Disability stigma reduction interventions study summary

2023

Ghana Somubi Dwumadie www.ghanasomubi.com is a four-year disability programme with a focus on reducing stigma for people with disabilities, including people with mental health conditions. Stigma reduction approaches included social behaviour change, advocacy, mental health self-help groups and district mental healthcare plans.

The study used a mixed methods approach to explore how Ghana Somubi Dwumadie interventions were designed, delivered, and monitored, and to identify what went well and what could have been improved in the implementation of the programme.

The objectives were to explore:

- The participatory approaches used in the design and delivery of stigma-reduction strategies and activities and the acceptability of processes, activities and materials
- How a diversity of intervention approaches can deliver coherent implementation of stigma-reduction interventions
- How experiences differ across gender (especially for women) and disability types (including mental health) and other relevant intersectional experiences
- How stigma can be understood and assessed to show change
- The early effects of stigma-reduction interventions on attitudes and behaviours.

Why is this issue important?

Stigma is one of the leading barriers faced by people with disabilities around the world, yet global evidence of how it's addressed is lacking. This study fills the gap in intervention studies exploring the effectiveness of mental health and/or disability interventions within the local context. It looked more broadly at participation for all stakeholders, but with particular attention to the value of a user-led approach.

What do the findings tell us?

1. Participatory approaches, acceptability and coherence

People with disabilities as contributors and leaders

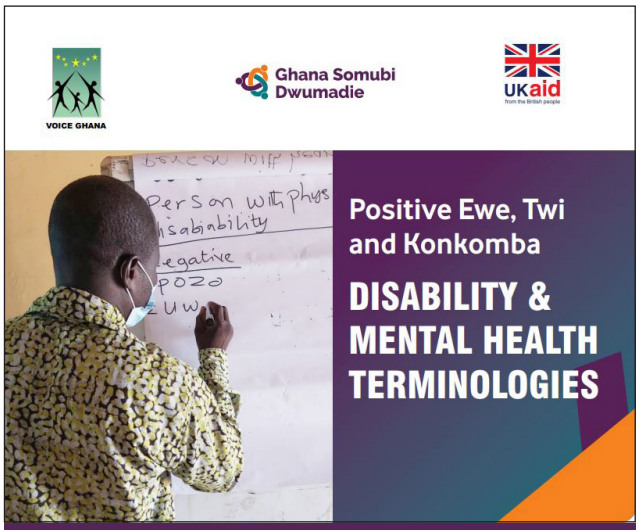
The study showed that people with disabilities and mental health conditions actively participated in both the design and delivery of stigma-reduction approaches. This was more notable in the social behaviour change (SBC) component of the programme through:

A formative study, which listened to people with disabilities, community leaders, health workers, the media and local government

Co-creation workshops, conducted with a diverse representation of people with disabilities and

Pre-testing of materials and quality assurance processes, resulting in various adaptations to suit cultural context and accessibility needs

The engagement of people with disabilities and key project stakeholders contributed to increased acceptability of the stigma materials, especially the development of 'positive local language' guides. Participants also drew on their social capital to fulfil a variety of empowering community roles. However, issues related to self-stigma, combined with limited support, meant that some participants (particularly women) struggled to implement activities. Here the Self-Help Group model appeared to offer important opportunities for solidarity and psychosocial support.



The VOICE Positive Language Guide

People in power

One consistent theme running through the study was engaging with influential people to address issues of power in stigma reduction. Evidence showed that the empowerment of people with disabilities to address stigma is not sufficient on its own. It is therefore crucial to create platforms which enable better direct access to power holders, and to leverage the support of influential people and organisations. This engagement adds to the acceptability of material for the local context which could include, for example, input from a traditional leader on stigmatising language. It also could result in people of power directly engaging in the implementation of stigma-reduction work.

Collaboration was more evident in some study sites, with partnerships being key to the programme's success. The benefits of collaboration included traditional leaders ensuring the programme's buy-in, engagement with duty bearers and entry into communities. The study also highlighted the acceptability and complexities of traditional authorities enforcing local laws to address stigma reduction.

Ama Talichir, president of Alleged Witches' Network, featured in Gnani camp

Designing for coherence

A diverse range of stigma-reduction approaches were used across the programme. The coherence of social behaviour change (SBC) approaches was facilitated by having one SBC strategy and an alignment of indicators and outcomes. However, there was no one single programmatic approach to understanding stigma or of stigma-reduction interventions across the deliverables. Cohesion could also have been improved between grantees and different Ghana Somubi Dwumadie workstreams.

Participants valued learning meetings and exchanges, but it was unclear how this translated into the uptake of stigma approaches.

What do you need to know?

Involve people with disabilities in the design and delivery of stigma-reduction approaches. This works especially well in social behaviour change approaches through cocreation and pretesting.

Disability-inclusion programmes would benefit from one overarching stigma-reduction strategy. This helps align different approaches, provide clear signposting for synergy and elevate the understanding of stigma as a priority issue. This could be further enhanced with a unified dissemination approach of resources and enhanced learning opportunities.

The model of inclusion champions appears to work particularly well where people with disabilities play a significant role to deliver activities alongside other key community members. However, any training package or self-help group should also explicitly address internalised (self) stigma and strengthen the role of people with disabilities, especially women, as champions.

Traditional leaders can utilise their positions of power to implement activities, leverage support and enforce change where culturally appropriate.

2. Intersectionality

The study illustrated the intersectional nature of stigma and the layers of power which contribute to it. In terms of gender, it revealed shifting social norms around the ability of women with disabilities to marry. However, the lower overall engagement of women in the stigma-reduction work, and the fact that men still dominate leadership positions of the SHGs and the OPDs, is consistent with literature in the Ghanian context.

The experiences of influencing stigma for people with mental health conditions was often linked to the ability to access medication. Representation of people with hearing impairments was low and highlighted a shortage of sign language interpreters. The lack of attention by duty bearers, is arguably structural stigma.

The programme would have benefited from an early gender analysis and application of a gender lens at the design stage. This would have further strengthened the understanding of how both women and men with disabilities experience of stigma and targeted engagement in stigma-reduction approaches.

What do you need to know?

Stigma reduction should be understood from an intersectional lens early on in programme design and subsequent data collection disaggregated by disability and gender. A gender lens can include targeted approaches to increase the participation of women with disabilities. Avenues to strengthen the participation of people with mental health conditions in programmes, alongside the adaptation of stigma resources for people with diverse disabilities, should also be considered.

Adaklu sopa SHG

3. Monitoring

Despite good alignment of partner indicators for stigma reduction, there were limited outcome indicators for assessment. Mixed-method approaches were used in the programme to monitor and evaluate stigma reduction and the use of qualitative approaches were helpful in capturing the intersectional experiences of stigma.

Survey questions were generally weighted towards understanding reported change to the stigma drivers, and the quality of grantee surveys to understand stigma reduction was mixed. The exception was a 'knowledge, attitude and practices' study.

What do you need to know?

If your programme aims to reduce stigma, then there is need for effective stigma assessment tools, especially at outcome levels. Given the complexity of measuring stigma, it is worth considering other proxy measures such as improved quality of life.

Build in longitudinal research to better understand stigma reduction over time and the factors that affect change. Conduct further research on the intersection of stigma and disability and there is also a need to better understand stigma by association e.g. that experienced by female caregivers and their role in addressing stigma.

4. Early Effects

The study captured evidence on the improvement in knowledge and awareness, combined with more acceptance of people with disabilities and mental health conditions in families and communities. This was especially evident in using non-stigmatising language. All interviewees gave examples of positive changes in disability-inclusive practice, such as invitations to community events and greater participation in family and community activities.

"The community now gives them the opportunity to participate in community activities. Some persons with disabilities are now members of Easter planning committees, school management committees, community water project committees and some are ushers in their churches."

FGD, grantee, Volta Region.

There is, not surprisingly, more to be done to address persistent challenges driven by stigma, but there was a recognition that change takes time.

Bohira nye Bangda self help group

Limitations and suggestions for future research

The methodology used a purposeful sample and therefore findings are not generalisable across the programme. However, we drew on experiences from multiple regions and data sources, besides conducting a workshop with key stakeholders to validate key findings.

It is sometimes difficult to disentangle what has been contributed by Ghana Somubi Dwumadie specifically. For example, some SHGs have been engaged in a variety of programmes. Nonetheless, this study offers key lessons on stigma reduction more broadly.

Finally, there was no disaggregated data collected on disability type or severity, making it difficult to reflect on the stigma experiences of people with different types of disability. We sought to address this with interviewees to collect primary data.

Recommendations for future research are made to cover four areas: **longitudinal research to better understand stigma reduction over time; the intersectional experience of stigma and disability; the linkages between stigma, access to medication, and treatment for people with mental health conditions;** and finally, **stigma by association, such as stigma experienced by female caregivers and the potential for expanding their role in addressing stigma.**

Learn more about

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- **Read the full report here** https://research.sightsavers.org/project/disability-stigma-reduction-intervention-study/