User-led approaches in Ghana: a reflection and response to 'Strengthening the call to involve mental health care service users and their families in psychosocial rehabilitation programmes' (WAPR bulletin 51)

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This article responds to a paper in WAPR bulletin 51 on 'Strengthening the call to involve mental health care service users and their families in psychosocial rehabilitation programmes', and reflects on what we can learn and what we can share from the programme we've been involved in.

Ghana Somubi Dwumadie (Ghana Participation Programme) is a four-year disability programme in Ghana, with a specific focus on mental health. This programme is funded with UK Aid from the UK government. The programme is run by an Options' led consortium, which also consists of BasicNeeds-Ghana, Kings College London, Sightsavers and Tropical Health. The overall goal of the programme was to ensure that 'all people with disabilities and mental health conditions are engaged, empowered, and able to enjoy improved wellbeing, social and economic outcomes and rights'.

The programme from the start had a strong focus on user-led approaches, by which we mean ensuring that people with disabilities or mental health conditions were in the lead, guiding and shaping programme design and implementation. This felt like a critical strategy from the start, working with and alongside the people benefitting from the programme. We established a Programme Advisory Group made up of experts across a range of relevant sectors, from health to media to law, of whom the majority are people with disabilities or mental health conditions. This Advisory Group has been integral to the user-led approach of the programme as it has provided strategic guidance and played an ambassadorial role in support of the programme and to help us achieve our objectives. Three of the authors of this paper are members of the Advisory Group.

Within the first six months of the programme's start-up, we conducted a review to examine existing models and tools around user-led practices, such as citizen involvement and participation, user engagement and empowerment of organisations of people with disabilities, among others, in an effort to deepen our understanding of user-led approaches. That review recognised the importance of actively empowering and engaging people with disabilities, people with mental health conditions, and their representative organisations to participate in the design and implementation of key programme activities and decision-making processes that affected them. The programme subsequently used these learnings to develop user-led approaches and apply them to various workstreams and activities across the four-year programme.

A user-led approach was defined as an approach guided by the needs and priorities of the people using a service. This includes meaningful consultation, engagement and improved systems for feedback, led by the users themselves. A user-led approach contributes to an increased sense of ownership and mutual trust among stakeholders involved. To achieve this, the programme used two key strategies: (1) implementation of user-led approaches within the programme design and activities, and (2) facilitation of user-led approaches via programme stakeholders.

User-led approaches in programme design and implementation

At the heart of it all sat our Advisory Group, who met regularly to critically advise the programme on it's approach, and to hold it to account and ensure that the voices of people with disabilities were heard and considered in programme design and implementation. The Advisory Group also supported with key activities such as leading panel discussions and conferences, representing the programme with the media on key discussions such as the need for investment in mental health, and supporting key international days such as World Mental Health Day or World Bi-Polar Day.

Esenam emphasises "I think the programme's user-led approach was the right approach because by involving people with lived experience, it gave the programme a rather unique opportunity to address the first-hand experiences and issues which other programmes would usually ignore because of their approach."

The programme sought to continually review and raise awareness of the importance of user-led approaches through its design and implementation, with the aim that this would lead to greater inclusion and representation of people with disabilities and mental health conditions in decision-making processes that affect them within wider society. It was envisaged that by employing and facilitating user-led approaches across all programme interventions, the programme would contribute to the design and implementation of services that meet the needs of service users and challenge negative attitudes via more effective user-led engagement from the government bodies and civil society organisations it worked with.

One user-led approach commonly used in this programme was the involvement of service users in the design of key interventions. For example, service users were involved in the design process, alongside service providers and other stakeholders, during the development and implementation of District Mental Healthcare Plans in three pilot districts. Participatory design workshops were employed to facilitate their input and ensure that the workstream aligns with their needs. Further, service users formed part of the District Mental Health Operations Teams and were included in the design stage, implementation and monitoring of programme activities. At the design stage, service users were involved at theory of change training workshops, as well as in subsequent progress review meetings throughout the programme. This strategy created a sense of ownership over the design process and mental healthcare plan by the District Mental Health Operations Team in each district.

Unfortunately, involvement of users in the implementation of the plans was limited (low representation on the District Mental Health Operations Teams). There were only three service users out of the total membership of 51 (one from each district) who were part of a District Mental Health Operations Team. This is because the formation of the operations teams was guided by the Mental Health Act 846, which proposes to have one service user among the district teams.

Elsewhere, participatory and user-led approaches were used in designing and delivering stigma-reduction activities and were seen as key to success. For example, during the design of programme social behaviour change strategy, organisations of people with disabilities such as Mental Health Society of Ghana (MEHSOG) were involved in the design of the social behaviour change interventions. James reflects on our stigma work "what stands out for me is the issue of stigma and how to reduce this within the communities and among duty bearers. If the environment in the families, communities and among duty bearers is not changed in terms of how people see persons with mental health conditions and appreciates or empathises with them in a positive way, the battle in the reduction of stigma will collapse. We should stop thinking about the negatives and seize the moment to understand and correct bad perceptions. Through our programme's intentional approach in encouraging families, self-help groups and community members to actively include persons with mental health conditions in daily activities at home and in society, we can make a world of difference in the lives of persons with mental health conditions and thereby help reduce stigma."

User-led approaches were also adopted in the implementation of advocacy activities, whereby programme participants and people with disabilities, including people with mental health conditions, were

involved to own and lead the advocacy engagements, especially activities like radio programmes where people with lived experience were engaged to tell their stories from their own perspectives. People with lived experience were trained and supported to lead a range of roles at the community level, including as disability champions, inclusion ambassadors, community volunteers and/or leaders of self-help groups. We found that working through key people in a community, who act as implementation agents, presents some benefits as these people know more about the local terrain. Encouraging local people to champion project interventions helps them to own the project, thereby promoting sustainability.

Facilitation of user-led approaches through programme stakeholders

The programme has also worked with key stakeholders to support user-led approaches by supporting organisations of persons with disabilities and self-help groups to be more actively involved in decision-making and working with Government of Ghana. The programme provided support and technical assistance to organisations of persons with disabilities and self-help groups to improve their capacity to engage meaningfully on mental health, gender and disability policy. This was complemented with mobilisation and facilitation of constructive engagements between organisations of persons with disabilities, self-help groups and key government officials. For example, during a review of the District Assembly Common Fund (DACF): Disability Component disbursement and management guidelines, the programme encouraged close working collaborations between key government ministries such as the Ministry of Gender, Children and Social Protection, together with the Ghana Federation of Disability Organisations, by bringing them together to revise the guidelines. A consequence of this collaboration was that the revised guidelines ensured that the fund is available to people with mental health conditions, as well as people with disabilities in Ghana.

Further, the programme facilitated meaningful participation by all during the review process by paying for all costs related to accessibility such as sign language interpretation, transportation and accommodation. Since the new DACF guidelines were drafted, the programme has sensitised hundreds of people with disabilities, including people with mental health conditions, on their content. The strategies have proven to be effective in bringing to the fore issues that affect people with disabilities and mental health conditions, and ensuring that people with lived experience are engaged throughout the review process. In this way, the programme's own user-led approach contributed to institutionalising user-led approaches within government processes.

Through the programme's grant mechanism, the programme supported grantees to apply more user-led and participatory approaches, which has proven to be effective in bringing to the fore issues that affect people with lived experience. For example, Ghana National Association of the Deaf was funded by the programme to research the unmet mental health needs of Deaf people in Ghana. Their unique study included using Deaf peer researchers to better engage with respondents and build trust in talking about an issue that was poorly understood and highly stigmatised. The adoption of the user-led approach by some of the organisations supported with grants by the programme has not only empowered people with lived experience to assert their rights, but has created legitimacy for the issues raised, and compelled stakeholders to respond.

The programme also focused strongly on accessibility in regard to engagement and participation in programme activities to ensure that people with disabilities or mental health conditions are not hindered by barriers that could be addressed, and to ensure that accessibility of documentation and sharing of information in different and appropriate formats was normal practice within the programme.

Our reflections on 'Strengthening the call to involve mental health care service users and their families in psychosocial rehabilitation programmes' (WAPR bulletin 51)

The authors found the paper insightful and relevant to our experience. Advisory Group member Adwoa felt that this paper's emphasis on lived experience and user-led design resonated deeply with her participation in the Advisory Group. The focus on incorporating the realities of those impacted by the issue into the development process is a refreshing shift from theoretical approaches.

Adwoa explains that "my own experience navigating psychosocial disorders highlighted the disconnect that often exists between proposed solutions and the practicalities of daily life. For example, during a job interview, I felt confident and capable. My responses were well-rehearsed, and I addressed all the interviewer's questions. However, the fluorescent lights overhead triggered a sensory overload, causing anxiety and making it difficult to concentrate. This resulted in fidgeting and stammering in my speech, which I'm sure came across as nervousness or a lack of preparedness. This experience highlighted the disconnect between how I felt internally (prepared) and how my external behaviour might have been perceived (anxious and unfit). This encounter solidified my belief that user involvement, particularly those with firsthand knowledge, is crucial for creating effective solutions.

The paper's exploration of various user-led methodologies, such as focus groups, offered valuable insights. The emphasis on creating a safe space for users to share their experiences and co-create solutions resonated with me, as it aligns with the importance of fostering a sense of ownership and building solutions from the ground up and offered valuable insights. The emphasis on in-depth conversations to understand user needs, motivations, and pain points resonated with me, as it aligns with the importance of uncovering the underlying reasons behind people's behaviour.

The inclusion of lived experience narratives within the paper was particularly impactful. Reading the stories of others facing similar challenges created a sense of solidarity and offered alternative perspectives.

However, the paper also acknowledged the challenges associated with integrating lived experience. A valid concern discussed in the paper was the potential for bias, particularly when user experiences are subjective and emotionally charged.

This resonated with me, as it's important to acknowledge that lived experiences can be shaped by individual perspectives. This is why a multi-pronged approach ensures that the final solutions are grounded in a variety of lived experiences while maintaining objectivity in the interpretation of those experiences.

Overall, this paper serves as a valuable resource for anyone seeking to create solutions that are truly user-centered. By prioritising lived experience and actively involving users throughout the design process, we can bridge the gap between theoretical ideals and the realities of everyday life. Furthermore, my own Advisory Group experience provided a platform for amplifying user voices and ensuring that our perspectives are integrated seamlessly into the development process. This combined approach holds immense promise for designing solutions that are not only effective but also truly impactful for those they aim to serve."

James also reflected on the article; "it educated me on some of the critical areas in psychosocial rehabilitation. The voice of lived experiences from persons with mental health conditions from different countries gave me an insight into the lives of the people and the challenges they face in coping with service providers. It also highlighted the need for active inclusion, respect for others irrespective of their circumstances. Our own programme may want to learn from this and consider providing two or three voices of lived experience in our next newsletter. Issues of human rights also came to the fore. We can use these experiences to increase awareness among communities, duty bearers and policy makers.

I think what the author of the paper may consider from our programme is to consider the use of our model of, at the onset co-creating user-led and policy level approaches by involving organisations of persons with disabilities and individuals with disabilities and mental health conditions, alongside healthcare workers, government agencies and civil society organisations, as this approach secured significant buy-in and sustain-

ability for us. Recognising that mental health is a fundamental part of our general healthcare, we have to be conscious and intentional in our choices for a healthy state of our well-being and those with mental health conditions. The issue of providing and / or using a multidisciplinary team consisting of psychologist, social workers, healthcare professionals, families, peer groups, civil society organisations and people with lived experience is not only important but a necessary intervention to support individuals with mental health conditions to recover and gain relative independence, dignity and self-esteem."

What we've learned from these reflections is that we can still do more. Committing to and supporting a user-led approach in all areas of programming raises awareness of its importance and leads to greater inclusion and representation of people with disabilities and mental health conditions in decision-making processes that affect them. Involving people with disabilities or mental health conditions in the process of developing and delivering their own programmes remains essential and such approaches ensure that interventions and policies meet the needs of service users. However, we can do more in the final months of the programme to uplift the voices and experiences of the people we're working alongside, to ensure that their views and perspectives are heard at all echelons of the programme, whether reporting to our funder, at stakeholder events, or on social media.

Our final thoughts

James encourages Advisory Boards to be determined and courageous and choose action over passivity because extreme patience, understanding, empathy and advocacy is needed to achieve the goals we set and achieve the desired results.

Esenam speaks passionately about the benefits of an experience like being on an Advisory Group "personally, being given an opportunity to be on the Advisory Group was truly an honour. Because, it is in very few instances like these that my lived experience expertise was valued and considered an asset. I was allowed to speak freely and contribute without feeling stigmatised or discriminated. This position also gave me the opportunity to build my capacity, collaborate and it also gave me the chance to see the evolution and success of the programme."

Adwoa says that "being part of Ghana Somubi Dwumadie's Advisory Group has been an incredibly meaningful journey for me. It's been a privilege to contribute to discussions, share insights, and advocate for inclusivity and accessibility. Being able to collaborate with such dedicated individuals who are passionate about making a difference has been truly inspiring. It's heartwarming to see the progress we've made together in raising awareness and implementing positive changes. Personally, it has been a deeply fulfilling experience to be part of a community that values diversity and actively works towards creating a more inclusive society. As I reflect on my time with the group, I am filled with gratitude for the opportunity to be involved in such important work, and I look forward to continuing this journey of empowerment and advocacy."

Lyla wants every programme, in every sector, to put users and people with lived experience at the heart of its design and implementation. "Imagine what can be achieved when we actually listen to and uplift the views and experiences of the people using the services we're developing. Imagine the trust that would be built by working in that way and the benefits it would bring. I hope to always be able to work alongside a wonderful Advisory Group like the one we had on Ghana Somubi Dwumadie."