

Improving user-led approaches in mental health and disability services

About this briefing

This briefing is for those who deliver services for people with disabilities, including people with mental health disabilities. It helps identify how to improve the way those services are delivered.

The briefing explains what user-led approaches to disability services are, specific to Ghana. Ghana Somubi Dwumadie wrote this report. The full report can be read by contacting the programme. Research done for this report in late 2020 identified that users of disability and mental health services wanted to be more engaged and consulted on issues relating to them.

Ghana Somubi Dwumadie (Ghana Participation Programme) is a four-year disability programme with a specific focus on mental health. This programme is funded with UK aid from the UK government and run by an Options-led consortium, which also consists of BasicNeeds-Ghana, King's College London, Sightsavers International and Tropical Health. It focuses on:

1. Promoting stronger policies and systems that respect the rights of people with disabilities, including people with mental health disabilities
2. Scaling up high quality and accessible mental health services
3. Reducing stigma and discrimination against people with disabilities, including mental health disabilities
4. Generating evidence to inform policy and practice on the effectiveness of disability and mental health programmes and interventions

Definitions

The following key terms are useful for understanding the range of engagement processes that can be part of user-led approaches or part of a process towards becoming a user-led agreement.

User-led approach: an approach is said to be user-led when it is guided by the needs and priorities of the people using that service. This includes meaningful consultation, engagement and improved systems for feedback and grievances in both civil society organisations and state-run services.

In Ghana, people with disabilities, including people with mental health disabilities, told us that they felt that all services for people with disabilities should adopt more user-led approaches.

User-led organisation: definitions of user-led organisations can vary but central to their definition is that they:

- are led and controlled by people with disabilities, including people with mental health disabilities
- actively demonstrate their commitment to people with disabilities, including people with mental health disabilities, by employing staff and volunteers with disabilities
- actively demonstrate their commitment to removing the societal barriers that prevent people with disabilities, including people with mental health disabilities, from attaining their fullest lives

People in Ghana with disabilities, including people with mental health disabilities, told us that they want to include the following definitions:

- the majority of the board of a user-led organisation of people with disabilities and at least 60% of staff in management positions should themselves be people with disabilities, including people with mental health disabilities

Disabled People’s Organisations (DPOs): central to this definition is that these are organisations **of** people with disabilities, with a focus on matters relating to the concerns of people with disabilities, including people with mental health disabilities. This is distinct from organisations which undertake activities or services **for** people with disabilities but are not led by people with disabilities. DPOs are usually user-led, but some may not meet every definition of being user-led.

Self-Help Groups (SHGs): these groups are a formal or informal group of people with mental health conditions and/or their families, with a common interest to promote their wellbeing and improve access to services.

Participatory approaches: enable people to play an active and influential part in decisions which affect their lives. It is assumed within participatory approaches that individuals have capacity to exercise autonomy and set their own goals.

User-led approaches are achieved through involving different types of participation. This process takes time, and needs collaboration between service providers and service users, as both gain experience and confidence. It requires a balance between partnership, delegated power and some level of citizen control or ownership over the design and delivery of services.

What Ghana Somubi Dwumadie is doing to support user-led approaches

Ghana Somubi Dwumadie is working with stakeholders to decide what form the programme’s support will take. This is likely to include supporting:

- DPOs/SHGs to become fully user-led organisations
- DPOs/SHGs to be more actively involved in decision making
- Government of Ghana and service delivery organisations to apply more user-led approaches in designing and running services.

Why user-led approaches are important

There is strong evidence that user-led approaches to delivering services for people with disabilities, including people with mental health disabilities, are more effective when they reflect the diverse priorities and needs of the very people who need and use the services.

Additionally, legislation and international conventions, including, the United Nations Convention on the Rights of Persons with Disabilities and the African Union protocol to the African Charter on Human and People's Rights on the Rights of Persons with Disabilities, of which Ghana is a signatory, call for people with disabilities, including people with mental health disabilities, to be more involved in decision-making that impacts their lives.

Current national legislation has opportunities to support the provision of structures for ensuring user involvement. For example, the Ghana Mental Health Act 2012 has provisions to ensure the involvement of service users:

Section 3. "To achieve its object, the Authority shall (a) consult persons with experience as service users as well as family members for the formulation, development and implementation of mental health policies."

Overcoming challenges to implementing user-led approaches

Attitudinal: The dominant ways a community or society think about and are presented with disability can positively or negatively influence people's ways of working with and responding to people with disabilities, including people with mental health disabilities.

For example, in Ghana it is not uncommon for disability to be seen as a curse by a deity, divine being or a spirit. In addition, disability in Ghana (as in other countries in Africa) is influenced by depictions in oral histories, customs and rituals of different ethnic groups. Colonial histories, differing religions, evangelical and missionary services and international charities and organisations have all influenced how disability is perceived, understood and measured in Ghana.

Practitioners, governments, and individuals in the community all have different views of disability, which are shaped by different sociological perspectives. These views will influence the implementation of user-led approaches.

Operational: Resources, funding and political drivers may also impact the success of user-led approaches if programme plans and delivery goals do not allow sufficient time, money or space to design and implement user-led approaches in addition to operational requirements.

It is important to build the skills of staff working with people with disabilities alongside building the skills of people with disabilities, including people with mental health disabilities, who may not have had previous opportunities to lead or exercise autonomy.

Recommendations for creating an enabling environment for user-led approaches

Recommendations for all in disability and mental health services

- Recognise people with disabilities, including people with mental health disabilities, as key users of services, and participants with the potential to inform better provision of the services they need.
- Adopt user-led approaches when engaging with services and undertaking advocacy, and support DPOs and SHGs to participate fully.
- Ensure adequate resourcing and capacity building so that DPOs and SHGs can lead and champion their issues, and manage and take decisions on matters that affect them directly.
- Design and deliver targeted behaviour change campaigns that shift attitudes so that disability is not seen negatively, society is more inclusive and people with disabilities, including people with mental health disabilities, are encouraged to fulfil their rights and overcome the multitude of attitudinal and socio-political barriers that limit their access to employment, education, health care and rehabilitation, transportation, and recreation.

Recommendations for Government

- Measure inclusivity in current services by assessing levels of citizen participation, consultation, engagement, and delegated power.
- Ensure that policies and services that affect people with disabilities, including people with mental health disabilities, are determined through genuine consultation and participation with these groups. Specifically include and accommodate people with disabilities, including mental health disabilities:
 - on governing boards and councils of state institutions that provide services that affect them, i.e. services which affect all citizens in implementation of genuine user-led and participatory approaches to healthcare and social services, including rehabilitation initiatives and/or programmes.



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