WAPR World Association for Psychosocial Rehabilitation
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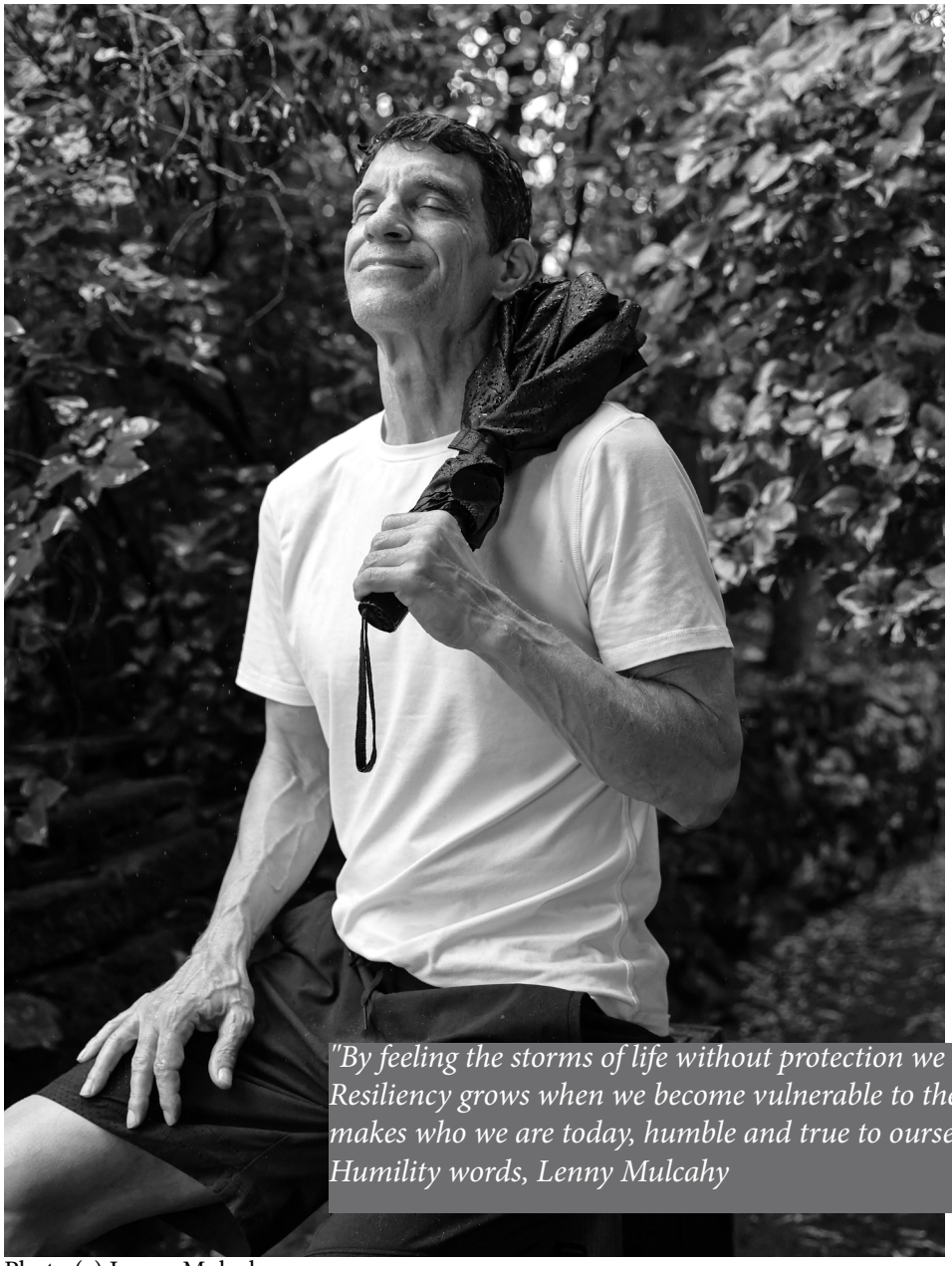
Recovery and rights-based approaches in mental health.



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Contributions
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WAPR HEAD OFFICE. Gabriele Rocca, WAPR President
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EDITORIAL

by Marit Borg and Michalis Lavdas

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The involvement of people with lived experiences of mental health problems and their families are central in WAPR aims and activities. WAPR urgently needs the knowledge and insights of people with such experiences in developing accessible and helpful service programs and inclusive social communities.

Let us remind each other of the statements in Article 19 in CRPD on "Living independently and being included in the community":

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

In the last Bulletin of 2023 we share a variety of evidence and experience- based knowledge. The article section starts with a call to further enhance multidisciplinarity in the mental health services, actively engaging with people with lived experience, peers and families. Voices from the Global Mental Health Peer Network further strengthen this call through their experience sharing. Following that, a study relating to psychosis and recovery in Malawi is presented, highlighting the collaborative perspective in research and practice. The Illness Management and Recovery (IMR) evidence-based practice is then discussed focusing on the partnership that is built throughout the program. Collaborative action is in line with a rights-based approach that you can find reflected in the experience shared from India where involving caregivers was prioritized as well. Further perspectives for the importance of involving family and service providers with service users are documented in a South African context closing on the Article section of this issue. The section that follows is an equally important one and quite relevant to the theme of this bulletin. Human Rights and Mental Health are well tied together and a it's well reflected in the first article relating to mental health, human rights and legislation. This section further devel-

ops through the experience of implementing WHO QualityRights intervention in Lebanon which present a rights-based practice that can further inspire others in supporting and promoting the rights of mental health service users within healthcare. The section for recent research develops on service user involvement with Esther presenting recent articles on the issue. The experience that are then shared introduce important knowledge-based dimensions on our theme. Christine Lingjærde starts with sharing her voice from the Mental Health Carers Association in Norway. Then, the importance of taking care of parents' mental health is emphasized in the experience shared by Clare O' Brien. Peter Salamon then presents how a group of Czech mental health service users were inspired through visiting Bergen in Norway and getting to know the activities there. Peter Yaro and HAnnan Legend Tizaa, in a different context presents activities from BasicNeeds Ghana promoting psychosocial rehabiltiation for survivors of turture and organized violence.

We are grateful in this issue to continue our tradition giving visibility to artists that have a lived experience in mental health. Through Anneliese we were fortunate to reach out to several artists that grace us with their artwork and photography. Lenny Mulcahy has taken a self-portrait relating to resilience that you can find on the cover. Derek Fulker, who is a Senior Training Associate and runs numerous classes at the Recovery Education Center at Boston University's Center for Psychiatric Rehabilitation has shared with us artwork that you can find relating to places that you might not find on any map, but in his words "They are a personal response to our and other worlds" that are "always felt". Lisa Murphy has given us the painting on Pride and Michael Johnston has further depicted connection and being together in the art introducing the sharing of experiences. The abovementioned artists are affiliated in different ways with the Center for Psychiatric Rehabiltiation at Boston University and we will continue to publish their work in issues to follow.

We hope you enjoy reading this issue!

Michalis and Marit

President's Message. *Gabriele Rocca, President of WAPR*

Gabriele Rocca
President of WAPR

I am very pleased to start this message by telling you all that the new WAPR website is up and running. This is our indispensable means of giving and receiving information, consulting documents, our aim and missions and confirming our history and identity. It is up to us all to make the most of it! On the homepage, you will find the announcement for the XV WAPR World Congress, which will be held in Vancouver from 29. September to 1. October 2025. Marianne Farkas (President Elect), Errico Landi (Treasurer), V.K. Radhakrishnan (Secretary) and myself as members of the Executive Committee have already been in preparatory contact with Vicky Huehn and Susan Boyce of the local organising committee. They are currently working on defining the type of conference it will be and developing strategies for involving the organisations and other subjects that will ensure a successful event. We will go on in this way and are confident that the final result will be highly positive.

Starting from next year we will be organising webinars as a further means of sharing experiences of psychosocial rehabilitation practices in various parts of the world. The webinars will involve people with lived experience of mental health problems, family members and professionals. Human rights will be a key issue. The webinars will not only provide valuable evidence of our commitment in areas with different mental health systems, but will also allow us to exchange knowledge and ideas that can promote new practice-models and different ways of approaching the relationships between individuals and institutions. Our Regional Vice Presidents will play an important role in these initiatives by making visible the way in which the general issues of PSR are addressed in different parts of the world. This will ensure that local cultures can influence and enrich the pluralism of the WAPR in such a way as to reflect different visions of psychosocial rehabilitation. It will contribute to regional congresses next year aimed at highlighting the significance of our scientific and culturally rich organisation.

ARTICLE SECTION

(c) Derek Fulker, Cityscape
"My landscapes are not usually of any particular place and will not be found on any map. They are a personal response to our and other worlds. Somewhat abstracted, sometimes surreal and always felt."

ARTICLES

Strengthening the call to involve mental health care service users and their families in psychosocial rehabilitation programmes.

Claudia Sartor[1]

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Introduction

This paper explores the benefits and value of involving mental health care service users in psychosocial rehabilitation but also encourages greater discussion on the reasons and the way in which to successfully do so via a holistic model of care and service delivery in global mental health. The approach can take the form of multidisciplinary teams, including psychiatrists, psychologists, and non-mental health professionals such people with lived experience, peers, and families. Existing global acknowledgement of this type of intervention aims to inspire healthcare services to be more focused on a holistic, person-centred approach to recovery, empowerment, and overall well-being. "The demand for greater partnership with users reflects a shift from decisions based on professional values to user values" (Petersen, Hounsgaard, & Nielsen, 2008). Mental health as a field is a broad and complex rhetoric and it is worthwhile exploring the term, mental health, to facilitate the discussion on psychosocial rehabilitation. According to the World Health Organisation (WHO), mental health is not the absence of an illness (WHO, n.d.). Having mental health does not mean or identify it as being a negative concept. In fact it reflects a healthy state of well-being. As stated in the WHO report on transforming mental health for all (WHO, 2022), mental health is a fundamental part of our general health and overall well-being and having good mental health means that individuals are better able to connect, function and optimally thrive.

In Weiten and Hassim (2016) the authors describe, for individuals to be optimally functioning in the settings of life, work, and within relationships, the different domains of wellness, key components of positive psychology, must be carefully worked on by every individual to ensure harmony and successful integration in community. The biological domain of wellness reflects an individual's physical well-being, genetics, and physiology while the psychological domain includes our memories, belief systems, perceptions, self-esteem, emotions, thoughts, coping skills, and strategies. The social domain of wellness refers to an individual's relationships, both social and personal, and further encompasses the individual's environment and their family context. Importantly, these dimensions do not exist in silos, affecting, either positively or negatively, the general state of well-being and mental health of individuals. (Weiten, & Hassim, 2016)

Psychosocial Rehabilitation

Psychosocial rehabilitation is an intervention tool based on principles that are used to support the individual to recover and regain their independence, and improve their quality of life (Cnaan, et al., 1988). This approach is not solely clinical or focused on symptom reduction, but encourages empowerment and support towards recovery.

Psychosocial rehabilitation programmes are characteristically provided by a multidisciplinary team of mental health professionals, including psychiatrists, psychologists, social workers, occupational therapists, peers, and people with lived experience of a mental health condition facilitating the individual's move towards optimal functioning. A key principle of psychosocial rehabilitation is that everyone's role and responsibilities ought to be made clear from the inception of care to ensure proper care is provided to individuals. The nature of psychosocial rehabilitation programmes promotes individuals' reintegration into

society and this can be delivered in various settings (Cnaan, et al., 1988). Settings include, but are not limited to, community mental health centres, residential facilities, vocational rehabilitation centres, schools, universities, and even correctional facilities.

Key components of comprehensive psychosocial rehabilitation

While the nature and objectives of psychosocial rehabilitation are agreed upon, it is necessary to also briefly mention the components that psychosocial rehabilitation programmes comprise of.

Capacity building and training are essential in psychosocial rehabilitation programmes because they involve teaching individuals how to identify and use specific skills that can help them manage their mental health symptoms and conditions and function more effectively in their daily lives. This can include social skills training, problem-solving skills, and coping strategies.

Relatedly, individuals learn how to **manage their medication**; when to take medication, why they taking it and how to take it, which may be crucial to their plan towards wellbeing. Managing medication cannot take place without capacity building and training.

Supportive counselling is crucial to psychosocial rehabilitation as it helps individuals learn to identify and manage their emotions and learn available coping strategies in a safe space, free of judgment and stigma.

These strategies can be applied at any given time outside the counselling space.

Peer support is an invaluable resource in any mental health setting. Having someone who can understand and recognise challenges is a powerful tool. Peers would have had similar experiences or would have been in similar situations as the service user and has the insight to provide hope and inspiration to the service user in an honest and compassionate manner. Importantly, there is no hierarchy in peer-to-peer relationships. Strategies for peer support-based service delivery is encouraged in psychosocial rehabilitation, because having the support of a peer who has been exposed to similar experiences allows for meaningful conversation in a safe environment (Sunkel, & Sartor, 2022).

The inclusion of **family support** in psychosocial rehabilitation, provides family members and caregivers the opportunity to play a significant role in the individual's recovery journey. However, they can only do so effectively with the guidance and education by the care team. Teaching family members and caregivers about mental health conditions, its symptoms, what to look out for and how to respond to and support the individual is crucial in their ability to support their loved ones along their recovery journey.

Another key component of psychosocial rehabilitation is **reintegration into the community** as it facilitates the process of individuals obtaining the necessary skills and tools to become independent and self-sufficient in the community. Psychosocial rehabilitation should involve **planning** that is led by the individual, whose choices about their reintegration are respected in the process.

The journey to **recovery** is not linear, nor is it a one size fits all approach and therefore should always involve the development of a cohesive and personalised plan. Goals that align with the individuals needs and aspirations must be set and there should be clear steps in place to achieve their respective goals. Family member and service user support can be a great path to enhancing this process of recovery and to help identify challenges and opportunities for recovery. Individuals must agree with the personalised plan, otherwise it may be a fruitless pursuit.

Critical reflections

It is established and globally recognised that involving mental health care service users in the design, delivery, and evaluation of mental health services is a crucial aspect of promoting patient-centred care and improving the overall quality of care and services. However, it is important to recognise that there remains global concern, which is related to power dynamics, inauthentic participation, tokenistic relationships and care, stigma, and bio-medical preference in care. It is necessary to move away from tokenistic approaches and approaches contributing to power imbalances and move towards creating approaches that ensures diversity among participants (Sunkel, & Sartor, 2022).

The medical field remains the primary rhetoric of health and it is relied upon greatly for recovery, at times ignoring other types of interventions that exist that are holistic and concerned with social as well as cultural aspects of health. This results in perspectives where society visualises "recovery as an add-on to conventional services, rather than a that all of us can find a way to participate in" (Ragins, & Sunkel, 2023, p. 2) .

The paper calls for this narrative to change, for mindsets to transition into a more recovery-oriented focus, focusing on individuals needs and goals in addition to medication. There is no doubt that medication may be necessary, however, people with lived experience and specific service users' involvement in psychosocial rehabilitation programmes would be the preferred method for improving the current state of mental health services.

There has been great emphasis placed on efforts made through mental health advocacy-led organisations and leaders, to improve mental health matters in the global mental health space. While these contributions do not go unnoticed, many countries, not only those in the lower-income regions of the world, continue to have limited or even no access to mental health care and treatment. The reasons for this limited or lack of access to mental health care and treatment may vary from restricted usage to only bio-medical treatment and perhaps the lack of awareness and access to psychosocial rehabilitation programmes. This may further be a result of understaffing or a lack of financial support to sustain such programmes. While the goal may be to move towards a more community-based approach to care, these challenges continue to exist.

Why psychosocial rehabilitation programmes work

Psychosocial rehabilitation programmes are a model of empowerment that benefits service users, creating safe spaces that allow for meaningful interactions and shared activities in the programme, promoting space for outcomes of gaining improved functioning including social functioning and improved quality of life. These programmes further create an inclusive and welcoming environment that values the perspectives of clients or patients, people with lived experience and their families. Alongside professionals and family members, people with lived experience bring unique and diversified experiential value to the psychosocial rehabilitation programmes.

Voice of Lived Experience

In this next section, country mental health advocacy leaders from the Global Mental Health Peer Network share their perspectives on psychosocial rehabilitation, based on personal experiences of involvement in such programmes. All statements in this article appear with the permission of those named.

Elizabeth Berk (South Africa)

When I was in a clinic myself and I was struggling with an eating disorder and substances I found being able to share my journey with a counsellor or support counsellor that had been where I had been refreshing. It allowed me to feel hopeful and realise as to why I was there. In the last couple of years in South Africa it has become evident that the system however has been abused in many ways. In some cases, not all, the counsellors are underpaid and treated as if the clinics are doing them a favour by employing them because they are in recovery and have the stigma of being a "drug addict or recovery person' attached to them. They might be a lay counsellor with 12 (twelve) years sober, yet are still identified and labelled as the addict. While rehabilitation centres often say that the lack of contact is more for the family than the individual in treatment as the family needs space, this is not communicated to the individual on admission. There is a lack of individualised treatment and there is very much a one size fits all and if you do not fit you are labelled as high risk for relapse.

Group counselling sessions can be a great benefit for rehabilitation centres if it is used as a peer support network instead of powerlessness and damage sessions. Group sessions need to be based on sharing

experiences that can build one another up, allow for flourishing and build resilience instead of a space where individuals are broken down.

Zivile Valuckiene (Lithuania)

What works in these programmes: support groups; education; psychotherapy; and active inclusion into activities, and society. What currently does not work in these programmes: institutionalization; medical treatment; and labelling (diagnoses).

Anto-Agus Sugianto (Indonesia)

The application of a human rights approach is equally critical. A programme rooted in respect for the fundamental rights of individuals ensures their dignity is upheld throughout the rehabilitation process. Human rights principles promote non-discrimination, equality, and the right to self-determination. A lack of understanding and appropriate policies from governments can lead to a breakdown in this essential dimension, jeopardizing the quality of psychosocial rehabilitation.

Laura Van Tosh (United States of America)

I am a member of a psychiatric rehabilitation programme called Seattle Clubhouse. Originally, I started my involvement in the 1980's at Fellowship House, a clubhouse programme in Miami, Florida (US). Both clubhouses are modelled after Fountain House, based in New York city. Clubhouse provided me with psychiatric rehabilitation and housing services. I also had social interaction which helped me to navigate support services. Lived experience opportunities were few and far between then, yet current clubhouse opportunities have developed over the years.

Keshnie Mathi (South Africa)

I believe that there must be a focus on full family wellness within the recovery journey. Currently it is done as an afterthought or a suggested intervention but recovery takes a community and often someone in recovery that returns to an unchanged environment does not cope well. Restrictions such as not having a cell phone and isolation from families also needs to be better explained. Even in expensive facilities, those in recovery are treated like prisoners with an emphasis on breaking down rather than digging into the why. Whilst this is needed, peer support is recommended to ensure that this is done ethically.

Recommendation

To address the critical issues discussed earlier, this paper calls for the herein listed recommendations to be considered to achieve inclusion of mental health service user involvement and family in psychosocial rehabilitation that is truly reflecting commitment and adaptability to the changes that need to be made. For this to be achieved there must be acknowledgement and changes made as far as increasing financial aid support for programmes and their continuity, increased human resources within the workforce space, and continued evaluation by beneficiaries of these interventions to monitor impact and outcomes.

Conclusion

In summary, the involvement of mental health service users is a significant step toward patient-centred care. However, to make service user and family involvement effective and efficient, it must be meaningful, authentic, empowering and transformative with a genuine commitment to challenging the status quo of mental health services. Therefore, a strong call for action is necessary to remove the existing power imbalances and tokenistic approaches and to cater for safe spaces. A call is made for the involvement of people with lived experience of mental health conditions as well as families and carers in the development, implementa-

tion, and facilitation of psychosocial rehabilitation programmes. Mental health advocacy efforts should take place not only at community level but at policy drafting and implementation levels too. These efforts, when supported by relevant stakeholders, promotes hope and complementary decision-making for individuals dealing with mental health conditions in advocating for systemic change.

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A long-lasting and recovery-oriented experience of Psychodynamic Multi-Family Groups in community mental health services in Rome.

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Family involvement in mental health care

Involvement of families is a key aspect of mental health care either in a structured way (psychoeducation, systemic approaches) or in an informal way, when families are updated by practitioners and free to express their needs and make suggestions on a routine basis. Many mental health service users live or are in regular contact with their relatives, who are often in the role of being the main caregivers with the related material and emotional burden (Awad, & Voruganti, 2008). We also know that the characteristics of the family atmosphere and communication patterns are associated with clinical course and outcome of the disorder of the family member with lived experience of the mental health condition (Leff, & Vaughan, 1985). Therefore, families need to better understand both the problem situation and how they can help their family member as well as how to help themselves and sustain their wellbeing.

Family interventions may have different approaches and adopt different techniques, but they share several characteristics and aims; offering information about the disorder and its potential consequences, supporting treatment adherence, assuming a non-pathologizing stance, strengthening communication, avoiding blaming, favoring empathy and mutual respect, sustaining personal growth and self-determination for all family members (Harvey, & O'Hanlon, 2013). The effectiveness of family interventions has a good evidence base, and they are recommended in clinical guidelines for the treatment of psychotic disorders (Dixon et al., 2010; National Collaborating Centre for Mental Health, 2009) as well as in other fields.

The Multi-family Group Model in mental health services in Rome

Some models include more than one family in the same treatment session (Asen, & Scholz, 2010; McFarlane, 2002). One of the potential strengths of such models can be seen in the mutual feedback among families, which has been shown to be more effective in enhancing support, motivation and encouragement than the actions of a therapist (McKay et al., 1995). The Psychodynamic Multi-Family Group Model is an example of such a model. This model was originally established by Jorge Garcia Badaracco. He observed that the discussion occurring in groups, including families and service users, and coordinated by a therapist was a natural and useful format to promote changes. The group provides a setting where it is possible for group members to become aware of what happens in their own family as a result of observing what happens in the other families, which may be different yet similar. This promotes a process of modifications to the atmosphere in the family, which is thus prompted to take responsibility to actively look for solutions to the experienced problems, thereby avoiding self-blaming (Badaracco, 1992).

In applying this model, it also allows the reframing of the therapeutic alliance in two ways: on the one hand, by reducing the influence of the biological paradigm of mental disorders and focusing on the social arena, where patients and families live their lives. On the other hand, it overcomes the blaming attitude toward the dysfunctional aspects in the families, which contributes to "a loss of trust in services and strained relationships between professionals and families" (Eassom et al., 2014).

This model has been applied in District 1 of the Department of Mental Health of the Health Trust Roma 1 since 1997 and gradually expanded to the other five Districts since then. Since 2011 multi-family groups are held weekly in all twelve community mental health services (CMHCs) of the Department of

Mental Health in Rome that serves a population of 1,041,220 people. Thanks to the regular registration of participation in Districts 1, 2 and 3 between 2015 and 2019, it was possible to have a wider picture of how the multi-family groups worked.

The psychodynamic multi-family groups are based on an open and free dialogue among participants, and employ three simple rules: 1) Participants speak one at a time about an issue chosen by him/herself and the others listen to them without interrupting; 2) All participants are asked to let go of the notion that they have the only correct opinion, and to be ready to listen to and respect others point of view; and 3) Participants must raise their hand and speak according to the order in which they requested to speak.

Two to three facilitators coordinate and facilitate the meeting, manage the requests by participants to speak and help to maintain a climate of openness. Facilitators do not make any diagnostic evaluations, suggest psychological interpretations, or address issues of possible etiopathogenesis of psychiatric disorders. Sessions are held weekly and last 90 minutes.

All service users are informed about the multi-family groups and are free to join if they want to, without needing referral from the treatment team. In any event, the treatment team may suggest joining the multi-family groups in complex cases or situations, like after discharge from an acute ward or residential facility, in cases with a history of repeated hospital admissions, or when a setback in the therapy occurs. The suggestion to join a group would depend more on these circumstances than on the specific mental health problems a person may have. Participation is completely free and participants can stop attending at any time. It is advisable that at least one member of the treatment team accompanies the participants to the first two to three multi-family group sessions. Approximately four to six members of the respective mental health services take part in the meetings.

Participation of service users, families and professionals in multi-family groups

Between July 2015 and November 2019, a total of 1,044 meetings were held in the six CMHCs, with the average number of participants per group ranging between 13 and 31 according to the CMHC. The total number of family units who participated in the multi-family group sessions was 439, corresponding to a total number of 794 persons. Family units were represented only by the patient in 180 cases (41%), >1 relative or other close person in 76 cases (17%), and >1 relative or other close person and patient in 183 cases (42%). Mean age of participating service users was 42.8, of which 43.6% were female. The most prevalent diagnosis of the service user participants was schizophrenia (169 patients, 38.5%), followed by personality disorders (94, 21.4%) and bipolar and depressive disorders (90, 20.5%). Mean duration of participation was 68.3 weeks, and the average rate of being present in the group during the period of participation was 56.5%. Very active participation was shown by 170 participants (26.7%), while 90 (21.1%) participants showed very low participation. Brothers or sisters showed the highest degree of active participation, followed by mothers, patients and fathers.

Service users who participated alone tended to be older than those from families participating with or without the service users themselves, particularly in comparison to family units where service users were present. Family units, including at least one family member and the service user, were more represented when the service user had a diagnosis of schizophrenia, and, to a lesser extent, in the case of a personality disorder. The former families also showed the longest duration of participation. As expected, the frequency of attendance tended to be higher when the duration was shorter, with very few people being able to maintain a very high frequency when their attendance lasted more than 40 weeks. However, about forty percent of families with the longest duration attended between 55% and 88% of the meetings.

Lessons learnt and suggestions for implementation

These results show a good rate of attendance persisting across the years of observation, with new entries and a portion of long-term participants. Most service user participants had experience of severe and persisting mental health disorders. We list several factors that can be useful in promoting and sustaining the implementation of such services and their frequency by users, families and professionals.

• Service users participating alone were as many as family units that included a service user. The high number of service users who attended alone suggests that such participation represented a free personal choice and corresponded to a self-perceived need.

• Family units consisting of family members or close persons without the service user were far fewer and showed shorter duration and less active participation during the meeting, confirming that the groups may work better when the service user is present.

• The high number of participants across the years may represent the need for permanent or long-lasting support, not necessarily mediated through negotiation with or referral by a team.

• The multi-family groups represent the only setting where service users can meet with other people and professionals in a free, yet still structured, way and where there are no strictly therapeutic objectives.

• The multi-family groups are permanently available. It has been suggested that, at least in the most complex cases, continuity of such treatment should be assured through ongoing support, even if informal (Lefley, 2001), or through an open-ended multi-family group structure for families in need (McFarlane et al. 2002).

• The combination of flexibility and continuity in the delivery of the services can help develop truly community-focused recovery-oriented interventions, dealing with the "real world" of patients and their families (Drapalski et al., 2008). With this perspective, a possible shift can be envisaged in involving families, moving from so-called behavioral family management, where the emphasis is on negative outcomes rather than building on strengths, to a consumer-driven support approach, where attention is paid to increasing communication and cooperation between mental health professionals and families (Glynn et al., 2006). The facilitators do not play the role of experts who educate and answer to questions. Rather they behave as real facilitators of an exchange of views involving as many people as possible and where everybody's standpoint about issues emerging in the discussion are taken into consideration.

• The implementation of family interventions in the treatment of persons experiencing severe mental disorders is still extremely limited, despite being considered major and effective components of care,. This might be due to severe workload, pressure on specialized services, organizational pitfalls, limited staff training and skills, as well as pessimistic views about recovery for people with severe mental illness (Prytys et al., 2011). Nonetheless, it is feasible, and it can be facilitated by a bottom-up and top-down approach where clear indications of the direction is coupled with interest by professionals, together promoting a real cultural shift.

• Lastly, yet importantly, listening and paying attention to different ideas coming directly from persons involved, like service users and family members in an unfiltered way, allow facilitators and professionals to learn about how services could best respond to people's needs as directly perceived and expressed by them.

All these reasons, together with the success that multi-family groups have shown as well as their feasibility in the long-term, suggest that it is advisable to make multi-family groups available to larger numbers of service users and families in as many services as possible.

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PROMISE in Action: Fostering Inclusive Research through Lived Experience Engagement in Malawi

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Introduction

Acknowledging lived experience viewpoints as valuable inputs into mental health research and initiatives is gaining considerable traction (World Health Organisation Global Coordination Mechanism Secretariat for NCDs, 2023). The Psychosis Recovery Orientation in Malawi by Improving Services and Engagement (PROMISE) study is committed to ensuring the meaningful inclusion of persons with lived experience (PWLE) to collaborate in the research work of psychosis identification and management systems. This necessitates recalibrating traditional research techniques to establish genuine collaborative partnerships, prevent tokenism and navigate power differentials (Sangill et al., 2019). Involving PWLE in research ensures distinctive findings compared to conventional research and has tangible implications for practice (Rose, 2014; Faulkner, 2004). Researchers with lived experience contribute their expertise and experience to projects, fostering a deeper understanding and raising pertinent questions. Their endeavours are driven by a desire to improve the lives of fellow PWLE. Under-involvement of PWLE and their families in the Global South is one of the most pressing concerns in research on psychosocial disability (Semrau et al., 2016; Ryan et al., 2019). Healthcare reform in high-income countries has benefited from lived experience-led research and co-production, in which PWLE and those with professional expertise collaborate as equal partners and co-creators. Examples of collaboration between researchers and PWLE include cancer research with patient advisory committees (PACs) (Lindberg et al., 2022). The evidence supporting "what works" to increase involvement in the Global South is limited. More Global South evidence and experience must be created to enable disempowered groups to have real input into research if the notion of nothing about us without us is to be given more than simply lip service (Faulkner, 2004; Abayneh et al., 2022).

In Malawi, people with psychosis often experience stigma and discrimination, have long delays in accessing appropriate care, and may not receive high-quality care in health facilities. Consultation with traditional or religious healers for mental health concerns is commonplace, owing to the alignment of these approaches to causal attributions held by community members, as well as limited awareness of biomedical explanations of psychosis and the ease of access compared to centralised and distant mental health services (Kokota et al., 2023). The PROMISE study is a collaboration between researchers in Malawi, UK and Australia that endeavours to build upon existing community and health service structures to establish and evaluate a sustainable system for the community-based identification, referral, and management of psychosis to promote recovery. In developing the intervention, PROMISE seeks to comprehend the perspectives on psychosis among persons with lived experience, caregivers, and key health stakeholders in Malawi, and the influence of these perspectives on help-seeking behaviours. PROMISE is initially implementing the project in two districts in Malawi: Chiradzulu in the Southern Region and Salima in the Central Region (Lawrie, in press).

PROMISE aspires to ensure the meaningful inclusion of PWLE at all stages of the study. The project protocol (Lawrie et al., in press) emphasises the need to have the lived experience expertise contribute to its success; "…co-produce psychosis identification and management systems" (Lawrie et al., in press, Methods

section), "…People with lived experience (PWLE) and caregivers will be closely involved throughout to steer the development of tools and interventions…" (Lawrie et al., in press, Abstract section), " …This sustained and analytic attention to lived experience will ensure that these initiatives are acceptable to and shaped by the communities concerned, and will interface with broader health, social and family support system…" (Lawrie et al., in press, Introduction section), and "…to explore and seek to understand how PWLE can be supported to contribute to the research: both as participants and through ongoing engagement with the research team as stakeholders in the intervention and shapers of this" (Lawrie et al., in press, Methods section). This article discusses how these ambitious goals are being approached in practice.

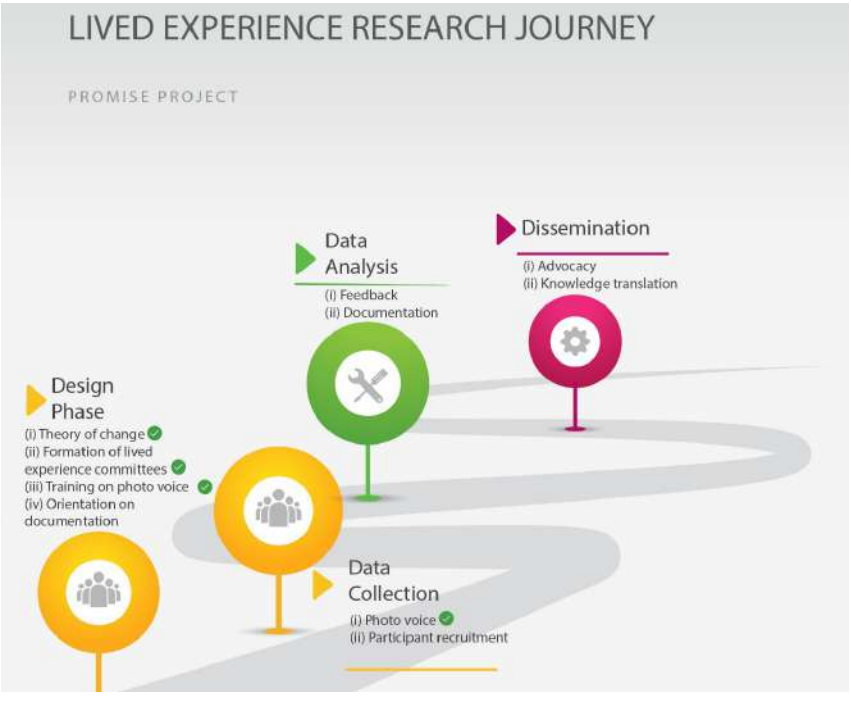
Methods and Results

The PROMISE project has adopted a multifaceted approach to engage persons with lived experience in research activities. A systematic approach to engaging PWLE was adopted from other mental health projects that have demonstrated best practices of lived experience involvement, namely: Support, Comprehensive Care and Empowerment of People with Psychosocial Disabilities in Sub-Saharan Africa (SUCCEED-Africa) (London School of Hygiene & Tropical Medicine, n.d.) and the Study of Context of Psychoses to improve outcomes in Ethiopia (SCOPE) (Hanlon et al., 2023). Key aspects of these projects include that they are both Africa-based and focused on people with psychosis. They are also pioneering engagement and involvement of PWLE (Abayneh et al., 2022)

The initial stages involve efforts to gain a comprehensive understanding of the lived experiences of individuals grappling with challenges related to the experience of psychosis in Malawi. Activities completed or underway include research team training; participatory research using Photovoice; Theory of Change development; and establishing Lived Experience Advisory Structures. The PROMISE project will also build capacity through PhD projects (such as that being undertaken by the first author) that focus on developing skills, knowledge, and resources that will enhance those with lived experience to support the research journey of the project. In other words, a meaningful approach to engaging PWLE will be employed in the project to ensure that people can openly express their views on the issues being discussed without fear and actively participate in project activities and decision-making. The involvement of PWLE to which the project aspires is depicted in Fig.1.

Figure 1

The PROMISE study lived experience research journey.



Research Team Training

Through community engagement training conducted in February 2022, the research team were equipped with the basic requisite skills and knowledge to effectively facilitate engagement with PWLE, including co-designing a Theory of Change (TOC). 16 research team members (5 Kamuzu University of Health Sciences, 7 University of Edinburgh, 1 Kings College London, 1 UK National Health Service (NHS), 1 University of Newcastle, 1 St John of God) took part. Key areas covered included defining participation, involvement, and engagement, along with a review of barriers to inclusion, different levels of participation, and guiding participation principles. In discussions, key barriers to inclusion identified included, similarly to those highlighted in the 2022 Advancing multisectoral and life-course approaches in mental health research workshop cofacilitated by the first author and initiated jointly by the Academy of Science of South Africa and the UK Academy of Medical Sciences (ASSAf & Academy of Medical Sciences, 2023), namely the need for more capacity of those with lived experience, financial resources to engage and train, the invisibility of those with lived experience, and limited research literacy. Specific strategies to mitigate the recognised barriers to engagement were identified, which were subsequently adopted as strategies for the project. These included lived experience capacity building, participation in decision-making processes, advocacy efforts, research activities, and leadership roles in various project components. In addition, it was agreed that there should be sustained efforts to involve mental health user advocacy groups, including Malawi's Mental Health Users and Carers Association (MEHUCA).

Participatory research using Photovoice

Through the participatory approach Photovoice (Wang & Burris, 1997), the project has fostered dialogue with PWLE and their caregiver's personal experiences through use of photographs. This approach provides a platform for meaningful engagement where PWLE and caregivers use mobile phones to take photos that draw attention to, and generate insights into, the challenges they face living with psychosis (or caring for a family member with this condition) and identify their needs and wants from their perspectives.
The project engaged six PWLE and caregivers in the Photovoice activity (detailed below). Moreover, the exercise highlighted several key recurring themes from the discussions in the two project districts. These included the significance of holistic support, both in terms of personal relationships and professional assistance, the importance of access to medication and healthcare facilities, the fight against stigma and discrimination, and the need for self-reliance among persons with psychosis and their caregivers. These themes shed light on the diversity of support and aid needed for persons with mental health challenges and the barrier they encounter on their path towards recovery and overall well-being. The outputs of the Photovoice activity form the basis of a short film created by the project that portrays the first-hand experiences of individuals with lived experience.

Theory of Change development

The project identified and involved six persons with lived experience from the two project districts to participate in the development of the project Theory of Change (TOC). Participation in the activity provided those with lived experience a platform to voice their perspectives and influence the development of the study path so that it can better cater to their needs and aspirations. Two key outcomes that can be attributed to the participation of PWLE in the TOC development are:

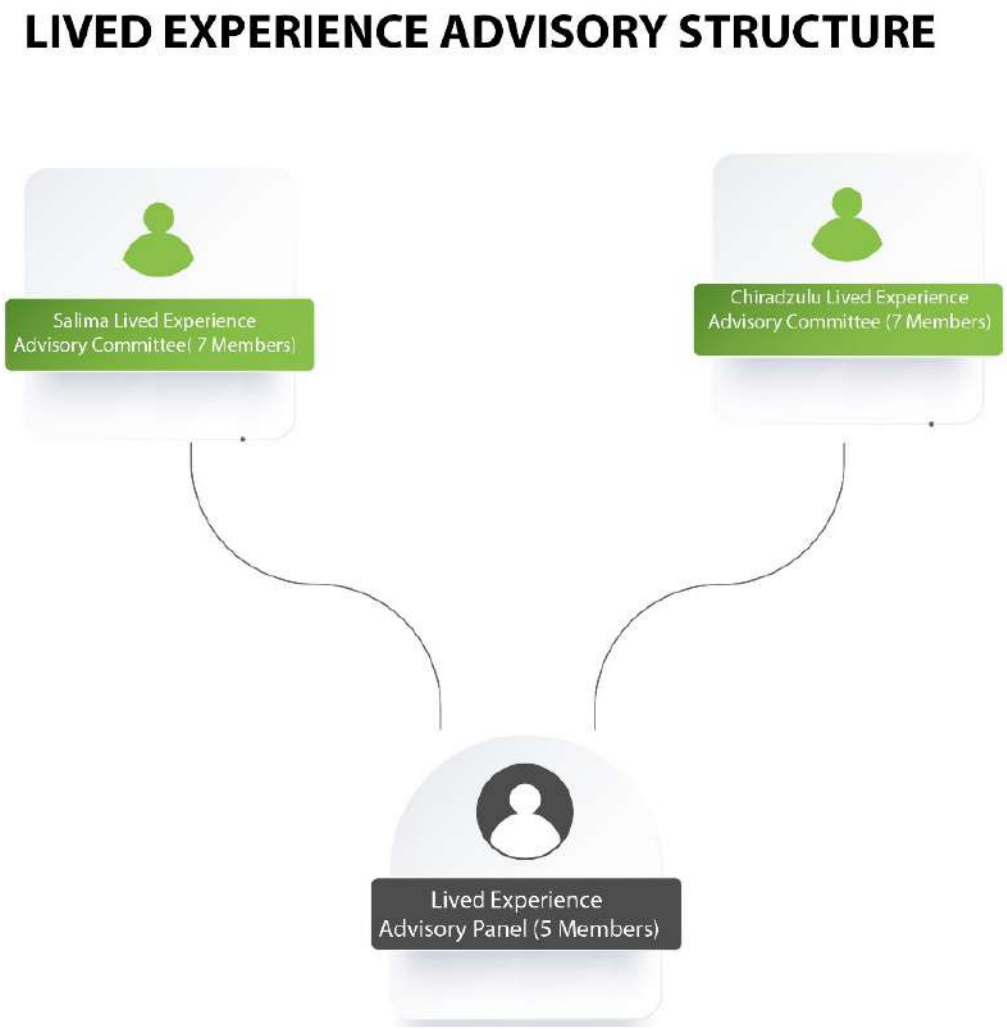
a) Empowerment: involvement in the process of conceptualizing the TOC empowered individuals by giving them a sense of agency and ownership over their experiences.

c) Increased self-awareness: reflecting on personal experiences and contributing to the development of the TOC facilitated greater self-awareness.

Lived Experience Advisory Structures

PROMISE will have a two-tier level of advisory arrangement in which those with lived experience will be engaged. At district level, two district Lived Experience Advisory Committees (LEACs) will be formed (with seven members per district). At national level, five members (selected from the two LEACs) will form the Lived Experience Advisory Panel (LEAP) (See Fig 2).

Figure 2
PROMISE Lived Experience Advisory Structure



The LEACs and LEAP aim to improve the representation and active involvement of PWLE in the research project at all levels of PROMISE work. The PROMISE lived experience advisory structure will adhere to the principles of partnership, learning, empowerment, transparency, responsiveness, and respect. In the PROMISE project, empowerment concerns PWLE gaining more control over the things that affect their lives. Through empowerment, people can express their needs, voice their concerns, and become involved in decision-making that will impact them. The objectives of the LEAP and LEAC advisory structures are to:

- Identify common challenges and issues relating to the engagement of PWLE in the PROMISE Project.
- Guide the PROMISE Project to improve the active engagement of PWLE in its work.
- Promote best practices and key considerations for improving the experience of PWLE involved in the PROMISE Project.
- Provide advice on ongoing PROMISE research activities, including nested PhD projects.
- Support advocacy work through various platforms and engaging in discussions with policymakers and stakeholders.

To establish PWLE advisory bodies, the project team identified potential members, ensuring diverse representation across various community segments. Identification processes were conducted in collaboration with MEHUCA in Salima and the District Mental Health Team in Chiradzulu. Requisites for inclusion were that participants fully understand the purpose, procedures, and potential risks and benefits of the research. An assessment employing a simple screening method was conducted to ascertain participants' capacity to comprehend and actively contribute to the research process. Fourteen individuals from the project sites in Salima and Chiradzulu were selected to form the LEACs, with representatives from these forming the LEAP.

Further planned activities

The project will hold orientation sessions on research for PWLE and implement use of adapted methods of documentation by the LEAP members. This is an approach intended to enhance those with lived experience to document their involvement experience in the PROMISE Project. The trained LEAC and LEAP members will assume their PROMISE advisory roles that include interacting with research participants, research assistants and research team leads at district and national level. Advisory team members will be key identifiers of other PWLE, carers, and traditional and faith healers to be part of other components of the project. They will also act as co-facilitators in the training of health surveillance assistants, traditional and faith healers, village health committees and traditional leaders about mental health. They will support PROMISE advocacy activities and later disseminate the project results locally or through other intended dissemination platforms.

Conclusion

The PROMISE Project's commitment to meaningful lived experience engagement is a testament to the advocacy of PWLE and their organisations for the transformative potential of integrating diverse perspectives into mental health research. The project has prioritised the voices and experiences of PWLE in the design of the intervention, and has established the advisory structures that support a comprehensive and inclusive approach. The planned orientation sessions in research data documentation by lived experience advisory team members are anticipated to enrich the research process further.

By actively involving PWLE in the research process, the project is seeking to foster a collaborative environment that values inclusivity, diversity, and empathy. The shared experiences and insights by the members will inform the development of tailored interventions that address the unique needs and challenges faced by individuals living with mental health conditions in Malawi. Alongside other projects such as SUCCEED and SCOPE, it is hoped that PROMISE will provide further impetus for future initiatives promoting lived experience-centric approaches to mental healthcare.

Acknowledgment

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Illness Management & Recovery, an Evidence-based Practice for Person-Centered Mental Health Services.

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The need of person-orientation in services

The practice described in this article assumes a person-centered vision of mental health services, that adapts to people's aspirations and needs, rather than people having to adapt to the requirements and priorities of services. Person-oriented approaches are holistic and built on individual strengths. The principles underpinning person-centered mental health services are that people with severe mental illnesses are people like others, wanting to live in a decent home, have a decent job, friends, partners, and attend school. They have feelings and opinions, not just compulsions or delusions, answer questions and give an opinion on questions asked of them. Rather than being oppositional or resistant, they are not motivated to change but they can have meaningful personal goals.

Person-centered services consist of programs that are initially conducted in institutional settings and progressively move into social environments. Performance of valid and useful tasks and roles results in learning and practicing skills while the person is being brought closer to the context (resocialization). Finally, the culture of person-centered services not only emphasizes the formal titles of staff, but highlights the importance of their personal qualities, their capacity to instill hope, to take care of the person, to be realistic, to believe in resilience, and to connect with people. It also underlines the importance of social exclusion as a contributing factor to the emergence and persistence of mental health problems.

All of this implies a relationship between professionals and the person that is radically different from the traditional one, which is characterized by power and dependence. A shift from staff who are experienced as distant, because they are considered experts who have authority, to staff who behave more like personal coaches or trainers. Such coach or trainer type staff help the person to set personal goals, equip themselves with skills, build social networks and supports and help them access the resources needed for their life, while at the same time the coach or trainer learns from the person (Robert & Wolfson, 2004).

Illness Management and Recovery (IMR)

Illness Management and Recovery (IMR) is an evidence-based psychosocial practice, of which the primary objective is to provide service users with the knowledge and skills necessary to cope with aspects of their mental health problems while maintaining and achieving goals in their recovery. Personal meaning, choice, and everyday life troubles are key issues.

The principles by which IMR is inspired are the following:

- Recovery is defined by the person.
- The Stress-Vulnerability model provides a framework for illness management.
- Collaboration with caregivers and significant others helps service users to achieve their goals.
- Planning relapse prevention reduces their frequency and intensity as well as in-patient needs.
- Service users can learn new strategies to manage symptoms, cope with everyday life challenges and improve their quality of life.

IMR is based on research showing that by learning how to manage symptoms people can take important steps toward recovery. IMR helps the persons to learn more about everyday life challenges, reducing relapses, hospitalizations, and distress or discomfort resulting from symptoms, and take medication in a more informed manner.

The main components of IMR are 1) psycho-education, which provides basic information on mental illness and treatment options; 2) behavioral tailoring, which helps service users to manage their daily medication intake by proposing targeted strategies for remembering to take them; 3) relapse prevention, which teaches service users to identify triggers and warning signs of crisis by developing a prevention plan, and 4) coping skills training, which identifies skills for coping with psychiatric symptoms.

The core values of IMR are 1) building hope; 2) recognizing the person with mental health challenges as an expert; 3) emphasizing personal choice; 4) establishing a collaborative relationship, and 5) demonstrating respect. Rather than trying to convince service users that they have a specific disorder, practitioners respect their beliefs, while seeking common ground as a basis for collaboration and agreement on issues such as symptoms, distress, and the difficulty of having an independent life or achieving a desired goal.

The process of treatment follows a specific pathway:

- The participant is referred to an IMR program by the service and begins weekly or bi-weekly sessions (in a group, individually, or both).
- The professional:
  - introduces the program to the participant and assesses the participant, using the IMR Knowledge and Skills Inventory;
  - offers the information contained in the IMR program and helps the participant to put knowledge and skills in practice, using exercises and homework assignments;
  - helps the participant to set and pursue personal recovery goals, using the goal and exercise sheets;
  - helps the participant to build support by involving family members or significant others, and
  - records the participant's progress, using the IMR Progress Note.

If necessary, the professional meets weekly with a supervisor for group or individual consultation.

The key role of the person

The involvement of the person and building partnership is an ongoing process and starts the moment the person is referred to the program. It is, however, difficult to interest the person in a treatment process in a meaningful way if practitioners do not know the needs and goals of the person, as well as those of their family members, and if services are not sufficiently attentive and available to spend time on this. To this aim, IMR practitioners meet the user (or other supporters) to understand their needs and to describe the program.

The involvement process never stops. Every time the practitioner meets the person to learn more about their interests, aspirations, and goals. Keeping the users involved means continuing to help them in a way that is meaningful to them. It may, however, take some time for the person to realize that the program is offering something different from what they have received in the past from mental health services.

It is also very important to explore the person's experiences, knowledge, and skills both in conversations and by using the Strengths and Knowledge Assessment Questionnaire. This focuses on the person's positive characteristics, rather than problems or deficits. It is advisable to build a good relationship with the person, be respectful and interested in their life situation, gather information in a friendly and respectful manner, ask questions calmly so that they don't feel interrogated, and allow time for discussion without declaring that every issue should be resolved. At the end of each session, it is recommended to ask for feedback on which parts of the program were most interesting to reinforce the involvement process.

IMR Program

The IMR Program consists of eleven modules, which are generally carried out in the order indicated: Recovery Strategies, Practical Facts on Mental Illness, Stress-Vulnerability Model and Treatment Strategies, Building a Social Support System, Effective Use of Medications, Drug and Alcohol Use, Relapse Reduction, Coping with Stress, Coping with Persistent Problems and Symptoms, Getting Responses to One's Needs from the Mental Health System, Healthy Lifestyles.

However, for some service users, it may be important to tailor the program to meet their individual needs. For example, when they are distressed by specific symptoms, Module 9 "Coping with Persistent Problems and Symptoms" is suggested. Yet, professionals should always use their own clinical judgment to define the order of topics to be addressed.

The IMR Program also provides the Practitioners Guide and Participant Handouts. The former, available for each module, provides a quick review of the general objective, topic, and recommended structure for each session, as well as pointing out exercises to do, stimulating links between the information contained in the Participant Handouts and personal recovery goals, and suggesting homework assignments that consolidate the knowledge and skills learned.

The Practitioner's Guide also suggests motivational, educational, and cognitive-behavioral strategies, appropriate to the subject area, and directions for conducting sessions in both individual and group formats. Participant Handouts, attached to each module, are distributed to the person, and reviewed with them during the sessions. They contain practical information and examples of skills they can use in the recovery process. They are written in a user-friendly language and include an information text, summary sheets, probing questions, and exercises to learn knowledge and skills, always related to the personal recovery objective.
Regarding the format of the sessions, the IMR program can be offered either in individual or group format or in a combination of the two.

Homework is essential to help service users to practice and to apply what they learn. With sufficient practice, they can integrate the new skills into their behavioral repertoire so that they become automatic and can be implemented naturally. When homework consists of practicing a new skill, it is useful for service users to make a specific plan of how this will happen. They should also be helped to overcome obstacles that might interfere with completing the task, which gives them some options and helps them to avoid distress.
The activity of monitoring assigned tasks involves asking service users to share their experiences of how they tried to complete them, praising them for their efforts, and asking them the following exploratory questions: What were you able to do? What were you not able to do? What could you do differently in the future to perform the tasks? If service users did not complete a homework assignment, identify obstacles they may have encountered, using problem-solving to overcome them.

As already pointed out, setting and pursuing personal goals is an essential part of the recovery process. In IMR, service users define what recovery means to them and identify personal recovery goals. The first IMR module, Recovery Strategies, contains specific information on goal setting. However, throughout the program, the focus on personal goals and their achievement is constant. In each IMR session, there are exercises to help service users define or review their goals and establish steps to pursue them, and in the case of multiple goals, there is a scorecard on which the total number of goals established during the IMR Program and the steps in achieving those goals are recorded. These should be monitored in each session and, if IMR is being offered in a group format, the goals of two or three service users can be discussed during each session. It is important that all group members can review their progress each week.
Another key element of IMR is to reward participants' achievements and, if it is delivered in a group format, applaud them for such successes and consider other rewards such as certificates or gifts. It is very important to keep service users' goals in mind throughout the IMR program and correlate them with any information and skills, discussed in the different sessions, that are useful to achieve them.

Raising the awareness of significant others should also not be neglected, as enhancing natural supports is an objective of the program. Indeed, when family members or significant others are involved, they are more supportive of their relative or friend's journey. Although there is a specific module, module 4 - Building Social Support, it is necessary to return to the topic of building a support network in each IMR session, starting with the orientation sessions, where the benefits of a support network and the different ways to build it should be explored. For example, families could be encouraged to participate in specific IMR sessions, where they could be guided to carry out the following supportive actions:

- Helping service users to review and to master the program information;
- Helping service users to practice the skills they have learned, and.
- Taking a role in the steps necessary for service users to reach their personal goals.
- Assume a role in the Relapse Prevention Plan, Plan for Managing Persistent Symptoms, or Plan for Coping with Stress.

Another possibility is to have a monthly group for service users, family members, and other supporters, where they can discuss how to enhance what their relatives or friends are learning in the IMR program. After each IMR session, the IMR Progress Note form should be completed to document the services and information provided, the type of interventions used (motivational, educational, cognitive-behavioral), the skills being taught (coping skills, relapse prevention skills, and behavioral tailoring skills), and the type of homework.

As in any evidence-based psychosocial practice, particular importance is given to the attitudes of the practitioners. They have to be able to empathically explore the service user's point of view about their situation, current life, and short and long-term personal future goals; come up with an explanation of the problems or obstacles identified by the service user as interfering factors in their current life; express the desire and pleasure in being with them, in a spontaneous and authentic way; emphasize the positive results that service users can produce in their daily life; identify obstacles that prevent the service user from participating in the group, and helping them to overcome these obstacles.

To quote what Liberman writes in his text, The Recovery from Disability, "Accentuate the positive aspects and praise the progress extensively, no matter how modest the steps may be. In your work you should function as if you were using a magnifying glass, to see the small progress made by patients. The practitioners' task is to catch something normal, good, appropriate, or useful that the person does or says for him/herself or others... and to tell the person how it made you feel. When using this intervention, be authentic and spontaneous in communicating appreciation, with a warm, confident tone of voice, maintaining eye contact, and praising the specific behavior, not the person in general" (Liberman, 2008).

From theory to practice

The decision to implement the IMR program in the Ferrara Department of Mental Health (DSM) was prompted by a strong push for change. This push for change was accelerated by the worsening of a number of critical issues, including the massive recourse to residential facilities, demonstrated by the annual increase in the number of people with mental health problems labeled hopeless, and relationships where people had no decision-making power or choice, were infantilized and considered only because they were diagnosed. Another critical issue was the scarcity of supported employment and housing programs, as discharges from residential facilities were few, and long stays, even for life, prevailed. For these reasons, the DSM management decided to introduce the practice of IMR in order to initiate a radical change in the culture of the service, starting with staff training that involved all the practitioners assigned to the service where the treatment was implemented.

From 2017 to 2021, 17 treatment groups were established in five mental health centers, four substance abuse services, three residential facilities, two day centers, one psychiatric acute ward, and one food behavior disorder center.

In 2018, the cross-sectional departmental group, made up of all the IMR practitioners (approximately 60 professionals), was established. It meets quarterly with the DSMDP director to monitor the implementation and its results, as well as to support and supervise the professionals. Since the start of the implementation process, around 300 people with mental health conditions have been supported through the program.

Conclusions

IMR can be implemented in different contexts and adapted to the specific needs of the person involved. The results obtained so far are encouraging, as they have confirmed the expected outcomes listed in Table 1. Interestingly, categories of service users hitherto not included in the research studies and different types of services were involved, and telemedicine was also used, confirming that IMR is suitable for different types of users and different healthcare contexts. Moreover, it appears to be a flexible and customizable model. However, further studies with control groups and a more structured assessment of clinical indicators (symptom severity scales, user experiences and satisfaction and use of health resources), caregiver burden, and intervention outcomes on persons having diagnoses other than those originally foreseen in the manual, are needed. A substantial knowledge base already exists, however, from other research literature, especially from the review on IMR (McGuire, 2014), in which 33 studies (including countries such as the USA, Netherlands, Israel, Denmark, Sweden, Taiwan, Japan, Singapore, Norway, Turkey, Australia), totaling a sample of 3,393 persons, with an average age of 43.6 years and with the most frequent diagnoses of schizophrenia, psychotic disorder, schizoaffective disorder (46.12% of the sample) were examined. The dimensions assessed were self-management, knowledge of mental health problems, and clinical, functional, personal, and social recovery. From this review we know that IMR has positive effects on people's perception of recovery, that it produces an improvement in the knowledge and management of mental health problems, that it can be implemented with good fidelity to the model in various settings with heterogeneous people, that the most frequent format is group-based (60.6%), the average duration is weekly sessions for 8-12 months, and the drop-outs variable (average 26%). Inconsistent results are shown with regard to hospitalization rates and it remains to be further investigated on which specific dimensions of recovery the effect is the greatest and which categories of persons with mental health problems can benefit the most.

Table 1

Measured and expected outcomes.

• Progress toward objectives.
• More knowledge and awareness of own problem.
• Utilization of the involvement of family and friends in the rehabilitation process.
• Increased number of contacts with people outside the family.
• More time engaged in structured roles.
• Less intensity and frequency of symptoms.
• Improvement of functioning.
• Reduction of the number of relapses.
• Reduction of the number of psychiatric admissions.
• Learning coping strategies.
• Involvement in self-help activities.
• Effective use of medication.
• Coping better with alcohol use.
• Coping better with drug use.

But the best conclusions seem to be those reported by service users and practitioners who have experienced the benefits of the IMR program. Some reports by service users and practitioners:

Service users
"I understood what bothers me and new strategies to avoid them!"
"The best group I have ever done! A bit difficult though..."
"Understanding the stress-vulnerability model has changed my life!"
"I finally got back in touch with a dear friend of mine."
"I am actively working to improve..."
"I understand what Recovery is and how I can finally achieve mine!"

Practitioners
"It finally allowed us to talk about Recovery!"
"We felt it was a useful tool to help users to set their goals and acquire skills to achieve them."
"Very useful the worksheets proposed by the manual, they are a good starting point for psychoeducation and coping strategies."
"We were able to inform about the importance of pharmacological and psycho-educational treatment, so as to develop more confidence and hope in the support provided."
"It was helpful for users to recognize triggers and relapse signals, so they were able to avoid more unpleasant episodes."
"It allowed the users to get to their goal faster."

The data acquired from the research, my direct experience in training staff and conducting IMR groups, and the voices of practitioners and persons further convinced me that the principles of recovery and the centrality of the person can be transferred to an entire Mental Health Department, demonstrating how, despite the difficulties that emerged, such as individual and system resistance, difficulty in abandoning the old way of operating, cultural prejudices, and lack of human resources, remarkable and significant results can still be achieved.

Above all, what struck me most was the change of lens of the service staff, who began to see the person behind the patient, the strengths behind the deficits, the emotions, and not just the symptoms, increasingly marginalizing the diagnosis while progressively focusing on what service users have in common with all other people. This serves to increase the motivation of those who had become disaffected and see themselves as guardians of the chronic people, forced to constantly repeat the same actions without significant results. And once again my Master Mark Spivak was right: "…. There are no intractable persons with mental health problems. Instead, there are helpless and hopeless practitioners because they lack the basic tools of intervention. There are partial and half-hearted programs, that need to be strengthened and corrected. There are oppositions and ideological blindness that avoid addressing the complexity of mental health problems. These are the conditions that produce "hopeless patients" (Spivak, 1987).

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The importance of family and service provider involvement with service users from three perspectives in a South African context.

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Recovery-oriented practice as a treatment approach for psychiatric disabilities is still an emerging area in the mental health field in South Africa. Existing research in recovery and recovery-oriented practice for serious mental illness in South Africa have thus far focused on exploring the perception of recovery among South African service users and their caregivers (Brooke-Sumner, 2016; De Wet et al., 2015; De Wet & Pretorius, 2021; Gamieldien et al., 2023). Recovery-oriented psychosocial interventions, including community-based psychosocial programs and peer-led recovery group interventions (Asher, et al., 2023; Brooke-Sumner, 2016; Brooke-Sumner et al., 2018), have also been developed and tested for its efficacy. Alongside these research developments, the newly adopted South African National Mental Health Policy Framework and Strategic Plan 2023-2030 is also advocating for recovery-oriented practice in public mental health care by incorporating recovery values and principles into its latest policy (South African National Department of Health, 2023).

Social support is one of the core facilitators of recovery for service users in both high- (Garverich et al., 2021; Leamy et al., 2011; Van Weeghel, et al., 2019) and low-and-middle-income countries (Brooke-Sumner et al., 2014; De Wet et al., 2015; De Wet & Pretorius, 2021). Furthermore, the South African National Mental Health Policy Framework and Strategic Plan 2023-2030 promotes the value of "social support and integration" in the public mental health care system, emphasizing that "maximum support should be provided to families, carers, and communities of those with mental illness to broaden the network of support and care…" (South African National Department of Health, 2023, p. 32). Now, more than ever, there is a growing need for workforce development based on the principles of recovery (Anthony, 1993) for clinicians in South Africa to ensure the successful adoption of recovery-oriented practice in mental health care. However, there are very few studies that have examined the perspectives of service providers (Bila, 2019; Chisholm et al., 2023; Gamieldien et al., 2022) on the delivery of recovery-oriented practice. Furthermore, there is still limited knowledge of how service users, caregivers, and service providers conceptualize support guided by recovery-based principles and values. This paper thus explored the perceptions of mental health service users, caregivers, and service providers in South Africa understand the role of clinical and social (e.g., caregiver) support using a recovery framework, to enrich the body of knowledge on recovery and recovery-oriented practice in South African contexts.

Materials and Methods

The present study is a qualitative sub-study of a larger mixed methods study conducted at three tertiary psychiatric hospitals in the Western Cape province of South Africa. The goal of the larger study was to develop a contextually appropriate measure of individual recovery for mental health service users in a South African context. Semi-structured, individual interviews were conducted with three cohorts of participants: service users, caregivers, and service providers. See Table 1 for further details of participants. Participants were consented prior to data collection.

Table 1

Participants in the larger study

Cohort of participants	Inclusion criteria
Service users (n=13)	1) At least 6 months in total in one of the tertiary psychiatric hospitals in the Western Cape; 2) Able to communicate in either English or Afrikaans without assistance of a translator; 3) Diagnosed with a chronic and severe psychosocial disability (for example schizophrenia, bi-polar disorder, schizoaffective disorder), and 4) In their time at the hospital participated in some form of recovery or psychosocial intervention or program, available to service users at the hospital.
Carers (n=12)	Family members or otherwise, who are involved in the financial or emotional support of and caring for service users.
Service providers (n=12)	Either directly or indirectly involved in the provision of services, interventions and programs to the service user participants at the hospitals, such as nurses, psychologists, psychiatrists, occupational therapists, social workers

All interviews were audio-recorded and transcribed verbatim. Ethical approval for the study was obtained from Stellenbosch University's Research Ethics Committee: Human Research (Humanities) and the Western Cape Provincial Department of Health.

Data was organized into three triads, comprising a service user, their caregiver, and their provider. Actual names were replaced with pseudonyms to protect privacy and confidentiality. Service providers' occupations were not included to protect their identity, since they are from a small pool of public mental health service providers at the three public tertiary psychiatric hospitals in the Western Cape province. The larger study included service providers consisting of social workers, nurses, psychologists, occupational therapists and psychiatrists. We used reflexive thematic analysis (Braun & Clarke, 2019) with the constant comparison method and generated themes by triad and examined where narratives varied or intersected by social role. Atlas.ti (Atlas.ti, Version 8.4.4, 2018) was used for analysis.

Results

Table 2 provides details of the nine participants.

Table 2

Details of participants and their group membership

Service user (SU)	Name: Adela Gender: Female Age: 30 Diagnosis: Bipolar disorder	Name: Mpho Gender: Male Age: 35 Diagnosis: Schizophrenia	Name: Enzokuhle Gender: Male Age: 29 Diagnosis: Schizophrenia
Carer	Name: Tamara Gender: Female Age: 38 Relationship to SU: Sister	Name: Hope Gender: Female Age: 61 Relationship to SU: Mother	Name: Felecia Gender: Female Age: 52 Relationship to SU: Aunt
Service provider	Name: Rita Age: Not disclosed	Name: Jonathan Age: Not disclosed	Name: Jana Age: 36

Service Users

Receiving Social Support

All three service users discussed the powerful role that social support plays in their recovery. Adela, a 30-year-old female, spoke of her support system both at home and the hospital playing a crucial role in her recovery. She described that she reaches out to her family when she recognizes her early warning signs of her mental health declining: *"I go to my support, like my father or my sister and I tell them, 'ok, I'm not feeling so well today.'"* Enzokuhle, a 29-year-old male, similarly reported that the support and sense of belonging he cultivated through close relationships with his service providers and friends were key contributors to his recovery. He stated: *"If you [have] a good support system, then you're going to be able to recover."* Enzokuhle also explained how his support system assisted him in his recovery through words of encouragement and positive affirmations:

> *All these people they started to motivate me and tell me and now this is not the end of the world…It's just trying to help you because we see there is a light in you. But you don't see it… So, they're trying to drag you out of the dark side in future with the light.*

He also referred to the importance of peer support, *"What helps me is also to talk with people... when you're running a [sic] groups, and there we talk [to] people and then I start to get some ideas from other people. The ideas that I was not thinking."* Mpho, a 35-year-old male, also shared how his relationships with others and the encouragement he receives from family and others helps his motivation to continue working on his recovery: *"…to have people who's going to advise you and encourage you and inspire you for you to go and reach your goals."*

Providing Social Support

Two of the service users discussed that providing social support was also a part of their recovery goals. For them, providing tangible support as a parent or partner was part of meeting their larger recovery goal of fulfilling meaningful social roles. Mpho, who has a history of psychiatric hospitalization over a span of 8 years, discussed that his current two recovery goals are to get a job and to support his mother and his child. *"When I get a decent job, then I can go live back with my mother and take care of her."* He shared that being able to support his child as a father is an important aspect of masculinity in his culture. He poignantly mentioned, *"I'm worried about my daughter. I want… I don't want her to depend on her mother only. She must also be supported by me, and she must know that her father loves her..."*

Enzokuhle had spent 3 years in a psychiatric hospital at the time of his interview. Similar to Mpho, an important aspect to his recovery was to earn a living to take care of himself financially and be independent. *"…that's [sic] someone is going to be able to be not depending on family in terms of money-wise that I can be able to look after myself… You know, can be able to take care of myself… A job is very important."* Having a family and children was also an important social recovery goal as well as part of his cultural values for Enzokuhle: *"It is important. I want to leave my… what do you call? My image. My image in the world. I don't want to die without children."*

Caregivers

Recognizing and Supporting What is Best for the Service User's Recovery

Tamara, a 38-year-old female, is Adela's older sister and caregiver. Adela had been living with Tamara and her family for several years. Tamara described herself as a compassionate yet assertive caregiver. She sets reasonable expectations for Adela to help her stay engaged in a healthy lifestyle. *"…we go out and we say* [to my sister], *'No, no, you're not staying at home today. Get up. We're going somewhere' and she has to go."* Tamara also discussed giving responsibilities at home for her sister to contribute as a member of her household: *"she takes a lot of my home responsibilities… I kind of insist on."* She also highlighted the importance of acknowledging and expressing positive comments and continuing to encourage the service user for any efforts they make, such as waking up in the morning, *"So, you got up today. You did something great."* Tamara emphasized

the importance of the person-centered approach where the service users themselves feel supported and empowered to take the lead in their recovery, *"recovery of yourself, your personality, your being"*.

Hope is Mpho's 61-year-old mother, who had been estranged from her husband and living alone in a neighborhood with high levels of drug abuse and poverty. She shared that she wanted her son to live with her as she needed his help around the house. Yet, she was afraid that living in her neighborhood could potentially increase the risk of her son's substance use to relapse. She shared, *"He needs not to come here, though I need him. I need him. But [he] doesn't need to come here. Because when he comes, when he comes here, it's hopeless. It goes back to square one."* Instead of having Mpho return to her home, she was looking for a safer community for him to live in upon discharge from the hospital. She also mentioned that if her son could find a job, it would be beneficial to them both: *"…And he even tells me if he can find a job and work, he will upgrade the house and everything."*

Felecia is the 52-year-old aunt of Enzokuhle. She serves as Enzokuhle's sole carer. Both of his parents are deceased. Felecia had been taking care of Enzokuhle since he was young, before his mother passed away after a long sickbed. Felecia, similar to Hope, also expressed her anxiety of having Enzokuhle back at her home after discharge, as their neighborhood also had seen high levels of substance use and crime. As his caregiver, Felecia wanted him to stay away from her community because of it risks that could possibly lead to symptom relapse (e.g., substance use). Felecia added that she hoped for her nephew to be *"a man,"* which in their culture meant having a family and a job, and wished for him to stay engaged in an activity or, *"…something to keep busy"* for his recovery.

Service Providers

Meaningful Social Connections

Establishing meaningful social connections, or relationships, was discussed by all service providers as an important aspect of recovery for service users. Jana, who worked as one of Enzokuhle's providers, expressed that social connections extend beyond family members: *"…if it's not family, then friends or somebody else that is an important figure in their life."* Rita, a provider in Adela's care team, also commented that the absence of family support can negatively impact service users' recovery processes. Jonathan, a clinician working as one of Mpho's providers, shared the perspective of the other two providers. He shared that one of the goals as providers is to help service users to learn how to establish and keep relationships to stay connected with others, especially families: *"...we have to help people re-connect with their families, which includes partners etc. That's basically what we have to do."*

Barriers to Providing Recovery-Oriented Support

Rita described that the lack of resources and pressure on public mental health services make it difficult for service providers to offer comprehensive support to service users. She discussed that the existing mental healthcare infrastructure is not conducive to providing long-term therapy or clinical interventions that assist service users in working on their recovery. Consequently, the clinical support they provide mostly focuses on treating acute symptoms and discharging service users to make space for others who also require care.

> *Psycho-education group, and then there's the support group that happens for the chronically, often chronically personality disordered individuals, [who] have been through individual therapy for years, but there's just no movement and they can't... we don't have the resources to keep them into individual therapy.*

Jonathan also described the limitations of recovery prospects for service users in the public mental health care unit where he worked. He supported and valued the role of medication as a critical component to recovery and relapse prevention. His narrative suggested that he had very little experience or exposure to recovery-oriented practice. He raised the issue of limited community-based recovery programs in South Africa which hinders the service users' recovery. He added that family-based supports are often not sufficient for his

patients to achieve recovery, especially when one has a comorbid substance use disorder.

> *So, their families can be very nice, they can be very supportive. Everything else can be in place. I can give lots of examples… you send [the patients] to learnerships. You put them into programmes. You've engaged with them, etc., etc. The thing is, they still keep using tik [methamphetamine]. They still keep using dagga [marijuana], and it counters, undo's everything.*

Rita also shared that the medical model of mental illness was still dominant within mental health care in South Africa, re-iterating the importance of more recovery-oriented programs for service users. Jana's narrative also asserted that South African mental health services ought to integrate the recovery model to better meet the needs of the service users. She commented on the inadequacy of existing mental health services: *"if your programmes are not relevant, if it's not appropriate, if it's not in tune with what the clients are saying, if you don't provide enough support. Those are the things that… that kind of work against recovery."*

Facilitators of Providing Recovery-Oriented Support

Providers also discussed current practices that they perceive to be effective if continued or enhanced. Jana discussed that provision of individualized care is usually received well by service users and results in the positive recovery outcomes. The approach she described is also consistent with recovery-oriented clinical practice of providing person-centered care (Farkas et al., 2016).

> *I think the clients value… you know, the fact that we focus on function. What can you do? What would you like to do? You know? That, I think, makes a huge difference umm… in terms of their lives, you know?"*

Jonathan spoke about the iterative, evolving process of tailoring the treatment plan for each service user, suggesting that there is no "one-size-fits-all" approach for recovery. Instead, plans are developed based on service users' choices, their preferences, goals, and needs:

> *"…So, it's not like there's this blue print, this is what we're gonna do. So, something just evolves over time. And, the patient goes out and tries it, comes back and reports, it worked, didn't work. Maybe something else he'd like. And, so just this ongoing, iterative process. Seeing, talking, trying, coming back."*

This included understanding the needs as well as the capability of each service user well. *"For different clients it will be different."* Rita also shared that most of her clinical work involved individual therapy with her clients, yet also shares the dilemma that she faces of being unable to respond to the high demand for individual work.

Providers also discussed using a recovery-oriented approach to skills training with their clients. Jana discussed that a key role of the service provider is to teach sustainable skills which focus on capacity-building for service users. Such skills included communication skills, conflict management, and problem-solving. She shared an example of how she interacts with her clients, reflecting on the role of providers in person-centered care:

> *I think also one's got to look at... so if this is the client's journey, and this [is] what their needs are, then how does one… you know, look at building on their strengths? Helping them… to develop their own capacity, you know, to be more in control of their own life. And sometimes that is about, you know… how do we help them to equip themselves with skills, or how do we equip them with skills?*

Jana further emphasized the importance of using role plays so that service users are better equipped to apply the skills they learn in real-life scenarios and situations. She reflected that service users also perceive this practice-based approach to skills training to be helpful and responsive to their needs and goals of building and maintaining social relationships. Jonathan similarly emphasized the importance of providers' work of teaching critical skills to service users, such as literacy, by way of empowering them to reach their recovery goals such as employment, or independent living. He stated:

> *…the one thing we haven't done and which I, I would like to do is to have a course of, or have some sort of system where we teach them basic literacy. Which involves maths and Eng…language and so on. People can be literate and work with numbers, they can do lot of things, they can open a bank account, they*

can fill out a CV, they can fill out a job application. So, a lot of these basic skills that if you could give them to, to patients or people, then you're enabling them.

Rita also shared similar sentiments around the value of skills development and capacity-building for service users, which reflected the recovery-oriented perspective that the focus is not on the elimination of symptoms and rather learning the skills to live with the symptoms/illness while achieving personal goals.

It's not that the mental illness goes away, it's always going to be with [the service user], *but* [they're] *going to need to learn skills in order to live with it, to understand it. To understand* [themselves], *to know* [themselves]. *And, and how best* [they] *can do that…*

Discussion

Nine semi-structured interviews conducted with service users, their caregivers, and service providers in Western Cape province of South Africa were analyzed to examine common themes that emerged across the three groups. Perception of social support as a recovery construct, was the focus of the present study. For service users, receiving social support through words of encouragement and affirmations, particularly from those close to them (e.g., family) played a significant part in their recovery process. Service users also highlighted that being in the position to provide support to their families and fulfilling their social role as a parent, child, etc. contributes to their recovery. Caregivers also reflected on their role as providers of support for their loved ones in recovery. The competence and strength of knowing what is best for the service user's recovery, being able to set aside personal desires and needs, and prioritize the service user's recovery were main themes that emerged from this triad. Finally, service providers echoed the perspectives of service users, and discussed the significance of making meaningful social connections on the path to recovery. Service providers shared their insights in the various ways in which they support service users to establish these connections.

These results align with previous research with service users and caregivers in the context that found that both receiving and giving of support are crucial to recovery (De Wet et al., 2015). Social connection also forms part of the *Connectedness* aspect of the recovery processes of the CHIME framework by Leamy et al. (2011). CHIME stands for *Connectedness, Hope and optimism about the future, Identity, Meaning in life and Empowerment*. Earlier work by Jacobson and Greenley (2001) also identified social connection as a dimension of recovery. The relational facet of recovery has also been included as part of the 10 guiding principles of recovery by the Substance Abuse and Mental Health Administration (SAMHSA) in the United States of America (n.d.). This relational facet of recovery emphasizes the importance of social connection by family members and others who aid service users to recognize their ability to recover and take steps to achieve change for themselves. To acknowledge the importance of support for mental health service users' recovery, in South Africa, the South African National Mental Health Policy Framework and Strategic Plan 2023-2030, in addition to promoting the value of "social support and integration", also mandates the development of peer support. (p. 32), which creates hope for future expansion of public mental health services to incorporate peer support, which has been advocated for before (De Wet, et al., 2022).

Engaging in meaningful social roles, e.g., as an employee or a parent, is another core value and common recovery goal for service users. In recovery-oriented practice, service providers play a critical role in supporting the development of relevant skills and capacities to meet these goals. The *meaning in life* process of the CHIME framework (Leamy et al., 2011) posits these life and social roles and goals that have meaning to the service user.

Lack of resources (e.g., financial, infrastructure), dependence on the biomedical model were raised as major barriers to the implementation of recovery-oriented practice within the South African public mental healthcare system. Few community-based recovery programs exist to refer service users to upon discharge from hospital. These opinions align with the dire state of public mental health care in South Africa that has been reported on in detail previously by the South African Human Rights Commission (SAHRC, 2017). De-

spite global efforts promoting a shift to recovery-based approach to assessment and rehabilitation of mental illness, the reliance on the biomedical model continues to endure (Bemme, & Kirmayer, 2020). Yet, service providers in this study shared their commitment to incorporating recovery-oriented practice in their care, through the provision of person-centered, individualized care with a focus on improving function and capacity to lead meaningful lives.

Limitations of the study

Given that the present study was a small qualitative study that took place in a specific geographic area in South Africa, the results have limited generalizability. Despite these limitations, the results contribute richness to the small existing body of knowledge on the understanding of recovery in the study context. Moreover, time constraints did not allow for validating the results through follow-up focus group discussions, or member checking, with participants from the three triads. Data from the larger study, which includes focus group data from the sample of this present study, was used to validate the overall findings.

Conclusion

Some efforts to improve public mental health services in South Africa have been examined and implemented, such as scaling up of services and improvement of community participation in mental health care as well as the development of recovery-oriented interventions, including community-based psychosocial programs and peer-led recovery group interventions (Asher, et al., 2023; Brooke-Sumner, 2016; Brooke-Sumner et al., 2018; Campbell, & Burgess, 2012; Petersen, et al., 2012). In addition, recovery-oriented care for public mental health service users in South Africa has been greatly anticipated, since the mandate was outlined by the South African government in 2013 (South African National Department of Health, 2013). However, implementation of this policy was marred by challenges (Lund, 2023) and recovery-oriented practice was consequently not incorporated in public mental health care. Thus, there is still work to be done before the wide-spread and successful implementation of recovery-oriented practice in public mental health settings in South Africa can be achieved.

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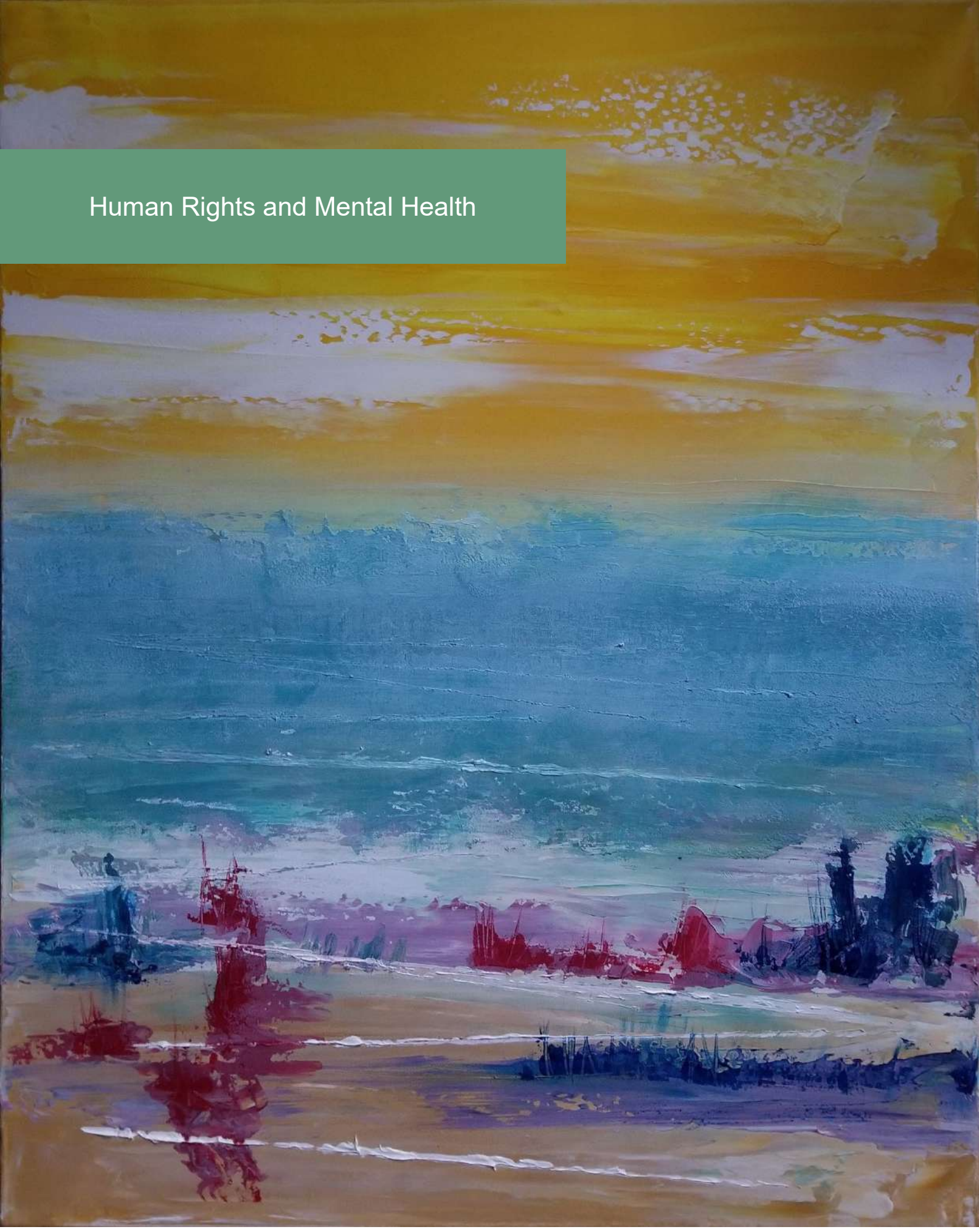
Human Rights and Mental Health



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Mental Health, human rights and legislation. Guidance and Practice.

Gabriele Rocca[1]

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A very important event took place on the 9. October 2023: The presentation of the *"Mental Health, human rights and legislation. Guidance and practice"* document co-published by the World Health Organization and the United Nations (on behalf of the Office of the United Nations High Commissioner for Human Rights). The joint participation of these two bodies underlines the relationship between mental health and human rights, and the need to create mental health systems capable of responding to population needs.
The Convention on the Rights of Persons with Disabilities (CRPD) clearly defined the boundaries within which legal relationships between citizens and institutions should be established: everyone (including people with disabilities) has the right to access high-quality care and support without discrimination or the violation of any of their human rights. With the aim of establishing mental health systems that are capable of providing person-centered care, the Guidance reaffirms these values and suggests operational models to promote personal autonomy and remove the barriers obstructing access to the full rights of citizenship. The implementation of rights-based mental health systems requires de-institutionalization, the ending of coercive practices, and the promotion of supported decision making. It furthermore requires community inclusion, and full participation in all aspects of life. It is emphasized that this requires action not only in terms of health care interventions, but also economic and social policies that commit governments, institutions and agencies to supporting them. Cross-sectoral reform is needed to activate all community resources, influence the social determinants affecting well-being, and create mental health services that are not limited to health care.

All of the phases of legislative action can be enhanced by the broad involvement of all stakeholders, including people with lived experience and their family members. The Guidance urges the participation of local and national associations as intermediaries representing particular interests that can provide qualified indications concerning the implementation of services, but the involvement of people with lived experience gives voice to their subjectivity and places the life stories of users at the center of the reform debate.
The constitution of the WAPR indicates that its main objectives include "promoting the adoption of policies and legislation by national governments and intergovernmental agencies designed to strengthen rehabilitation services, opportunities, and financial resources, to meet both the basic and special needs of the population". This means we have to go beyond seeing mental health as a medical issue. One of the qualifying aspects of the care of and collaboration with persons with a mental health condition is an ability to face social stigma. We must create conditions that ensure respect for legal capacity and that informed consent is included in any therapeutic project. Respect for human rights and the involvement of people with lived experience cannot be considered mere ideological dressing but need to represent substantial technical aspects of everyday practice that affect the quality of care and, consequently, treatment outcomes. Furthermore, appropriate consideration of social determinants requires the implementation of mental health services that, without losing any of their healthcare specificity, are integrated with social and other services in order to overcome the barriers limiting full participation in social life in the community.

To do this, it is necessary to promote pathways aimed at developing new rules and designing new institutional structures capable of reflecting the complexity of the issues involved while fully respecting the history and culture of individual countries. These pathways require the broad involvement of various stakeholders in order to ensure that mental health system reform goes hand in hand with legal and cultural

change, particularly in the crucial field of the relationships between individuals and institutions.

The recent joint publication of the WHO and UN gives substance to the principles inspiring possible reforms and simultaneously provides the elements necessary to define an operational process that is capable of meeting the challenge represented by the complexity of mental health.

Finally, I would like to take this opportunity to thank Michelle Funk and Deborah Kestel for inviting the WAPR to contribute suggestions during the drawing up of the Guidance. Our collaboration with the WHO forms of part of our history and will also characterize our activities in the future.
https://www.who.int/publications/i/item/9789240080737

Turning crises into opportunities.

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Background

Lebanon, a small country in the Middle East, has been enduring a severe unprecedented crisis, with more than 80% of the population residing in Lebanon not having access to the most basic rights, such as adequate living, access to health services, etc. (World Report, 2022).

The compounded crises in the country, including the COVID-19 pandemic, the Beirut Port Explosion in August 2020, the ongoing severe socio-economic and financial crises have had their toll on the country's services and resources. In fact, the situation in Lebanon was considered by the World Bank as being in the top ten -possibly top three- most severe crises since mid-nineteenth century (World Bank, 2021). This is coupled with the recent effect of the Gaza war on Lebanon.

These compounded crises have put more pressure on the health- and mental health- system. Lebanon's health system is characterized by a public-private mix. For mental health, the MOPH expenditure is spent mostly on hospitalization and medications; and the mental health services are more skewed to the private sector and more concentrated in central rural areas.

Institutionalized individuals are considered one of the most marginalized population groups. Psychiatric institutions worldwide are associated with several human rights violations, ranging from degrading treatment and abuse to violence, seclusion and restraint, in addition to other violations spanning basic political, social, and civil rights.

The mental health reform

The Ministry of Public Health (MoPH) established the National Mental Health Programme (NMHP) in 2014. In 2015, the NMHP launched the first National Mental Health Strategy for Lebanon (2015-2020) to reform the mental health system in the country. The strategy is aligned with the World Health Organization (WHO) Global Action Plan (2013-2020) and human rights principles. The vision of the strategy is that "all persons living in Lebanon have the opportunity to enjoy the best possible mental health and well-being".

A major pillar of the reform is directed toward monitoring and improving human rights for persons with psychosocial disabilities and scaling up community-based mental health services including the integration of mental health in primary health care, in addition to the work on reforming the mental health law in line with the Convention on Rights of Persons with Disabilities (CRPD).

The QualityRights experience in Lebanon

Process of implementation

In Lebanon, the WHO QualityRights initiative has been used in different ways to support the ongoing reform and continues to be highlighted as an important tool in the revised National Mental Health Strategy for Lebanon (2023-2030), expected to be launched in November 2023.

The NMHP with WHO have been implementing the QualityRights initiative since 2017 through different phases (Figure 1 below). Phase 1 started with a pilot implementation that included training and adaptation of the QualityRights toolkit to the Lebanon context and piloting in two private general hospitals that have psychiatry wards. A pre-requisite to join the assessors' training was to complete the QualityRights e-training on Mental Health, Recovery and Community Inclusion. Following the online module, the training of the assessors included a theoretical overview of the QualityRights toolkit as well as an on-the-job practical session that focused on how to conduct the assessment. The theoretical part covered the different themes within the toolkit, which are based on the articles in the CRPD as well as the structure of the toolkit (themes, standards, and criteria). The training was led by WHO international trainers aiming at building the capacities of a national multidisciplinary team and service users. Following the training, the assessment team members were invited to attend a one-day adaptation workshop prior to the actual assessment to go over the Arabic version of the toolkit and adapt the language to the local context particularly with regards to some of the scientific and social jargon.

Phase 2 involved roll out of the assessments in four hospitals using the QualityRights toolkit. Phase 2 also included a refresher training of the previously retained assessors, in addition to recruiting new assessors and training them. In the roll out, the new assessors were teamed up with the previous more experienced assessors.

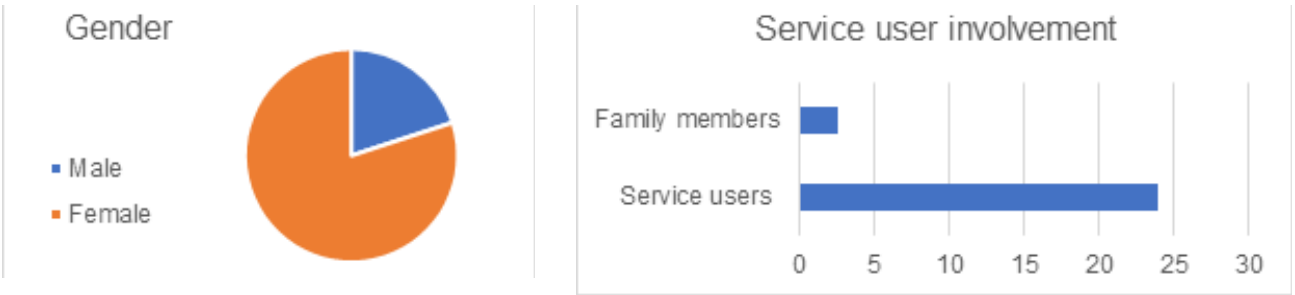
Figure 1

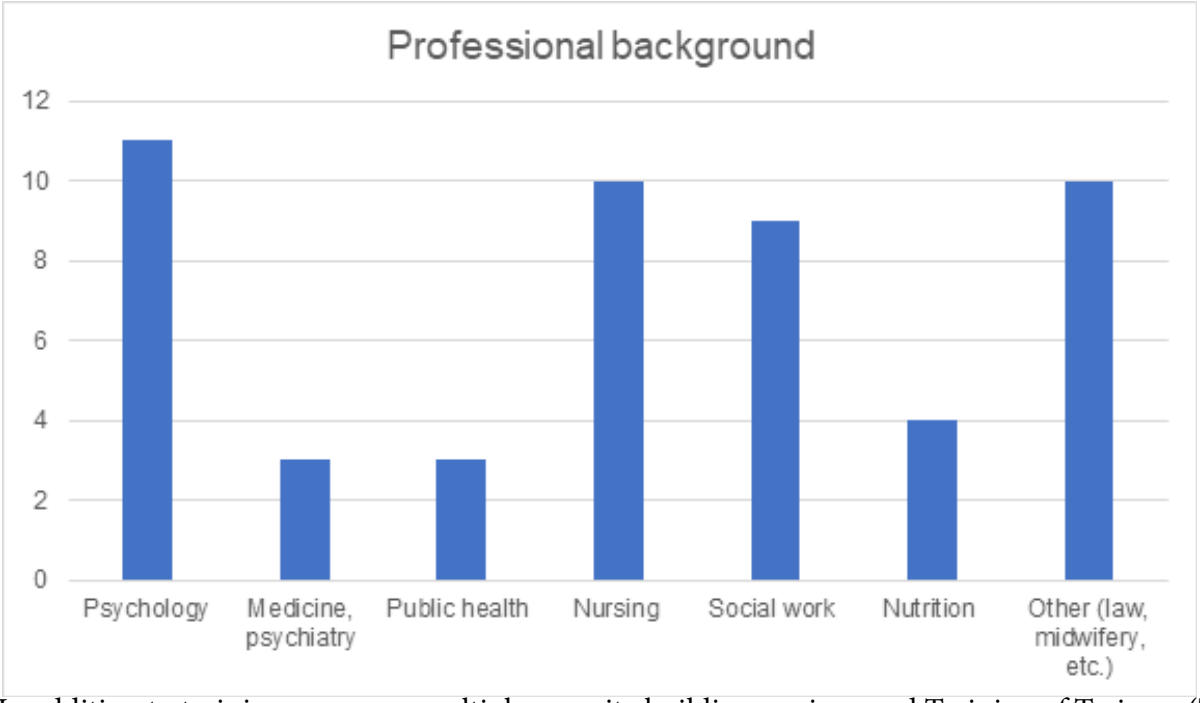
Process of Implementation

Currently, the NMHP has a team of 50 assessors from different backgrounds and different geographic locations in Lebanon. Figure 1 provides a summary of the assessors' details. Service users play a key role in the preparation, monitoring, and improvement of facilities since the pilot of 2017. Currently, the number of persons with lived experience in mental health conditions reached 24 out of the total 50 assessors and 7 are family members of persons with lived experience in mental health conditions. In addition, two members from the NMHP and 1 member of WHO are part of the management team; all members have been involved in the QualityRights in Lebanon since the pilot in 2017.

Figure 2

Details of assessors





In addition to training assessors, multiple capacity building sessions and Training of Trainers (ToT) were conducted to health care professionals and mental health professionals. A total of 467 participants also completed the QR e-training (data until September 2023).

Results of the assessments and discussion

The table below (see Table 1) provides a summary of the ratings for all six facilitieis assessed.

Table 1

Summary of ratings for assessed facilities

Rating	**Theme 1** The right to an adequate standard of living	**Theme 2** The right to enjoyment of the highest attainable standard of physical and mental health	**Theme 3** The right to exercise legal capacity and the right to personal liberty and the security of person	**Theme 4** Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse	**Theme 5** The right to live independently and be included in the community
Average Rating	A/P Achieved partially	A/I Achievement initiated	N/I Not initiated	A/I Achievement initiated	N/I Not initiated

The overall results indicate that theme 1 was partially achieved; the physical structure in terms of buildings, rooms, etc. was found to be in overall good condition in the assessed facilities. Living conditions in terms of lighting, ventilation, hygiene and sanitation, as well as access to food was found acceptable in the assessed facilities. Access to natural lighting was a feature in almost all facilities. Service users' privacy and confidentiality were more or less respected; however, practices of involuntary admission, seclusion and restraint were still prevalent.

In terms of theme 2 on the right to enjoyment of the highest attainable standard of physical and mental health, treatment and care provided in the facilities was found more skewed to the biological rather than the psychosocial approach with no active participation of service users in their own health and health care.

Although care was provided by multidisciplinary teams (e.g., physician, nurse, psychologist, etc.), interprofessional collaboration was still suboptimal.

Theme 3 on the right to exercise legal capacity was not initiated by facilities; users' preferences and opinions were not always considered when providing care. Involuntary admissions are prevalent and service users were kept against their wills, for different reasons, sometimes such as not having anyone to support them in the community.

Although some practices of advance directives were noticed, they remained sporadic and limited to personal initiative.

The low rating of theme 3 is mainly due to the current national legislative framework governing the legal capacity of people with mental disorders, in particular a law that dates from 1983 that allows hospitalization without consent in certain cases while omitting to address or formalize any preventive and protection measures to guarantee users' rights. The NMHP is advocating for a reform of the mental health law that aims at protecting the rights of persons with psychosocial disabilities; this draft law is in line with the CRPD and is under review in the parliament.

For theme 4, facilities still resorted to restraint and seclusion in several instances. Several of them are receiving training on de-escalation techniques and crisis management. It is worth highlighting that the inexistence of an independent legal body outside the facility as a safeguard to prevent torture or cruel, inhumane, or degrading treatment affects tremendously the rating, particularly standards 4.5. This is mainly due to the current legal framework governing the mental health sector in general; and as mentioned above, the adoption of a new reformed law which is currently an ongoing process, will remedy and improve the situation.

As for theme 5, efforts for reintegration of service users in the community are increasing despite the little knowledge of available community services and resources. These efforts rely more on personal initiative. Policies and procedures are needed at facility level for service users' integration.

Discussion

The introduction of *QualityRights* approach in Lebanon started in 2017, targeting all mental health institutions. However, despite these efforts, several violations of human rights were reported on the media (Gerges, 2019; Khazem, 2021) regarding the abuse and maltreatment of patients with mental disorders in several residential facilities providing mental health services.

The first violation occurred in 2019 in a long-stay private institution. The second violation occurred in 2021. Subsequently, the facilities were shut down by the Ministry of Public Health. In both instances, with the support of WHO a multidisciplinary team conducted physical, social and psychological assessments for the service users in these institutions and a total of 252 inmates were relocated to other more *QualityRights-compliant institutions*.

The highly mediated violations opened doors for improvement in human rights conditions of persons living in institutions and excluded from society. With this momentum created, QualityRights provided a structured framework for assessing and improving human rights conditions in the facilities providing mental health services.

Moreover, the *QualityRights* tool and assessment were the basis of the concrete actions taken by the MOPH. In fact, following these two incidents, the MoPH issued several ministerial decisions including decision 650/1 (issued on 18 July 2023) asking to establish a high-level multidisciplinary team to oversee the human rights situation in long-term institutions; this has remarkably added to the governance capacity.

This momentum allowed for serious discussions and the initiation of a de-institutionalization process in one of the main long-stay mental health facilities in the country. This is in close collaboration with the facility's management and staff.

In addition to these cumulative steps towards better protection of Human Rights, Lebanon has recently ratified the CRPD. We hope that with the new law project in the pipeline, the commitment of the MoPH to human rights for persons with psychosocial disabilities and the coordination with partners, further steps will be taken to improve the quality of care and services.

Previous experiences in Lebanon could serve as the basis for enhancing the implementation of the national mental health strategy and deepening reforms in the mental health system.

Conclusion and Way forward

Lebanon is one of the very few countries in the region to implement the *QualityRights* initiative. Based on Lebanon's experience, the *QualityRights* tool was a leverage for improving quality of care and institutionalizing standards of quality in mental health institutions. The buy-in of the relevant stakeholders was encouraging as the tool provided an objective measurement of rights and quality of mental health care for institutionalized patients, and the MoPH governance capacity improved significantly as the tool allowed close monitoring based on well-defined indicators.

The way forward for the *QualityRights* implementation is to strengthen the implementation of the improvement plans in the facilities assessed as well as to provide needed training for the facilities staff on human rights and community inclusion. In addition to the facility level, there is a need to increase the uptake of the *QualityRights* e-training across health, social and other sectors.

More advocacy efforts will be needed to ensure the passing of the draft law as well as to support the facilities in the implementation of the law.

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Person-centric, Rights-based approach for mental illness applicable vis a vis to all countries? Need to include caregivers and role of bystander in India.

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In every country, there exists a distinct mental healthcare system that encompasses the identification, assessment, and management of individuals with mental illnesses, as well as unique mental healthcare laws. These laws are formulated based on factors such as resource availability, the acceptability of the local population, affordability, legal considerations, and political influences. The less-discussed aspects revolve around culture and its impact on the aforementioned factors. Neglecting cultural aspects can result in reduced acceptability and a loss of trust in the system. Consequently, all stakeholders must adapt the necessary laws to suit their specific country. Failure to customize these laws is akin to attempting to fit a square peg into a round hole.

Cultural aspects in India that influence caregiving by family.

Caregiving is a multifaceted aspect of healthcare. The nature of caregiving in India significantly differs from that in Western countries. India, like many other Eastern nations, falls into the category of low-middle income countries (LMICs), sharing certain commonalities in healthcare systems influenced by shared ideologies. India boasts a rich cultural diversity, with its foundation deeply rooted in societal and familial values. These values serve as the driving force behind an individual's actions, desires, decisions, and way of life. More often than not every individual's personal, career, marriage, and all other decisions are usually taken at the family level. The need for approval from all is high. Hence, they foster harmony, and inter-dependence, and often follow patriarchal (though some are matriarchal) lineage, shaping holistic development and promoting mutual support.

In India, parents regard their children as a "blessing from God," resulting in an elevated sense of responsibility to ensure their care, even as they grow into adulthood. It's not unusual to encounter an elderly mother, frail and aging, accompanying her son to the hospital and taking care of him. Similarly, the general expectation is for children to care for their elderly parents, who are revered as equivalent to "God" to attain Punya*.

Furthermore, Indian culture places great significance on various activities and categorizes them as good or bad. Providing care for an ill person is considered a virtuous act, not just pleasing to the elders within the family but also fulfilling a kinship obligation. Family members are driven to support individuals with mental illness due to feelings of closeness, belongingness, and interconnectedness (Guberman et al., 1992). This act brings about "good karma," garners praise, and brings support from other family members or friends. Conversely, neglecting the care of an ill person is viewed as morally wrong, inviting negative consequences (Karma)** and societal disapproval. The cultural imperative of acceptance and interdependence underscores the need to assist others and seek help when needed in return.

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* Punya – In Hinduism, generally refers to virtue or merit, and the activities that allow one to acquire this attribute, in order to achieve liberation from samsara, the cycle of birth and death in the material world. ("Punya (Hinduism)," 2023)

** (in Hinduism and Buddhism) the sum of a person's actions in this and previous states of existence, viewed as deciding their fate in future existences. (Karma Meaning - Google Search, n.d.)

Caregiving

In both in-patient and out-patient settings in India, hospitals typically have a "healthy" individual accompanying the "ill" patient. This accompanying person is commonly referred to as a bystander, attender, onlooker, or informal caregiver, among other terms. The term "bystander" traditionally means a person who stands by and observes, but in a hospital context, it refers to someone present with the patient. Bystanders are typically close family members such as parents, siblings, grandparents, aunts, uncles, friends, and occasionally neighbors. Predominantly, these bystanders are often children, parents, or wives, and they are mostly female. Although the term "bystander" carries a passive connotation, in reality, they play a substantial role in caring for the person in need. An active bystander is one who proactively engages to bring about change.

When you walk through a hospital, you will observe anxious-looking bystanders rushing around for tasks such as registration, admission processes, scheduling scans, depositing samples for investigations, settling bills, collecting medications from the pharmacy, and carefully carrying cups of tea, coffee, or juice while attending to the needs of the sick. In addition to tending to the personal needs of their loved ones, they also assist nurses and hospital aides in caring for the sick person. This includes tasks such as changing diapers, positioning hands for IV lines, comforting the patient during procedures, notifying the nursing staff of any complications or deterioration, monitoring the IV drip, and sometimes pushing wheelchairs for consultations, investigations, and other activities. Alongside these responsibilities, bystanders actively seek to understand the nature of the illness, the treatment process, the expected duration of treatment, the need for follow-up care, symptoms of adverse effects, early warning signs of the illness, and monitoring.

In cases of in-patient care, aftercare often requires a caregiver to ensure treatment compliance, enhance social and occupational outcomes, reduce the risk of relapses, and improve the patient's overall quality of life. It's essential to acknowledge that bystanders or family members are typically the ones responsible for covering hospital bills.

However, the current facilities provided for bystanders often fail to meet basic living standards. Issues include a scarcity of drinking water, inadequate bed availability, poor sanitary conditions, and numerous other challenges. Moreover, bystanders often need to give up their responsibilities, jobs, and other commitments to care for the person requiring hospitalization. They provide physical, emotional, social, and financial support.

In India, 90% of persons with mental illness live with their family in the community and families take care of their basic needs(Chadda, 2001; Thara et al., 1994; Trivedi, 2009). Governmental and non-governmental institutions currently available cannot adequately meet the needs of the population requiring long-term or institutional care for individuals with mental illness. The government does not cover the entire cost of hospitalization for people with mental illness, and very few private insurers offer such coverage. The premiums for these insurances are often unaffordable for those with low or low-middle socio-economic backgrounds. This leaves health professionals with no choice but to rely extensively on the support of family and friends to facilitate treatment. Extensive literature supports the positive impact of involving family in the treatment process, including psychoeducation, family therapy, handling of expressed emotions, rehabilitation and process of reintegration across various psychiatric disorders(Bharat, 1991). Autonomy versus family-centered decision is one of the main connectors of differences between Western and Eastern societies(Gangadhar, 2013).

As bystanders play an active role in the entire process, implementing a person-centric and rights-based approach in India comes with challenges. If forcefully enforced, it could potentially jeopardize the support listed above, leading to increased suffering for individuals with mental illness or placing an even greater burden on already strained government resources, resulting in poor-quality care and uninhabitable living conditions.

The current Mental health policy of India, excluding the family a stepping stone to failure!

The Government of India ratified the United Nations Convention on the Rights of Persons with Disabilities in 2007. During the following decade, the Mental Health Care Act (MHCA) of 2017 was enacted. The MHCA adopts a Western approach of being person-centric, rights-based, with a strong focus on in-patient care. However, it notably lacks provisions for out-patient, post-discharge care or community reintegration(Rao et al., 2016). This stands in stark contrast to the deinstitutionalization movement, a noble concept that unfortunately neglects the crucial role of key stakeholders such as family, friends, and other relatives who serve as active and primary caregivers. This brings out a mismatch of a western concept enforced on Indian cultural dynamics(Pavitra et al., 2019). The exclusion of these caregivers increases the risk of families becoming disengaged and withdrawing their support, ultimately widening the treatment gap.

In our democratic and welfare-oriented society, it is imperative that governing laws and acts are not only synchronized but also aligned with our cultural values. The MHCA has provisions for both voluntary and involuntary admissions. Involuntary admissions are for PWMI who lack insight have impaired judgment and have symptoms of aggression or suicidal thoughts/actions, thus posing a high risk to themselves or others. In such cases, involuntary admission becomes necessary. The role of the family is straightforward when an Advanced directive/Nominated Representative has not legally been processed. However, in cases where the provisions related to Advanced Directives (AD) and Nominated Representatives (NR) are present, the decisions cannot be made without the NR and thus challenges when modifications to AD are required. The cumbersome process of filling out forms, applying to the Mental Health Review Board (MHRB), and waiting for their recommendations can lead to delays in intervention. The role of the family is a supportive or secondary role which is contrary to the cultural norms.

Furthermore, limiting the family's previous rights and role creates a more defensive approach among psychiatrists(Pavitra et al., 2019). While the act does not grant family members the right to take necessary actions, it does expect their involvement. This paradoxical situation results in a back-and-forth, reluctance to assume complete responsibility and a sense of helplessness among immediate caregivers.

Conclusion

In conclusion, the invaluable role of family members throughout all phases of care for Persons with Mental Illness (PWMI) cannot be overstated. Their involvement is not merely beneficial but essential in achieving the goals of inclusion and community integration for PWMI. When legal constructs exclude families from crucial decisions and caregiving responsibilities, it can lead to feelings of despair and overwhelming burdens in the caregiving process. To truly serve the best interests of PWMI, it is imperative that we recognize, appreciate, and encourage the role of families in in-patient, out-patient, and home care settings. The identification of the caregiver at home, will help identify whom to psycho-educate and give information on rehabilitation. The "voice" of a bystander should be accorded the same respect and consideration as that of a PWMI, for it is together, as a collective force, that we can provide the most effective care and support to those in need, fostering a more compassionate and inclusive society.

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Recent Research
Service User Involvement
by Esther Ogundipe

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Introduction

The focus of this issue is service user involvement. The concept of service user involvement is underpinned by the notion that persons with lived experience of mental health challenges and/or substance use challenges have expertise and knowledge that are valuable in designing services and research (Bell et al., 2023).

The first paper presented is by Jay Bell, Anita Lim, Rachel Williams, Sonya Girdler, Ben Milbourn, and Melissa Black. They sought to understand the ingredients of effective co-production in developing an online mental health resource for university students. The second paper by Yun Chen, Yeqing Yuan, and Beth Glover Reed is a systematic review of qualitative evidence on experiences of peer work in drug use service settings. The final paper is by Alison Faulkner and Rose Thompson and addresses the emotional labor of involvement and co-production in mental health research as experienced by researchers with lived experience and research managers.

Paper 1. 'Nothing about us without us': co-production ingredients for working alongside stakeholders to develop mental health interventions.

DOI: https://doi.org/10.1080/18387357.2021.2020143

Bell et al. (2023) aimed to explore the ingredients of effective co-production. A steering group, comprised of five persons with lived experience or interest in mental health, informed the development of an online program named "Talk to Me" Massive Open Online Course (MOOC). The MOOC was designed to build the skills and knowledge of university students about managing their own mental health and supporting their peers. It included six modules: (1) mental fitness; (2) strategies to increase mental fitness; (3) non-suicidal self-injury; (4) suicidal behavior in young adults (SBYA); (5) interventions in SBYA; and (6) gatekeeper interventions. Three steering group meetings were held. The meetings focused on members 'experiences of co-producing. The audio recordings of these meetings were transcribed verbatim and analyzed following Braun and Clarke's (2006) approach to thematic analysis. Three overarching themes concerning the steering committee members' experiences of co-producing the MOOC and participating in the steering group were developed: (1) safety, (2) group dynamics, and (3) developing working partnerships. The authors conclude that effective co-production requires consideration, power-sharing, and planning to ensure that a person's involvement is productive and valuable.

Paper 2. Experiences of peer work in drug use service settings: A systematic review of qualitative evidence.

DOI: https://doi.org/10.1016/j.drugpo.2023.104182

Chen et al.´s (2023) systematic review aimed to: (1) examine how peers, clients, and other stakeholders experience peer work in nonpeer-led drug use service settings; (2) how peer work may benefit the field; and (3) how various organizational conditions may affect these experiences. Thirty-three qualitative studies examining the experiences of peer work in nonpeer-led drug use service settings were synthesized. Studies were conducted in the United States (n = 13), Canada (n = 10), the United Kingdom (n = 4), Australia (n = 2), India (n = 1), Senegal (n = 1), Indonesia (n =1), and Norway (n = 1). The thematic analysis resulted in 5 themes: (1) uniqueness of peer work in terms of shared experience; (2) benefits of having peers in nonpeer-led service settings; (3) benefits of conducting peer work for peers; (4) challenges due to the uniqueness of peer work; and (5) organizational facilitators and barriers to peer work. Their findings suggest that the involvement of peer workers in nonpeer-led settings provided benefits at the client, organizational, and societal levels. At the same time, the unique shared experience of peers was accompanied by challenges such as triggering, boundary negotiation, and feelings of being trapped by their peer identity. Overall, the five themes underscore the need to recognize, commit to, and engage with the uniqueness of peers who share lived or current experiences of drug use and services with service users. The authors call for more research exploring context- and setting-specific peer roles, organizational enablers, and barriers.

Paper 3. Uncovering the emotional labor of involvement and co-production in mental health research.

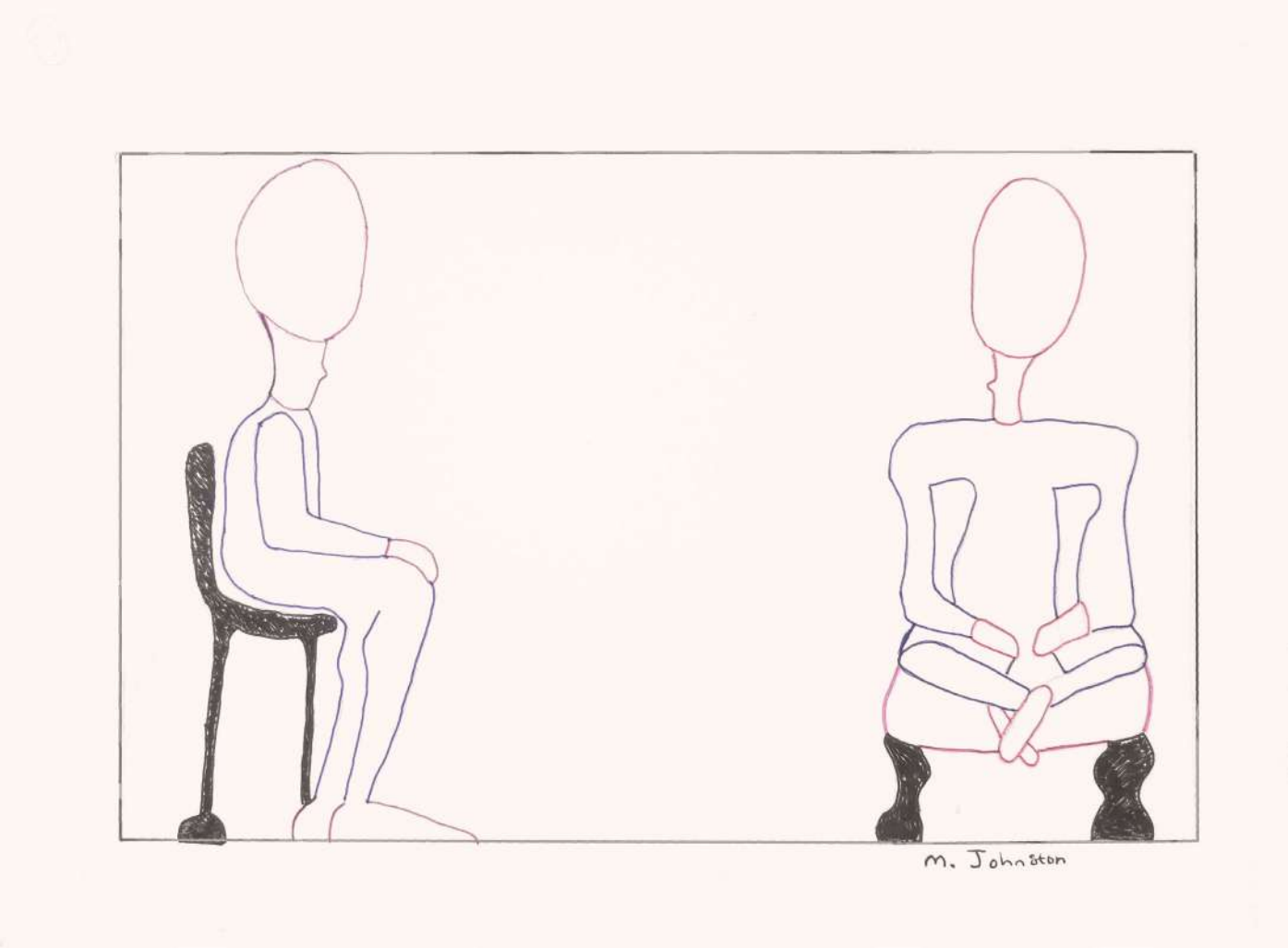
DOI: https://doi.org/10.1080/09687599.2021.1930519

Recognizing the need for more knowledge on how persons with substance use challenges understand and experience user involvement while receiving care, Faulkner and Thompson (2021) carried out a systematic review of qualitative studies that explored how persons with substance use challenges understood user involvement and their experiences and practices for achieving user involvement. Their review included 12 papers, and they used Noblit and Hare's meta-ethnography, revised by Malterud, to identify, translate, and summarize the reported findings. Three understandings of user involvement were described: (1) user involvement as joint meaning production, (2) points of view represented, and (3) user representation in welfare services. Seeing and respecting the service user as a unique person, the quality of the interactional process, and the scope of action for people with substance use challenges, and professionals, including issues of stigma, power, and fatalism, were reported as key practices for achieving user involvement. The authors underscore the ambiguity of the concept of user involvement and the importance of including the service user's perspective when defining user involvement. Due to their findings on key practices, they suggest that relational processes and contextual aspects need to be considered when developing user involvement concepts.

Recommendation: If you would like to read about how the concept of service user involvement has evolved in mental health care literature, then I recommend reading Samantha L. Millar, Mary Chambers, and Melaine Giles's (2015) literature review. In this review, they explored and analyzed the concept of service user involvement as used within the field of mental health care.

DOI: https://doi.org/10.1111/hex.12353

Sharing of Experiences around the Globe!



Artwork (c) Michael Johnston

Preventing a problem, the politicians created themselves

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Like a worm in a fruit, profit-oriented policies have slowly but steadily weakened welfare and solidarity in many countries. This article describes how the Norwegian health- and welfare services have been affected and how the situation for patients, families and carers is nowadays in Norway.

The Mental Health Carers Association in Norway (LPP) turned 30 years of activity last year. Unfortunately, we have just recently and perhaps too late become aware of what kind of barriers we have been and are still dealing with. These policies are extremely powerful in their New Public Management way and hide behind good intentions and beautiful promises. As a result, we mental health carers have turned into the role of watch dogs and whistle blowers.

LPP and many voluntary organisations and health and welfare associations have protested and sent alarm warnings which have fallen on deaf ears. We try to make our politicians aware of the severity of the situation. At the same time, we keep on reminding them of the importance of upholding essential values like solidarity and compassion alive.

The Scandinavian welfare model has typically been described as an excellent example of public welfare but is now in jeopardy. How is this possible? The answer can be found in the political model called New Public Management, which has ravaged the world for decades. This policy can be explained in a very simple way, and this also sheds light on what is happening with the health and welfare sector in many countries. It can be best summed up in one phrase: everything in society that is not profitable in the short term must go. Efficiency, keeping the budget and production are the key terms and issues. It is not difficult to understand why mental health care and care for the elderly have been hit so hard.

Both patients, carers and professionals are worried. As carers we feel that we're at rock bottom in Norway. Unfortunately, it looks this way after almost 10 years of gradual erosion of our health and welfare services.

Many will ask if the situation really is that bad. The Norwegian government has never spent as much money on the health and welfare sector as they are doing now. They seem to be particularly focused on new ways of organizing health and welfare services as well as more efficient ways of using the professionals. A problem we have noticed is that the professionals that have grown in number the recent years, are not those working with patients. It's the bureaucrats and controllers needed to run New Public Management procedures.

Though it is true that the health budget is higher than ever before, the question remains, "where has all the money gone?" In LPP we know that a great deal of the funding is used to produce countless reports, studies and strategies on rationalization, reorganizing and keeping the budgets. In addition to this there are the revisions and reforms of laws and regulations. Not to mention inquiries, especially during the pandemic. We are acutely aware of this because this abundant activity also produces a multitude of hearings, meetings, and investigations, all of which we are privy to. This huge amount of information has kept us so busy reading and responding that we've hardly been able to see the forest for the trees.

Today we are witnessing the consequences of this health policy. Nearly 40% of the beds in mental health hospitals have disappeared the last 18 years (Sykepleien, 2022). The inpatient service has not been replaced by adequate and accessible community mental health services. Several psychologist positions in hospitals have been removed. Rehabilitation centres are closing down. Insufficient housing and residential facilities are being built. Many voluntary organisations have lost all or some of their financial support and have had to cut down their activity or close down entirely.

As careers we are very worried about the politicians not seeming to see or respect the needs of people with the most comprehensive problems and those most vulnerable.

The consequences of this policy are dramatic:

- The suicide rate is not decreasing.
- Families' suffering and worries are increasing.
- The number of people who need help is increasing.
- In-patients beds are far too few.
- Patients are being discharged too early and follow-up after discharge is insufficient or absent.

LPP will soon submit advisory responses on suicide prevention. Our response will be clear and unambiguous: The best prevention begins with understanding the cause(s) of a problem. If the reason why a person does not want to live anymore is not known, then of course it won't be easy to help the individual.

We are dealing with a great paradox here. The health authorities want to prevent something they themselves have created with a policy that leads to a deep sense of hopelessness among the most vulnerable in society and their families:

- People who ask for help when help has become virtually non-existent.
- People who require follow-up and care in hospital are discharged, and there is lack of resources and expertise.
- People who require a longer stay in hospital when 38% of the beds have gone.
- People who require housing support when houses ares no longer being built.
- People who unfortunate enough end up in drug hot spots, when living on the streets is their only alternative.

This list is by no means complete but provides a few examples to highlight how hopelessness is directly linked to a policy that creates hopelessness.

When considering reasons why something is not going well, we can also focus on how this health and social policy is creating this hopeless situation through a marked based service organisation. People we talk about here need tailored services, not fragmented and product based.

In addition to having to endure this policy, many countries have experienced services and trends that promote cheaper, quick-fix solutions for patients. In short, you go home (if indeed you have a home) after shortterm in-patient services, either alone or with your family. A nurse or team will pop in x number of times a week, or you'll have to visit the outpatient clinic.

Naturally this is a reasonable course of action for those with less severe problems. However, it does not meet the needs of people with severe mental health problems.

These measures are discriminatory towards the person and the relatives/caregivers. It seems like it is taken for granted that relatives are available and can function as nurses, psychologists, social workers, and occupational therapists. Not to mention supporting the patients financially, as is often the case. In a way this is quite a money-spinner because relatives provide the help that expected from services.
In some countries families are natural caregivers due to culture and traditions. In Norway this used to be the situation decades ago, but the typical situation now is that family members work full time, and children move out and live their independent life. It is well known that families support their loved ones in a many facetted ways all year around. However, if the amount of support and worries becomes too much, this may lead to even more sick and vulnerable people who require help. When relatives themselves must go on sick leave or even quit their regular jobs, the result is one more patient and one less taxpayer.

This article begins with the claim that we've hit rock bottom. It seems that we will have to endure even more serious consequences to shake those responsible out of their drowsiness. Many families have simply given up, and for many it is too late. The obvious questions are, how many more and for how much longer?

LPP's priority in this situation is the same as it was during the pandemic: damage-control. We are doing everything we can to help and support each other so that as few of us as possible lose out in this fight.

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The importance of a parent community for support.

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Raising a child with mental health challenges is often an isolating and overwhelming experience for the parents or caretakers of that child. Finding the answers for assistance and the pathways toward resources can be grueling, taking hours of work and energy. I experienced this firsthand with my now 18-year-old daughter who has struggled with her mental health since she was 7 years old.

Although I had earned an advanced degree in Counseling and had spent several years doing crisis intervention with university students, I realized that the type of resilience needed as I cared for my own child in crisis was completely different. The hurdles I needed to overcome as I sought out assistance for her seemed never-ending. Back at the beginning of my journey in 2012, when there were signs that my daughter needed therapeutic support, it took 17 phone calls to find a children's therapist who was taking new clients and then another 10 calls to find a psychiatrist when it became apparent that her treatment required medication. My husband and I were worn out and overwhelmed when the psychiatrist diagnosed my daughter with obsessive compulsive disorder (OCD). Luckily, I learned that the International OCD Foundation's conference was being held nearby for people and families of children with OCD. Attending that conference helped me to feel less alone in our family's struggles. Sessions and social events for parents of children with OCD were built into the conference program. Suddenly my husband and I were able to have open conversations about our challenges and learn about types of therapy and medication that contributed to successful treatment. My daughter saw that she was not the only one struggling and my son connected with other siblings in families and learned techniques to help him interact better with his sister. With the resources, encouragement and support I gained, I was able to find a local, effective children's center where my husband, my daughter and I could work to learn the CBT skills needed to treat her OCD and keep it at bay.

Years later, when our daughter's depression entered the picture, our hope started to wane again. We couldn't find the right medications to help, even though her psychiatrist had attempted over 15 different combinations. We were overcome with shock when suicidal ideation became part of the equation and knew she needed to be treated on an inpatient basis, but there was no guidance on how or where to go. I reached out to another local parent who I knew worked in the mental health field. She not only gave me guidance but accompanied my daughter and I to the inpatient facility and stayed with me during the difficult intake process. It was a heart wrenching experience to leave my 14-year-old at a mental health hospital, and I don't know how I would have been able to do this without another parent's help. I promised myself that at some point in the future I would give another parent the same support.

There were three 60-minute seminars on parenting skills during my daughter's next two inpatient stays which were informative but did not allow for any interaction with other parents. My sense of isolation and stress grew as I tried to navigate her lack of progress in school, how much to share of her story with friends and family and finding any future care she might need. Luckily the town board of health offered a few programs about mental health where I was able to connect with other parents who shared information which helped me design a roadmap for the accommodations and academic support my daughter needed. This advocating took off some of the pressure I was feeling at the time, and it empowered me take the necessary steps my daughter needed as she reacclimated into school.

During 2021 and COVID my daughter was diagnosed with a chronic illness, and immediately

taken off the psychiatric medications she had been on, for fear that it was contributing to her physical symptoms. She immediately went into a bout of deep depression where every day was a struggle to persuade her to stay alive. All mental health hospitals and floors were filled over capacity. Her suicidal ideation grew, and at home we put all our energy into trying to keep her alive. My husband and I sought a couple's therapist to help guide us to work together, but the anxiety and exhaustion we felt day after day was unbelievable. There were no other parents to connect with in-person, so I went to Facebook and found a helpful group for parents of children with mental health issues in my state.

Suddenly I could reach out and ask questions since it was a private group. It was awkward, but through group posts, I learned that there were ways to find out which facilities had the lowest wait times. This often ranged from 6-12 weeks at the time, with children waiting in chairs in ERs or on gurneys in hospital hallways. My daughter's mental illness ran our household due to the accommodations my husband and I felt forced to make. We re-entered the stage of isolation as we were stretched thin trying to meet our professional and family responsibilities. My search for assistance with my daughter continued as I watched her lose hope in getting any relief. I put her on a three-month waitlist for a partial hospitalization program (PHP) for depression and OCD at a hospital I had read about online in a nearby state. As we inched closer to the start date, she limped through her remaining days of the schoolyear. My fatigue grew with trying to get her out of bed each morning, and my negotiating skills were put to the test as I tried to work with her school to find nonexistent accommodations, offering her sufficient support.

Had it not been for the parents I spoke with through connections born on the parent Facebook group, I may have lost complete hope when our daughter's long-awaited outpatient program had to unexpectedly defer new patients to an unknown date due to construction issues. I knew from my communication that other parents had faced even more challenging situations, but my heart was breaking as I watched my child's desire to live in such pain fade. At that point the waitlists at most Boston area hospitals were down to two weeks and with the help of her psychiatrist, we were able to get her a bed within a couple days of arriving in an ER.

Three difficult months went by with her sitting inpatient where we were unable to find a step-down program. Due to COVID regulations, we were only allowed to see and communicate with her once a week. Her depression grew and she began to self-harm at any point possible. During that time, I found myself trying to research every avenue to find a better spot for her, to no avail. Finally the deferral for the PHP for depression and OCD came through with a start date, but due to the distance from our home and my daughter's physical and mental state, she would not be able to make the daily 3-hour commute. We decided that the most effective option was for she and I to stay in a hotel near the hospital. Unfortunately, this PHP program did not connect the participants' parents in any way. It was clear though that our daughter might still need more support, and another step might be necessary before we could bring her home. At her psychologist's urging, I put her on a waitlist for a couple of residential programs. We also hired an educational consultant to guide us through the process. The greatest support I found at this point was again in a Facebook group for parents of children searching for mental health residential programs.

Another helpful form of support was the weekly, three-hour DBT training my husband and I participated in online. There were 10 participants in the 14-week Family Connections program and six couples in the 16-week IOP program we attended. It was nice to know we weren't alone in our struggles with our daughter, but neither program had much social interaction for support or resource sharing for future needs. A few months later, I joined a free, virtual 6-week program for parents of young adults with mental health needs out of Boston University called Flourishing Families. Participants shared their own experiences in breakout groups as we practiced therapeutic coping skills we were learning to use for ourselves to give us more strength and resilience as we made our way through the daily challenges of having a family member with mental illness. Local resources were also shared which added to the won-

derful support that this well thought out program offered. In addition, each member of the group had the opportunity to meet with one of the group facilitators individually each week during the program. Individual goals for self-care were established and implemented during those sessions.

I used the Flourishing Families program as a model when I decided to create a support group in my town for parents of children struggling with mental health. I wanted to prevent parents from feeling that sense of isolation and hopelessness that I once felt. The board of health and the town manager were open to sponsoring the group when it became apparent that more assistance was needed for families in our town. I have been able to co-facilitate the monthly group with two newly hired Community Wellness Coordinators. Parents attend and we begin each session with a mindfulness activity. I then share a DBT skill with the parents that they might use with their child. This is followed by conversations around support that members might need. We complete the 90-minute drop-in sessions by sharing resources for the parents on mental health supports both online and in our community. Facilitating this group has opened the door to others who are parenting a child with mental health challenges to seek me out individually as well. It never surprises me to receive a text or phone call from a parent searching for resources for their child.

When my daughter moved to the long-term residential program, it was a much better fit. She was able to catch up on the school she missed and graduate from high school. She learned leadership skills and was a member of a close community of girls which assisted her with her social skills. One of the best aspects of this 18-month program has been the family-centered model they prioritize. We have family therapy once a week, have therapeutic family and parent weekends every two months, with support groups built into the schedule. Her residential treatment center also holds virtual parent meetings twice a month. The mothers of the students have established a chat group with all of us chiming in often on parenting topics. These activities have facilitated communication among us outside of scheduled events. Many of the friendships I have formed continue long after the students may have completed the program. There were many times that I struggled to keep my head above water as I tried to navigate the challenges I faced with our daughter. Knowing that my situation was not an isolated experience and that there were other parents dealing with similar issues gave me the strength and encouragement that I needed to make decisions and seek the necessary assistance during each stage of my experience as a parent of a child struggling with her mental health.

Czech delegation visits Bergen, Norway and brings back inspiration for mental health care.

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I love finding out about towns and cities where locals have found ground-breaking solutions to common problems. Inspiring places like that can be found all around the world. In the Czech Republic, several municipalities have come up with interesting projects for eco-friendly energy management that don't involve pollution. One example is the White Carpathian village of Hostětín, which was even visited by King Charles III of the United Kingdom. Other European cities, such as Freiburg in Germany (Vauban district), have reduced traffic congestion by encouraging other modes of travel, while maintaining the same level of mobility for local residents.

As a person with experiences of mental health problems, I was excited that there are also places offering inspiration in terms of care for people with mental health challenges. Apart from Trieste, known to people thanks to a film documentary, there is the very interesting city of Bergen in the western part of Norway. I came to know Bergen through my participation in a project under the Polytechnic University of Jihlava. Thanks to this project, I could also visit the city in person and now I'm happy to share my take-aways from the expedition.

Our impressions of Bergen's social services

We were a group of several people with lived experiences who visited Bergen for a week. Our experiences with this city and its health and social services were very pleasant and emotional. The facilities we saw were often very spacious and designed to feel modern and comfortable. We were able to get a glimpse of the health and social workers' lives and share some insights of our own as well. We also met a lot of peer support workers. Music was made on several occasions – we listened to originals and covers played by the service users, like gentle folk songs and hard rock tracks by Judas Priest. In return, our colleague Tibor played his song with a light mystical touch to the Norwegians. We tried peanut soup – as a big fan of peanuts I was surprised I didn't know such a delicacy existed!

We found some aspects of local life in Bergen particularly interesting. For example, the users of the Bergen services aren't called "patients" as is customary in the Czech Republic, but "members". The Norwegians we met also put great emphasis on the healing power of music in mental health care. Music rehearsal rooms were a frequent feature, and we were told locals can study music therapy at university when they wish to.

In Bergen, people with mental health problems are not hidden away from the public; they are part of the local community's daily life. During an excursion to ALF, an organisation that mediates jobs for people with mental illness, I learned that we were actually staying in a hotel run as a social enterprise. The reception, breakfast, afternoon tea and daily cleaning were mostly in the hands of ladies who had previously struggled with mental health problems themselves. We bought souvenirs at the local ALF shop that sells products handmade in supported workshops. We even met the same people in health and social services and then later on in local bars.

The road is long, but we can get there too

Compared to the Czech context, there were many peer support workers in the facilities. But this had not always been the case. Audun Pedersen, senior advisor, told us how he and his colleagues had to fight in the past to have the city government recognize peer support workers as an enrichment of care given by professionals with no lived experience with mental health challenges. They didn't give up, though, and now there are several dozen peer sup-

port workers in the city's various services.

Audun Pedersen's determination and drive are a source of admiration for me. He is active in developing political action plans in the mental health and substance abuse field. Together with colleagues he has dedicated his efforts to making sure that his city's community services are progressive and meet high quality standards. And he has already come such a long way. I've personally been interested in politics for a long time, but people around me think it's impossible to get anything done. That's why I am always happy to see others work close with the political level to push public affairs forward. It shows me that it's worth trying to make a difference, either in the civic sphere or in politics. And perhaps it is the municipal level that is richest in opportunities.

Wrapping up the week

We exchanged contacts so that we could keep on sharing experience and best practices between our countries. It's possible that some members of the Czech expedition will soon go back to Bergen for an internship.

On the last day, peer support worker Suzanne from the Bergen Recovery College told us her life story and brought many of us to tears. Audun Pedersen, the main organizer of our itinerary for the week, revealed that the staff of the facilities we'd visited felt happy and proud to be able to share experiences with peer support workers and university people from abroad the useful work they were doing.

We were lucky to see a great deal of interesting projects, and also quite tired on our way back to the Czech Republic. But the inspiration had already taken root and I looked forward to coming home and writing up reports from our visit to Norway.

Each of us was personally inspired.

I believe our trip was significant not just because we visited places we were curious about. We found inspiration for what could be done back home. Some of us, for example, dream of setting up an equivalent of the Norwegian Amelie Skrams Hus. This is a place where people with hurting souls can come to make music, draw, work with wood, etc., which empowers them and brings out their strengths and potential.

As an active author and editor in the field of mental health care, I was inspired in my own way. I learned that in the past, people with mental health problems could sell the magazine of the local ALF organisation in Bergen and keep part of the earnings. Also, one morning during breakfast, we discovered a supplement in the local newspaper with stories of several people suffering from mental health problems, written in a highly destigmatizing manner. I took several copies of various newspapers and magazines home with me, and my mind is already busy with ideas. Perhaps in the next couple of years, I might try to set up a mental health section in Nový prostor ("New Space"), a Czech street magazine sold by the homeless? Or pioneer a destigmatizing supplement in one of the national dailies? The sky is the limit!

The author is involved in the project "Innovation and development of mental health courses" funded by the EEA Grants 2014–2021, Education Programme, and is a member of a patient organisation of people with mental illness – Spolek Kolumbus (www.spolekkolumbus.cz).

BasicNeeds Ghana promotes psychosocial rehabilitation for survivors of torture and organized violence (TOV).

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In 2018 BasicNeeds-Ghana and Mental Health Society of Ghana (MEHSOG) established a partnership with DIGNITY-Danish Institute Against Torture, a renown human rights organization in Denmark. The partnership was to enable BasicNeeds-Ghana and MEHSOG to promote Mental Health and Psychosocial Support Services (MHPSS) in Ghana. This became necessary to deal with growing cases of TOV among service users and carers during health-seeking encountered in the course of their work. BasicNeeds and MEHSOG identified this need but was unable to adequately deal with it until the coming of DIGNITY.

The partnership was to achieve the following objectives primarily: Influence policy in favour of survivors of TOV; build the capacity of BasicNeeds and MEHSOG staff to promote the trauma informed MHPSS in Ghana; Build the capacity of Service providers of formal and informal sectors to provide MHPSS without exposing service users to Cruel, Inhuman and Degrading Treatment (CIDT); Create awareness among the populace on causes and treatment of Psychological Trauma. It began with a pilot phase within two districts namely Ga West in Greater Accra and Zabzugu in the Northern Region. The pilot phase confirmed the prevalence of TOV among service users and their carers during their health-seeking. For example, it came out that the primary reason for seeking care from a Healing Centre was spiritual concerns and also that 30% of respondents indicated they experienced at least one potentially harmful treatment during one or more of their visits to a Healing Centre.

For the past four-and-half years, the project undertook the ensuing activities.

First and foremost, it has provided trainings on Psychological Trauma and trauma-informed MHPSS for Community Mental Healthcare Workers, Community Mental Health Volunteers, Traditional/Faith-based Healers, Government Human Rights Agencies and Key Influencers. These trainings have increased their understanding of the causes, symptoms, and management of psychological trauma. The beneficiaries have therefore become able to promote timely and quality rehabilitation for survivors of TOV.

In addition to the above, two rounds of Relationship Building Meetings were held between traditional/faith-based healers and Community Mental Healthcare Providers to dissolve their differences and build synergies for better service delivery. These were aimed at creating opportunities for joint service delivery to enhance recovery.

Furthermore, there were also Community Mental Health Durbars to educate the populace on the causes, symptoms, and psychological management. These durbars were also used to encourage the populace to eschew stigmatization and discrimination of survivors of TOV and embrace their acceptance. During the durbars, the traditional rulers made public declarations in support of timely rehabilitations for survivors of TOV and warned of consequences for abusing them.

Also, Media Engagements were also undertaken to amplify the reach of the awareness creation. These were in the form of Coverage of Project activities and Radio Talk shows. The engagements were in both English and Local Languages (Twi, Ga, and Dagbani).

Finally, a Research was conducted on the identification and facilitation of trauma informed MHPSS for survivors. The research revealed that most survivors are exposed to TOV in prayer camps and traditional healing centres. It also revealed interestingly that psychological trauma also happens to service users in the formal sector. On the most prevalence stressful life event, the research revealed that assault (69.9%) of any form emerged.

From the activities the achievements chalked up by the project are as below.

One, through the project, 510 traumatized individuals were identified and provided various forms of trauma-informed Mental Health and Psychosocial Support. Of these individuals, 153 survivors representing 30% registered improved conditions.

Two, four District Referrals Networks have been established in Ga West, LEKMA, Tamale Metropolis and Zabzugu Districts for dealing with issues militating against referrals. These networks have also reduced referrals time making rehabilitation timelier and more efficacious. The Referral Networks have also developed sustainability plans to ensure the gains of the project outlive the project lifespan.

Three, the National Stakeholders Forum has been established to drive the efforts at influencing policy in favour of survivors of TOV and sharing information on best practices regarding timely rehabilitation. The institutions constituting the Forum have added advocacy efforts at ensuring that Mental Healthcare is covered by the National Health Insurance Authority.

Four, through Community Durbars, Community Awareness Events and Media Engagements about 3000 persons were directly reached by the project activities. These people, hitherto, did not know about psychological trauma from TOV and are therefore now able to deal with survivors better. This has supported the fight against stigmatization and discrimination of survivors of TOV.

The lessons learned are limited media coverage on mental health are not necessarily as a result of disinterest but as a result of lack of capacity. Another lesson is that most mental healthcare providers are motivated more by recognition that material compensation. Finally, it was also realized that Government Human Rights organizations were in dire need of capacity building in MHPSS.

Artwork (c) Lisa Murphy, Pride
"Artmaking pulls my emotions and expresses the transformation of depression and anxiety into a tangible workable being. My Blackness, my gayness, and my femaleness shape the lens in which I see the world. I desire to create images, colors, and outlines that express my feelings and excite my eyes. Colors win me over every day and give me a reason to continue to put ideas to canvas, paper, and board."

https://www.artlifting.com/collections/lisa-murphy

USEFUL LINKS

In this section we offer links important for our field. If you have suggestions for websites and links, please mail the Bulletin Editor: *marit.borg@usn.no*

Check the dedicated website on WHO QualityRights where you can find news, resources, training opportunities and other useful information on the project: https://qualityrights.org/

Boston University Center for Psychiatric Rehabilitation:
https://cpr.bu.edu/

Toolkit and information about policy and implementation of human rights and recovery perspective can be found in:
https://www.who.int/publications/i/item/9789241548410

Convention on the Rights of Persons with Disabilities:
http://www.un.org/disabilities/default.asp?id=150

Implementing Recovery through Organisational Change:
http://www.imroc.org/

Yale Program for Recovery and Community Health:
http://www.yale.edu/PRCH/

Movement for Global Mental Health
http://www.globalmentalhealth.org/

The Gulbenkian Global Mental Health Platform
http://www.gulbenkianmhplatform.com/

The Mental Health Innovation Network (MHIN)
http://www.mhinnovation.net/

Mental health publications can be downloaded from the links below or ordered from the WHO bookshop:

The WHO Mental Health Gap Action Programme (mhGAP):
http://www.who.int/mental_health/mhgap/en/

The WHO Mental health action plan 2013 – 2020:
http://www.who.int/mental_health/publications/action_plan/en/

WHO QualityRights Project:
https://www.who.int/mental_health/policy/quality_rights/en/

WHO MiNDBank (online databases of good practices worldwide):
http://www.mindbank.info/

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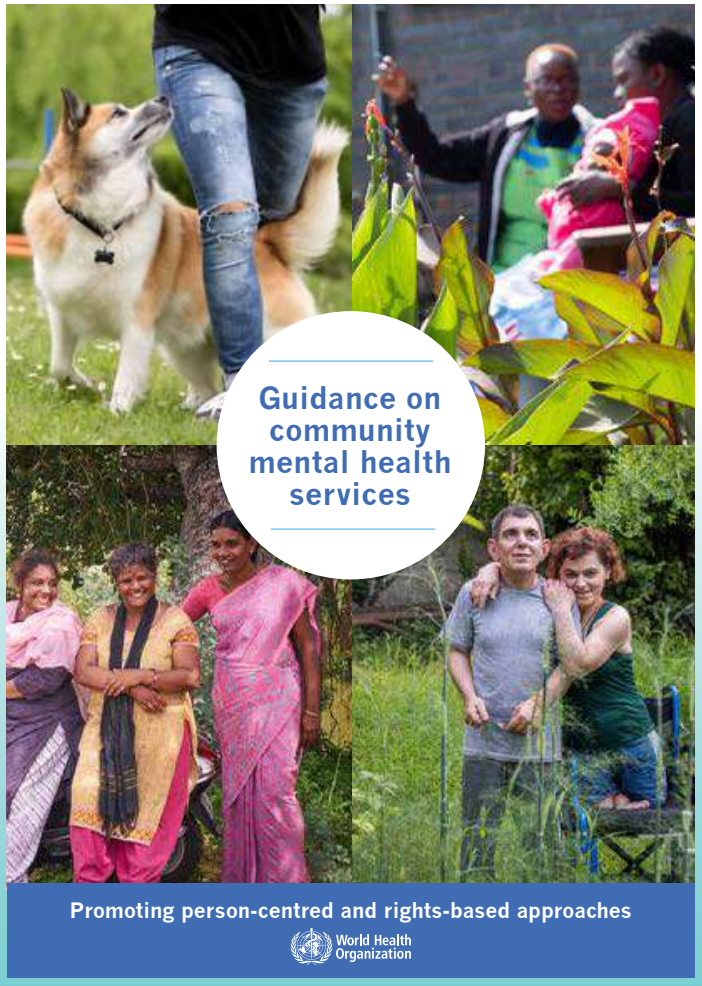

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