Khandaker M, Jurado P, Niemann M, et al. Using Instagram to Address Epilepsy-Related Stigma Among Youth: A Community-Based Participatory Social Media Campaign. *BCPHR*. 2026;February 2026(94). doi:10.54111/001c.159383

Boston Congress of Public Health Review - 2025-Present

Using Instagram to Address Epilepsy-Related Stigma Among Youth: A Community-Based Participatory Social Media Campaign

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Keywords: epilepsy, youth, co-design, stigma, social media, campaign

https://doi.org/10.54111/001c.159383

Boston Congress of Public Health Review (BCPHR, Formerly HPHR)

Vol. February 2026, Issue 94, 2026

Background

Stigma is a major concern for youth with epilepsy (YWE), contributing to psychosocial difficulties, poor mental health outcomes, and reduced health-related quality of life. While several studies have described how stigma is measured, few have described interventions actively partnering with youth to address stigma at a population level. Social media is a potential tool to address stigma in public health.

Objective

An established study team from a large, urban hospital partnered with YWE advocates to implement an epilepsy-based Instagram campaign utilizing a public health framework of anti-stigma messaging.

Methods

A mixed-methods approach was used to collect data and included youth interviews and focus groups, Instagram engagement analytics, follower surveys, and an ambassadorship program. Using community-based participatory research principles, youth advocates with epilepsy co-designed an Instagram campaign guided by the matrix of anti-stigma messaging. YWE reviewed campaign materials and provided feedback, which the study team implemented into the creation of 36 posts, including educational materials and personal narratives. Engagement data was collected from Instagram from February-August 2023 to evaluate exposure and interest. Polls were given to campaign followers to receive feedback.

Results

The account had 36 posts and 142 followers and reached 5,452 accounts. We identified personal narratives as a key facilitator to reducing stigma on social media. Posts featuring personal stories from youth ambassadors received the highest interaction of all posts. However, it was found that use of anti-stigma strategies did not correlate to increased engagement.

Conclusions

Youth co-designed social media campaigns are feasible and may address epilepsy-related stigma by increasing contact, visibility, and accurate knowledge. Personal stories are important for resisting epilepsy-related stigma on social media. Those who care for YWE could implement lessons from this project, such as providing content with personal stories of lived experiences to youth. To our knowledge, this is the first Instagram advocacy project used to study YWE's reactions to the content produced. We identified key strategies for developing a youth-centered anti-stigma social media campaign.

INTRODUCTION

Epilepsy affects nearly 1 in 100 individuals in the United States, including approximately 470,000 children and adolescents aged 0-18 years.[1] Youth with epilepsy (YWE) frequently report stigma in school, work, and social settings.[2] Globally, 20% to 36% of YWE experience epilepsy-related stigma, and tend to feel more stigmatized than older people with epilepsy (PWE).[3-5]

Stigma arises from negative societal attitudes toward a group's characteristics and involves prejudicial beliefs and discriminatory behaviors.[6] The "hidden distress model of epilepsy" distinguishes two kinds of stigma: enacted stigma, defined as direct experiences of discrimination against YWE, and felt stigma, which includes internalized shame and fear of discrimination by PWE.[7-9] Enacted stigma has been found to be associated with lower epilepsy knowledge among those without epilepsy; felt stigma, which is particularly pronounced in YWE, is associated with lower epilepsy knowledge among YWE, diagnosis concealment, and poorer psychosocial outcomes.[10-13]

YWE report experiencing negative social relationships with peers, including bullying, social exclusion, avoidance, and rejection in school due to stigma.[14-16] Stigma in YWE and their families may be associated with reduced family dialogue and greater secrecy about epilepsy.[14] Misconceptions, such as beliefs that epilepsy is contagious, remain prevalent and contribute to social exclusion.[13] These social effects can contribute significantly to mental health and epilepsy morbidity and may be as debilitating as seizures.[17,18]

There has been significant research on quantifying stigma experiences related to YWE, including measuring stigma using validated scales and surveys focused on disclosure behaviors, quality of life, and mental health.[19] However, there has been limited work on interventions partnering with YWE designed to address stigma in everyday contexts. Thus, we aimed to partner with youth to implement an anti-stigma social media campaign to improve awareness of epilepsy and target stigma and misinformation.

THEORETICAL FRAMEWORK

Harwood et al. proposed a public health framework ("the matrix") for developing interventions to target health-related stigma.[20] The matrix builds on previous anti-stigma intervention and evaluations by providing a structure for program design to systematically make progress and improve public health.[20] The matrix identifies three forms of discrimination through which stigma operates: Direct (interpersonal interactions), Structural (institutional policies and practices), and Psychological (self-stigma).[20] The matrix further describes three intervention strategies for addressing stigma: Education (increasing accurate knowledge and countering misinformation), Contact (promoting interactions between the stigmatized group and others), and Protest (challenging stigmatizing norms and practices).[20] These strategies can be applied to address both enacted and felt stigma.[20] Direct and structural discrimination refer to situations of enacted stigma, while psychological discrimination refers to felt stigma. By using strategies targeting these sources of discrimination during our campaign, we aimed to address both felt and enacted stigma.[20] The anti-stigma strategies we used are described in Table 1.

While the matrix has been used to analyze qualitative data related to stigma in other chronic conditions, its application to social media content development for epilepsy has not been previously described. For instance, a previous study interviewed patients with sickle cell disease about their perspectives on living with sickle cell disease; the researchers coded the interviews using the matrix to determine strategies to mitigate sickle cell stigma, which included educating patients and providing counseling.[21]

The matrix aligns with existing disability frameworks, such as the Health Stigma and Discrimination Framework (HDSF), which supports intervention design across several health conditions, including epilepsy.[22] The HDSF framework describes stigma as a process that operates on several levels: intrapersonal (including internalized beliefs), interpersonal (including interactions with others), societal (including cultural norms), and structural (including discriminatory policies); HDSF thus reflects the matrix's categories of discrimination.[22] HSDF additionally identifies targets for effective interventions, including misconceptions.[22] This approach aligns with the matrix's mixed strategies of Education, Contact, and Protest, allowing us to situate our youth-designed social media content within existing public health and disability frameworks.

SOCIAL MEDIA AND YOUTH ENGAGEMENT

Social media platforms play a central role in youth communication and health information-seeking.[23-25] Youth often use social media for health-related information.[23,24] Instagram is particularly popular among adolescents and young adults (individuals born between 1997 and 2012) and prioritizes visual storytelling, which aligns with youth engagement preferences.[26-29] Compared with other platforms, Instagram posts tend to generate higher engagement metrics.[30]

With this knowledge, we predicted that Instagram could be a promising platform to engage YWE and reach community members by providing accurate epilepsy information to address stigma. Misinformation and lack of knowledge of epilepsy have been described as major contributors of epilepsy-related stigma in the literature.[13-16] This project therefore aimed to evaluate the acceptability, engagement, and youth perceptions of a co-designed theory-informed Instagram campaign targeting epilepsy-related stigma.

Other epilepsy campaigns have successfully reached people through mass media channels, educational toolkits, community education programs, Facebook, and Twitter.[31-34] This includes a previous epilepsy awareness campaign launched as a one-day social media event on International Epilepsy Day, February 13, 2023.[31] It was developed by the International Bureau for Epilepsy and the International League Against Epilepsy to combat epilepsy-related stigma worldwide by encouraging users on various platforms to trend epilepsy hashtags or share their epilepsy journeys.[31] However, campaigns have rarely included YWE in the design and implementation of their materials.

METHODS

An established study team from a large, urban hospital in Boston, Massachusetts co-developed an Instagram campaign utilizing the matrix framework of anti-stigma mes-

Table 1. Anti-stigma strategies used for our campaign. Adapted from the anti-stigma intervention strategy matrix outlined by Harwood et al., 2022.[20] The first row describes the types of stigma and the first column describes the strategy type.

	Direct Discrimination	Structural Discrimination	Psychological Processes (Self-Stigma)
Protest	Condemn the discriminatory behavior of an individual	Recognizing policies or practices of organizations that may contribute to discrimination	Identify negative stereotypes and misconceptions portrayed in media
Contact	Facilitate contact with other people in the stigmatized group who are role models or prominent in their field	Increase the visibility and presence of people from the stigmatized group	Maintain social connections with others in the stigmatized group (online or in person)
Education	Explain the negative impacts of labeling and stereotyping, explain how to reduce discriminatory behaviors	Educate people about the legal rights of those from the stigmatized group	Educate people from the stigmatized group about how to cope with discrimination and self-stigma

saging with YWE possessing advocacy and leadership experience. Of factors contributing to enacted and felt stigma in YWE, we targeted 3 areas: lack of awareness and understanding about epilepsy (Education and Protest), lack of resources (Education), and lack of family and social support (Protest and Contact).[20] To target these sources of stigma, we involved youth advocates in creating content.[35] The campaign was aimed at the general Instagram youth audience. As the literature suggests misconceptions and lack of knowledge are major sources of stigma among YWE, we assumed providing accurate information could combat these sources of stigma.[13-16] This campaign fills the need for more work on youth-partnered anti-stigma programs, centered on YWE specifically.[19]

STUDY DESIGN

This study was a quality improvement project reviewed by the Institutional Review Board at our institution as part of an existing education and awareness campaign (H-35782). We did not collect any patient information from medical records or investigate human subjects research questions.

The campaign was developed using community-based participatory research (CBPR) and co-design principles, directly involving youth with lived epilepsy experience throughout project phases. CBPR and co-design ensure the unique perspectives of individuals from the affected population are incorporated in study design.[36]

PHASE I: CONTENT CREATION

Six YWE from an existing advisory council collaborated with the study team to develop campaign goals, messaging strategies, and content. The study team selected anti-stigma strategies from the matrix based on their applicability to a youth audience on Instagram and whether they could be conveyed effectively through Instagram content. The selected strategies informed content development. Content focused on addressing stigma-related mechanisms including lack of epilepsy awareness and understanding (Education), limited access to supportive resources (Education), and insufficient peer and social support (Contact and Protest).[20]

Campaign content included “image carousels” centered around YWE’s personal narratives. An image carousel refers to a continuous series of image-based posts that a user needs to scroll through. Our image carousels included youth photographs and text-based graphics sharing their stories and experiences with epilepsy. Content also included short-form videos and infographic-style image posts.

For example, the study team created a video based on the Education (Direct Discrimination) strategy, which explains the negative impacts of labeling and stereotyping; this video discussed common misconceptions about epilepsy, including that epilepsy is contagious.

All content was reviewed by a pediatric neurologist for appropriateness and accuracy before posting, though the study team ensured no medical advice was provided (such as advising YWE to try certain medications). We additionally included this information in the captions of our posts and recommendations to ask a doctor about medical questions.

PHASE II: YOUTH REVIEW OF CONTENT

Fifteen YWE aged 13-26 years were recruited through research assistant visits to pediatric neurology appointments at our institution and outreach to two YWE-led organizations. Inclusion criteria included an epilepsy diagnosis for at least six months. Researchers used purposive sampling, or “selection of participants based on the researchers’ judgment about what potential participants will be most informative”, to identify youth with existing anti-stigma advocacy skills necessary to provide feedback and feasible suggestions.[37]

The study team conducted four in-depth interviews and two focus groups with 12 total participants. Interviews took place on Zoom for 90 minutes, with two study team members serving as facilitators per session. Participants viewed a series of sample posts created by the study team and YWE advisory council and provided feedback on acceptability and perceived relevance. Study team members used a semi-structured guide and an adapted nominal group technique to see whether participants felt the anti-stigma strategies utilized in our content were appropriate and effective.[38,39] The nominal group technique allows participants to share their opinions and have their thoughts heard; through silently generating ideas, verbally listing them, and ranking them to identify the most important.[38, 39] Participants were compensated $75.

Facilitators took field notes during each session. Sessions were recorded using the Zoom record feature, transcribed, and coded using content analysis methods determined by three researchers.

Three researchers independently coded each interview transcript. An initial codebook was developed using the matrix strategies and was refined through iterative transcript review. 13 code categories were identified: one for each of the 12 anti-stigma strategies and one for general social media strategies. Each code was then classified as either a facilitator or a barrier to effective anti-stigma messaging, depending on whether participants described the strategy as enhancing or undermining effective anti-stigma messaging. Coding discrepancies between researchers were resolved through consensus meetings.

PHASE III: AMBASSADORSHIP PROGRAM

Five additional YWE were recruited as ambassadors to create posts highlighting diverse lived experiences. Ambassadors gave the study team consent to participate in content creation and to be featured in campaign content. We did not include anyone under the age of 16, and any ambassador under the age of 18 required parental consent. The study team provided ambassadors with information on internet safety and disclosures, as well as resources. We also encouraged ambassadors to contribute in any way they felt comfortable and only involve personal narratives they wished to share.

Ambassadors completed post-participation reflection surveys about their experience.

PHASE IV: ONGOING SURVEYS

Instagram story polls were used to collect follower feedback on preferred content formats and themes. Poll participants were compensated $15.

PHASE V: ENGAGEMENT ANALYSIS

Campaign content was posted two to three times weekly. Engagement metrics (likes, comments, shares, reach, and followers) were directly collected from the Instagram app and stored in REDCap to understand engagement and acceptability. Data collection occurred from February through August 2023. Engagement metrics were used as indicators of exposure and user interest rather than as direct measures of stigma change.

We used paid promotion on six of our posts. Paid posts appeared in the feeds of the audience we decided to target, youth ages 12-26, for about one to three weeks. We spent a total of $86.96 on paid promotion, with each post costing about $15-20.

RESULTS

CAMPAIGN OVERVIEW

The campaign, “HYPE PEERS” (Helping Young People Endorse and Promote Epilepsy Education and Reduce Stigma), published 36 posts (21 videos and 15 image-based posts) over a 7-month period. Content was categorized by matrix-based anti-stigma strategies. Posts that encompassed multiple anti-stigma strategies were coded by all strategies they included; thus, some posts were categorized more than once.

YOUTH FEEDBACK ON CONTENT

66.66% of interview participants were over the age of 18. 66.6% of interview participants self-identified as female. 25% of participants were on public insurance. 58.3% were either in school or employed. One participant spoke a language other than English, Haitian Creole.

Coding is described in Table 2.

The most reported facilitator to successful anti-stigma messaging was personal accounts of YWE (frequency: mentioned in both focus groups and 75% of IDIs). Personal stories encompassed several anti-stigma strategies - Education (Self-Stigma), Education (Direct Discrimination), Education (Structural Discrimination), and Contact (Direct Discrimination).[20] The most reported barrier to the campaign was that youth tend to believe everything they view on social media.

Some participants felt content disproving common misconceptions, such as epilepsy being contagious, was unnecessary because they perceived it as common knowledge. However, belief in contagion is a common contributor of epilepsy stigma.[13]

ENGAGEMENT OUTCOMES

Interaction, which includes total likes, comments, shares, and saves on a post, reflected engagement with the post. Reach reflected the number of unique users who viewed the post.

The campaign reached 5,452 accounts (defined as the number of people who have seen any post by the campaign, with each user counted once), generated 1,563 profile visits, and gained 142 followers. Paid promotion accounted for 61% of total reach. Of the 5,452 accounts reached, 3,317 were through posts that were paid to be promoted. The post receiving the most reach was able to reach 1,112 unique accounts, of which 90 were organic and 1,049 were seen through paid promotion.

Unpromoted ambassador posts featuring personal stories generated the highest interaction of all content, including paid posts, and were categorized as Contact (Structural Discrimination and Direct Discrimination) (see Table 3).[20] Posts with lowest interaction were Education (Structural Discrimination and Self-Stigma), Contact (Structural

Table 2. Quotes from participants in IDIs and focus groups that are either facilitators or barriers to successful anti-stigma messaging. Quotes are aligned with an anti-stigma strategy and campaign content that was developed based on each strategy.

Anti-Stigma Intervention Strategy	IDI/Focus Group Quote	Barrier or Facilitator?	Associated Campaign Content
Education (Self-Stigma): Educate people from the stigmatized group about how to cope with discrimination and self-stigma	"...we should be getting across the idea that…we're just normal people, there's nothing abnormal about this…some people have diabetes, some people have other conditions, but this is epilepsy, so this is just what makes somebody else unique. So I would just use firsthand experiences."	Facilitator	Famous figures with epilepsy and brief descriptions of their careers. The figures featured were Beethoven, Danny Glover, Leonardo Da Vinci, Prince, Melanie Griffith, and Camila Coelho
Education (Direct Discrimination): Explain the negative impacts of labeling and stereotyping, explain how to reduce discriminatory behaviors	"...the [campaign] should aim to…bring [people with epilepsy]...[and] be part of bringing epilepsy into the cultural mainstream…have it be recognized as a very common thing, and not…crazy people who fall on the ground and shake a lot."	Facilitator	Video about what having low self-esteem may feel like and the ways in which volunteering in your community can positively affect your confidence.
Contact (Structural Discrimination): Increase the visibility and presence of people from the stigmatized group	"...it helps to show that…there's a variety of people...in a range of fields that have epilepsy, and you might not know that."	Facilitator	Post highlighting [Ambassador]'s experience with being diagnosed with epilepsy and how she has navigated life.
Contact (Direct Discrimination): Facilitate contact with other people in the stigmatized group who are role models or prominent in their field	"I really like hearing people's firsthand accounts and struggles…that helps…for people to relate…I like to see people that maybe can offer tips, say: 'Hey, I tried this, when people started approaching me saying [stereotypes] about how I'll have a seizure if I go into a nightclub, like this is my tip for you.'"	Facilitator	Post highlighting [Ambassador]'s experience with being diagnosed with epilepsy and how she has navigated life.
Social Media Strategy (What doesn't work)	"I tend to believe a lot of things I hear on the internet." "People, they believe each other in the comment section. I'm the same…I see someone who, I don't know if they're actually a doctor. But I'm like, oh, yeah, that is totally…real…And I have to catch myself doing that."	Barrier	All content was reviewed by a pediatric epileptologist before posting

Discrimination and Direct Discrimination) and Education (Self-Stigma and Structural Discrimination).[20] While posts with the highest interaction were categorized as Contact, there were also posts receiving the lowest interaction that were also categorized as Contact.

Image-based posts received higher interaction (median 14 likes, comments, and shares) than videos (median 10 likes, comments, and shares). Video posts achieved greater reach (median 95) than images (84) but were viewed for an average of six seconds. The average length of our videos was 76 seconds. Most poll respondents indicated a preference for infographic-style content (69% of fourteen total respondents).

Engagement metrics varied across posts and did not consistently align with specific anti-stigma strategies. While ambassador stories received the most engagement, they involved different strategies.

AMBASSADORSHIP PROGRAM FEEDBACK

All ambassadors reported positive experiences and perceived increased epilepsy knowledge and social connection. Four out of five expressed interest in continued participation.

One participant shared, "One thing I got out of this campaign was that spreading awareness and destigmatization can not only happen in a big and super popular advocacy campaign/group but that it can happen in a small campaign/group as long as there are people passionate about the mission and that are willing to share their stories. This really showed me that just a few people can make a huge difference, even if it isn't immediately obvious or visible."

Another shared, "As one living with epilepsy, I feel it is extremely important to share our unique stories and experiences in order to spread awareness. This campaign through social media was one of the best ways to promote and spread awareness to a wide variety of people."

Table 3. Summary of metrics for top organic (unpaid) posts by reach, defined as reaching the highest number of accounts, and posts by interaction, defined as receiving the most likes, comments, shares, and saves. The top posts by reach and interaction are compared to typical engagement numbers received by our campaign posts (bottom row).

Post Type	Post Description	Anti-stigma strategy	Likes	Comments	Shares	Accounts Reached
Top post by reach	Video featuring famous public figures with epilepsy	Contact (Structural Discrimination)	8	0	1	713
Top post by reach	Video tutorial of study team member making ketogenic egg muffins	Education (Self-Stigma)	19	2	4	424
Top post by interaction	Image carousel of ambassador personal story	Contact (Structural Discrimination) Contact (Direct Discrimination)	46	8	4	223
Top post by interaction	Image carousel of ambassador personal story photo post	Contact (Structural Discrimination) Contact (Direct Discrimination)	34	3	5	196
Top post by interaction	Photo post of ambassador celebration event featuring ambassadors	Contact (Structural Discrimination) Contact (Direct Discrimination)	24	7	2	194
N/A	Typical post metrics*	N/A	8-17	0-1	0-2	93-147

DISCUSSION

This project demonstrates the feasibility and acceptability of a youth co-designed anti-stigma social media campaign through a novel application of the matrix of anti-stigma messaging. Familiarity about epilepsy is a significant determinant of epilepsy-related knowledge and attitudes, so increasing contact and visibility of those with epilepsy through campaigns may be helpful for addressing stigma.[2,40,41]

By involving youth advocates in the design and implementation of an Instagram campaign, we incorporated youth perspectives to enhance understanding of epilepsy and YWE's engagement patterns with anti-stigma content. To our knowledge, this is the first Instagram advocacy project used to study YWE's reactions to the content produced. Our findings provide insights into possible strategies addressing stigma through social media for YWE.

Consistent with existing literature, personal stories were the most reported facilitator to successful anti-stigma messaging in focus groups and IDIs and were mentioned in nearly all interviews and had the most interaction. The top posts by interaction (highest engagement) incorporated the Contact (Structural Discrimination and Direct Discrimination) anti-stigma strategies.[20] These strategies are the most closely related to personal stories. Stories can contribute to other strategies, especially Education (Direct Discrimination and Self-Stigma).[20] Thus, personal stories can be used for multiple strategies to target stigma by providing relatability.[20] This aligns with existing disability frameworks that emphasize the importance of lived experience, social contexts, and structural forces in affecting disability identity.[42] Since personal stories of lived experience received the most engagement, this suggests that users may prefer peer visibility, relatability, and authenticity.

While our posts centered around Contact (Structural Discrimination and Direct Discrimination) had the highest interaction, this does not suggest a relationship between these anti-stigma strategies and engagement. Some of our lowest-performing posts by interaction and reach were Contact (Structural Discrimination). No strategy consistently received the highest or lowest reach or interaction. Engagement numbers depend on many factors, such as content type. In general, we found that image series were preferred to videos as they received more interaction. Knowing how to align content delivery with audience preferences can inform future campaigns.

Our campaign reached 5,452 users. While our reach may not be high for a social media campaign, we feel we reached our audience as YWE on social media make up a small subpopulation. In the era of social media, 93-97% of adolescents aged 13-17 use social media platforms for 3-4 hours a day.[43-46] While a campaign on its own may not be sufficient to address sources of stigma, it may still be helpful in addition to other modes of epilepsy education, due to the sheer number of youth who use social media.

This project assessed engagement, acceptability, and perceived relevance, rather than explicitly evaluating stigma reduction, which could include changes in stigma-related behaviors and attitudes using validated outcome measures. Engagement metrics should therefore be interpreted as indicators of exposure and interest rather than direct evidence of stigma reduction. Additionally, the sample size was small, and engagement metrics were not experimentally controlled. Future studies should use validated stigma scales and pre/post designs to assess whether exposure to youth-centered narrative content leads to changes in stigma-related knowledge, attitudes, and disclosure. Future studies could additionally involve pre/post comparisons of stigma-related attitudes and behaviors among youth without epilepsy.

This project's findings can be used clinically, as those who care for YWE could provide content with personal stories to them. For example, epilepsy care teams may supplement education by sharing this kind of content during clinic visits.

From a practice perspective, this campaign offers a template for youth-serving organizations, schools, and advocacy groups seeking to address stigma through participatory social media approaches. Strategically combining ambassador partnerships, interactive features, and targeted promotion may enhance reach while maintaining authenticity. At a policy level, these findings support investment in youth-centered anti-stigma communication as part of public health promotion.

LIMITATIONS

We were limited in our engagement because we chose to use Instagram instead of TikTok due to safety concerns. Promotion of products that are harmful to health, such as alcohol and drugs, is rampant on TikTok.[47,48] Several dangerous viral trends on TikTok have led to injuries, hospital admissions, and deaths in youth.[49-51] However, youth use TikTok more than Instagram.[52]

We were also limited in reach because of Instagram's algorithms, which significantly shape how users receive and interact with information on the platform.[43] The algorithms determine the visibility of content, influencing which posts users see and how they engage with various types of information.[43] Instagram's algorithms prioritize content based on user interactions and engagement, which can contribute to the spread of misinformation; it can cause selective visibility of content that aligns with the user's existing beliefs or interests.[53-55] Posts evoking emotional responses or featuring relatable content, especially those with a negative emotional tone, often receive more interaction than posts that provide accurate information.[55-57]

Influencers on Instagram further complicates reach and information dissemination. Algorithms can make certain voices more visible while silencing others.[58,59] The tendency for virality to dominate over substantive discourse and the design of Instagram prioritizing engagement can perpetuate misinformation and stigma; users may gravitate towards sensationalized narratives from people with a large following rather than engaging with more informative content.[58,59] Our campaign involved youth advocates as ambassadors, allowing content to reach their followers, and attempted to connect with influencers, but was not able to leverage influencer partnerships.

We did not collect feedback on campaign materials prior to campaign launch from youth without epilepsy, who may have a different knowledge level of epilepsy than YWE. Future work should involve them to understand how campaigns could de-stigmatize epilepsy for those without lived experiences.

Equity should be considered along with our findings. Youth without consistent internet access, or without a device to access Instagram, were not included in this project. Identity as a person with epilepsy may overlap with other marginalized identities, such as ethnicity, which may impact the felt or enacted stigma faced by YWE. Future campaigns could include content available in multiple languages and accessibility features, such as alternative text on posts; they should also feature narratives from those with overlapping identities. Future work may additionally include partnerships with schools or community-based organizations to reach youth beyond social media campaigns. As some youth use different social media platforms than Instagram, campaigns may consider leveraging multiple platforms. While further research is needed to assess impact on stigma outcomes, these findings provide actionable guidance for developing equitable, youth-driven social media campaigns addressing epilepsy-related stigma.

CONCLUSION

This work emphasizes the importance of CBPR approaches in designing anti-stigma health campaigns. By incorporating the perspectives of YWE, we can ensure that interventions are relevant and engaged with. A social media campaign thus may be an effective method for sharing personal narratives. While further research is needed to assess impact on stigma outcomes, these findings provide actionable guidance for developing equitable, youth-driven social media campaigns addressing epilepsy-related stigma.

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ACKNOWLEDGMENTS{#ACK}

We would like to thank the youth with epilepsy from Boston Medical Center for their time and participation. We would also like to thank the Epilepsy Youth Advisory Council at Boston Medical Center and the Youth Leadership Network at the Epilepsy Foundation New England for their involvement in the creation of campaign content. This work would not have been possible without our youth advocates.

DISCLOSURE STATEMENT

This work was supported by the Epilepsy Foundation New England Blue Skies Grant. The authors have no relevant conflicts of interest.

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Submitted: January 27, 2026 EDT. Accepted: March 05, 2026 EDT. Published: March 22, 2026 EDT.

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