sharing of stories from PWE	======================= If this isn't prioritized by policymakers and decision-makers, you know, it's not maybe getting the funds that some of the communicable diseases are getting in Africa that are now better understood. - Partner #2	
		===================== So if I was doing a project on interventions into stigma in the epilepsy stigma, I want to be very clear that the goals of that intervention were very clear, concise, reasonable and had value.- Partner #4	
	============ Changes in policy	But you need to demonstrate to us how you are going to to or what information do you have that justifies the intervention that you want to do.- Partner #1	
	============ Focusing on specific goals		

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