Technical package

Peer support mental health services

Promoting person-centred and rights-based approaches

World Health Organization

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QualityRights

Peer support mental health services: promoting person-centred and rights-based approaches

(Guidance and technical packages on community mental health services: promoting person-centred and rights-based approaches)

ISBN 978-92-4-002578-3 (electronic version)

ISBN 978-92-4-002579-0 (print version)

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Suggested citation. Peer support mental health services: promoting person-centred and rights-based approaches. Geneva: World Health Organization; 2021 (Guidance and technical packages on community mental health services: promoting person-centred and rights-based approaches). Licence: CC BY-NC-SA 3.0 IGO.

Cataloguing-in-Publication (CIP) data. CIP data are available at http://apps.who.int/iris.

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Design and layout by Genève Design.

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Foreword

Around the world, mental health services are striving to provide quality care and support for people with mental health conditions or psychosocial disabilities. But in many countries, people still lack access to quality services that respond to their needs and respect their rights and dignity. Even today, people are subject to wide-ranging violations and discrimination in mental health care settings, including the use of coercive practices, poor and inhuman living conditions, neglect, and in some cases, abuse.

The Convention on the Rights of Persons with Disabilities (CRPD), signed in 2006, recognizes the imperative to undertake major reforms to protect and promote human rights in mental health. This is echoed in the Sustainable Development Goals (SDGs) which call for the promotion of mental health and wellbeing, with human rights at its core, and in the United Nations Political Declaration on universal health coverage.

The last two decades have witnessed a growing awareness of the need to improve mental health services, however, in all countries, whether low-, medium- or high-income, the collective response has been constrained by outdated legal and policy frameworks, and lack of resources.

The COVID-19 pandemic has further highlighted the inadequate and outdated nature of mental health systems and services worldwide. It has brought to light the damaging effects of institutions, lack of cohesive social networks, the isolation and marginalization of many individuals with mental health conditions, along with the insufficient and fragmented nature of community mental health services.

Everywhere, countries need mental health services that reject coercive practices, that support people to make their own decisions about their treatment and care, and that promote participation and community inclusion by addressing all important areas of a person's life – including relationships, work, family, housing and education – rather than focusing only on symptom reduction.

The WHO Comprehensive Mental Health Action Plan 2020–2030 provides inspiration and a framework to help countries prioritize and operationalize a person-centred, rights-based, recovery approach in mental health. By showcasing good practice mental health services from around the world this guidance supports countries to develop and reform community-based services and responses from a human rights perspective, promoting key rights such as equality, non-discrimination, legal capacity, informed consent and community inclusion. It offers a roadmap towards ending institutionalization and involuntary hospitalization and treatment and provides specific action steps for building mental health services that respect every person's inherent dignity.

Everyone has a role to play in bringing mental health services in line with international human rights standards – policy makers, service providers, civil society, and people with lived experience of mental health conditions and psychosocial disabilities.

This guidance is intended to bring urgency and clarity to policy makers around the globe and to encourage investment in community-based mental health services in alignment with international human rights standards. It provides a vision of mental health care with the highest standards of respect for human rights and gives hope for a better life to millions of people with mental health conditions and psychosocial disabilities, and their families, worldwide.

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WHO Headquarters, Regional and Country Office contributions

Nazneen Anwar (WHO/SEARO); Șebnem Avșar Kurnaz (WHO/Turkey); Florence Baingana (WHO/AFRO); Fatima Batool (WHO/HQ); Andrea Bruni (WHO/AMRO); Kenneth Carswell (WHO/HQ); Vanessa Cavallera (WHO/HQ); Claudina Cayetano (WHO/AMRO); Daniel Hugh Chisholm (WHO/EURO); Neerja Chowdhary (WHO/HQ); Alarcos Cieza (WHO/HQ); Catarina Magalhães Dahl (WHO/AMRO); Tarun Dua (WHO/HQ); Alexandra Fleischmann (WHO/HQ); Stéfanie Freel (WHO/HQ); Brandon Gray (WHO/HQ); Fahmy Hanna (WHO/HQ); Mathew Jowett (WHO/HQ); Tara Mona Kessaram (WHO/Indonesia); Dévora Kestel (WHO/HQ); Kavitha Kolappa (WHO/HQ); Jason Ligot (WHO/WPRO); Aiysha Malik (WHO/HQ); Maria del Carmen Martinez Viciana (WHO/AMRO); Hernan Montenegro von Mühlenbrock (WHO/HQ); Melita Murko (WHO/EURO); Brian Ogallo (WHO/Sudan); Sally-ann Ohene (WHO/Ghana); Renato Oliveira E Souza (WHO/AMRO); Khalid Saeed (WHO/EMRO); Giovanni Sala (WHO/HQ); Alison Schafer (WHO/HQ); Nicoline Schiess (WHO/HQ); Katrin Seeher (WHO/HQ); Chiara Servili (WHO/HQ); Julie Storr (WHO/HQ); Shams B. Syed (WHO/HQ); Mark Van Ommeren (WHO/HQ); Martin Vandendyck (WHO/WPRO); Jasmine Vergara (WHO/Philippines); Edwina Zoghbi (WHO/Lebanon).

WHO administrative, editorial and other support

Administrative support: Patricia Robertson, Assistant to Unit Head, Policy, Law and Human Rights, Department of Mental Health and Substance Use, WHO, Geneva, Switzerland;

Editing of the Guidance on community mental health services: Promoting person-centred and rights-based approaches: Alexandra Lang Lucini (Switzerland);

Editing of the Technical packages on community mental health services: Promoting person-centred and rights-based approaches: Tatum Anderson (United Kingdom) and Alexandra Lang Lucini (Switzerland);

Drafting of initial summaries of the 25 good practice services: Elaine Fletcher, Global Policy Reporting Association (Switzerland); Tatum Anderson (United Kingdom);

Graphic Design: Jillian Reichenbach-Ott, Genève Design (Switzerland);

Other support: Casey Chu, Yale School of Public Health (USA); April Jakubec Duggal, University of Massachusetts (USA); Adrienne W.Y. Li, Toronto Rehabilitation Institute, University Health Network (Canada); Izabella Zant, EmblemHealth (USA).

Financial support

WHO would like to thank Ministry of Health and Welfare of the Republic of Korea for their continuous and generous financial support towards the development of the Guidance and Technical packages on community mental health services: Promoting person-centred and rights-based approaches. We are also grateful for the financial support received from Open Society Foundations, CBM Global, and the Government of Portugal.

Special thanks

Aung Clinic – Yangon, Myanmar would like to thank the study participants of the evaluation research for the Aung Clinic Mental Health Initiative, service users and their families, and networks and partnerships of local and international organizations/people; and the peer support workers and peer group of Aung Clinic Mental Health Initiative for advocacy and coordinating initiatives for people with psychosocial and intellectual disability.

East Lille network of mental health services – France would like to acknowledge the support to their service of the following individuals: Bernard Derosier, Eugéne Regnier, Gérard Duchéne (deceased), Claude Ethuin (deceased), Jacques Bossard, Françoise Dal, Alain Rabary, O. Verriest, M. Février, Raghnia Chabane and Vincent Demassiet.

BET Unit, Blakstad Hospital, Vestre Viken Hospital Trust – Viken, Norway would like to acknowledge Øystein Saksvi (deceased) for his mentorship, inspiration and important contribution to BET Unit.

Shared Lives – South East Wales, United Kingdom would like to acknowledge the following people for their key role in the development of their service: Jamie Harrison, Annie Llewellyn Davies, Diane Maddocks, Alison Minett, Perry Attwell, Charles Parish, Katie Benson, Chris O'Connor, Rosemary Brown, Ian Thomas, Gill Barratt, Angela Fry, Martin Price, Kevin Arundel, Susie Gurner, Rhiannon Davies, Sarah Bees, and the Newport Crisis Team and Newport In-patient Unit, Aneurin Bevan University Health Board (ABUHB); and in addition, Kieran Day, Rhian Hughes and Charlotte Thomas-Johnson, for their role in evaluation.

Peer Support South East Ontario – Ontario, Canada would like to acknowledge the support of Server Cloud Canada, Kingston, Ontario, Canada, to their website for the statistical data required for their service (https://www.servercloudcanada.com).

Executive summary

Mental health has received increased attention over the last decade from governments, nongovernmental organizations (NGOs) and multilateral organizations including the United Nations (UN) and the World Bank. With increased awareness of the importance of providing person-centred, human rights-based and recovery-oriented care and services, mental health services worldwide are striving to provide quality care and support.

Yet often services face substantial resource restrictions, operate within outdated legal and regulatory frameworks and an entrenched overreliance on the biomedical model in which the predominant focus of care is on diagnosis, medication and symptom reduction while the full range of social determinants that impact people's mental health are overlooked, all of which hinder progress toward full realization of a human rights-based approach. As a result, many people with mental health conditions and psychosocial disabilities worldwide are subject to violations of their human rights – including in care services where adequate care and support are lacking.

To support countries in their efforts to align mental health systems and services delivery with international human rights standards, including the Convention on the Rights of Persons with Disabilities (CRPD), the WHO Guidance on community mental health services: Promoting person-centred and rights-based approaches calls for a focus on scaling up community-based mental health services that promote person-centred, recovery- oriented and rights-based health services. It provides real-world examples of good practices in mental health services in diverse contexts worldwide and describes the linkages needed with housing, education, employment and social protection sectors, to ensure that people with mental health conditions are included in the community and are able to lead full and meaningful lives. The guidance also presents examples of comprehensive, integrated, regional and national networks of community-based mental health services and supports. Finally, specific recommendations and action steps are presented for countries and regions to develop community mental health services that are respectful of peoples' human rights and focused on recovery.

This comprehensive guidance document is accompanied by a set of seven supporting technical packages which contain detailed descriptions of the showcased mental health services

1. **Mental health crisis services**
2. **Hospital-based mental health services**
3. **Community mental health centres**
4. **Peer support mental health services**
5. **Community outreach mental health services**
6. **Supported living for mental health**
7. **Comprehensive mental health service networks**

Key messages of this guidance

- **Many people with mental health conditions and psychosocial disabilities face poor-quality care and violations of their human rights, which demands profound changes in mental health systems and service delivery.**
- **In many parts of the world examples exist of good practice, community-based mental health services that are person-centred, recovery-oriented and adhere to human rights standards.**
- **In many cases these good practice, community-based mental health services show lower costs of service provision than comparable mainstream services.**
- **Significant changes in the social sector are required to support access to education, employment, housing and social benefits for people with mental health conditions and psychosocial disabilities.**
- **It is essential to scale up networks of integrated, community-based mental health services to accomplish the changes required by the CRPD.**
- **The recommendations and concrete action steps in this guidance provide a clear roadmap for countries to achieve these aims.**

Introduction

Reports from around the world highlight the need to address discrimination and promote human rights in mental health care settings. This includes eliminating the use of coercive practices such as forced admission and forced treatment, as well as manual, physical or chemical restraint and seclusion[a] and tackling the power imbalances that exist between health staff and people using the services. Sector-wide solutions are required not only in low-income countries, but also in middle- and high-income countries.

The CRPD recognizes these challenges and requires major reforms and promotion of human rights, a need strongly reinforced by the Sustainable Development Goals (SDGs). It establishes the need for a fundamental paradigm shift within the mental health field, which includes rethinking policies, laws, systems, services and practices across the different sectors which negatively impact people with mental health conditions and psychosocial disabilities.

Since the adoption of the CRPD in 2006, an increasing number of countries are seeking to reform their laws and policies in order to promote the rights to community inclusion, dignity, autonomy, empowerment and recovery. However, to date, few countries have established the policy and legislative frameworks necessary to meet the far-reaching changes required by the international human rights framework. In many cases, existing policies and laws perpetuate institutional-based care, isolation as well as coercive – and harmful – treatment practices.

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[a] Strategies to end seclusion and restraint. WHO QualityRights Specialized training. Course guide. Geneva: World Health Organization; 2019 (https://apps.who.int/iris/bitstream/handle/10665/329605/9789241516754-eng.pdf).

Providing community-based mental health services that adhere to the human rights principles outlined in the CRPD – including the fundamental rights to equality, non-discrimination, full and effective participation and inclusion in society, and respect for people's inherent dignity and individual autonomy – will require considerable changes in practice for all countries. Implementing such changes can be challenging in contexts where insufficient human and financial resources are being invested in mental health.

This guidance presents diverse options for countries to consider and adopt as appropriate to improve their mental health systems and services. It presents a menu of good practice options anchored in community-based health systems and reveals a pathway for improving mental health care services that are innovative and rights-based. There are many challenges to realizing this approach within the constraints that many services face. However, despite these limitations, the mental health service examples showcased in this guidance show concretely – it can be done.

Examples of good practice community mental health services

In many countries, community mental health services are providing a range of services including crisis services, community outreach, peer support, hospital-based services, supported living services and community mental health centres. The examples presented in this guidance span diverse contexts from, for example, the community mental health outreach service, Atmiyata, in India, to the Aung Clinic community mental health service in Myanmar and the Friendship Bench in Zimbabwe, all of which make use of community health care workers and primary health care systems. Other examples include hospital-based services such as the BET unit in Norway, which is strongly focused on recovery, and crisis services such as Tupu Ake in New Zealand. This guidance also showcases established supported living services such as the KeyRing Living Support Networks in the United Kingdom and peer-support services such as the Users and Survivors of Psychiatry groups in Kenya and the Hearing Voices Groups worldwide.

While each of these services is unique, what is most important is that they are all promoting a person-centred, rights-based, recovery approach to mental health systems and services. None is perfect, but these examples provide inspiration and hope as those who have established them have taken concrete steps in a positive direction towards alignment with the CRPD.

Each mental health service description presents the core principles underlying the service including their commitment to respect for legal capacity, non-coercive practices, community inclusion, participation and the recovery approach. Importantly, each service presented has a method of service evaluation, which is critical for the ongoing assessment of quality, performance and cost-effectiveness. In each case, service costs are presented as well as cost comparisons with regional or national comparable services.

These examples of good practice mental health services will be useful to those who wish to establish a new mental health service or reconfigure existing services. The detailed service descriptions in the technical packages contain practical insights into challenges faced by these services as they evolved, and the solutions developed in response. These strategies or approaches can be replicated, transferred or scaled up when developing services in other contexts. The guidance presents practical steps and recommendations for setting up or transforming good practice mental health services that can work successfully within a wide range of legal frameworks while still protecting human rights, avoiding coercion and promoting legal capacity.

Significant social sector changes are also required

In the broader context, critical social determinants that impact people's mental health such as violence, discrimination, poverty, exclusion, isolation, job insecurity or unemployment, and lack of access to housing, social safety nets, and health services, are factors often overlooked or excluded from mental health discourse and practice. In reality, people living with mental health conditions and psychosocial disabilities often face disproportionate barriers to accessing education, employment, housing and social benefits – fundamental human rights – on the basis of their disability. As a result, significant numbers are living in poverty.

For this reason, it is important to develop mental health services that engage with these important life issues and ensure that the services available to the general population are also accessible to people with mental health conditions and psychosocial disabilities.

No matter how well mental health services are provided though, alone they are insufficient to support the needs of all people, particularly those who are living in poverty, or those without housing, education or a means to generate an income. For this reason, it is essential to ensure that mental health services and social sector services engage and collaborate in a very practical and meaningful way to provide holistic support.

In many countries, great progress is already being made to diversify and integrate mental health services within the wider community. This approach requires active engagement and coordination with diverse services and community actors including welfare, health and judiciary institutions, regional and city authorities, along with cultural, sports and other initiatives. To permit such collaboration, significant strategy, policy and system changes are required not only in the health sector but also in the social sector.

Scaling up mental health service networks

This guidance demonstrates that scaling up networks of mental health services that interface with social sector services is critical to provide a holistic approach that covers the full range of mental health services and functions.

In several places around the world, individual countries, regions or cities have developed mental health service networks which address the above social determinants of health and the associated challenges that people with mental health and psychosocial conditions face daily.

Some of the showcased examples are well-established, structured and evaluated networks that have profoundly reshaped and reorganized the mental health system; others are networks in transition, which have reached significant milestones.

The well-established networks have exemplified a strong and sustained political commitment to reforming the mental health care system over decades, so as to adopt a human rights and recovery-based approach. The foundation of their success is an embrace of new policies and laws, along with an increase in the allocation of resources towards community-based services. For instance, Brazil's community-based mental health networks offer an example of how a country can implement services at large scale, anchored in human rights and recovery principles. The French network of East Lille further demonstrates that a shift from inpatient care to diversified, community-based interventions can be achieved with an investment comparable to that of more conventional mental health services.

Finally, the Trieste, Italy network of community mental health services is also founded upon on a human rights-based approach to care and support, and strongly emphasizes de-institutionalization. These networks reflect the development of community-based mental health services that are strongly integrated and connected with multiple community actors from diverse sectors including the social, health, employment, judiciary and others.

More recently, countries such as Bosnia and Herzegovina, Lebanon, Peru, and others, are making concerted efforts to rapidly expand emerging networks, and to offer community-based, rights-oriented and recovery-focused services and supports at scale. A key aspect of many of these emerging networks is the aim of bringing mental health services out of psychiatric hospitals and into local settings, so as to ensure the full participation and inclusion of individuals with mental health conditions and psychosocial disabilities in the community. While more time and sustained effort is required, important changes are already materializing. These networks provide inspiring examples of what can be achieved with political will, determination and a strong human rights perspective underpinning actions in mental health.

Key recommendations

Health systems around the world in low-, middle- and high-income countries increasingly understand the need to provide high quality, person-centred, recovery-oriented mental health services that protect and promote people's human rights. Governments, health and social care professionals, NGOs, organizations of persons with disabilities (OPDs) and other civil society actors and stakeholders can make significant strides towards improving the health and well-being of their populations by taking decisive action to introduce and scale up good practice services and supports for mental health into broader social systems while protecting and promoting human rights.

This guidance presents key recommendations for countries and organizations, showing specific actions and changes required in mental health policy and strategy, law reform, service delivery, financing, workforce development, psychosocial and psychological interventions, psychotropic drugs, information systems, civil society and community involvement, and research.

Crucially, significant effort is needed by countries to align legal frameworks with the requirements of the CRPD. Meaningful changes are also required for policy, strategy and system issues. Through the creation of joint policy and with strong collaboration between health and social sectors, countries will be better able to address the key determinants of mental health. Many countries have successfully used shifts in financing, policy and law as a powerful lever for mental health system reform. Placing human rights and recovery approaches at the forefront of these system reforms has the potential to bring substantial social, economic and political gains to governments and communities.

In order to successfully integrate a person-centred, recovery-oriented and rights-based approach in mental health, countries must change and broaden mindsets, address stigmatizing attitudes and eliminate coercive practices. As such, it is critical that mental health systems and services widen their focus beyond the biomedical model to also include a more holistic approach that considers all aspects of a person's life. Current practice in all parts of the world, however, places psychotropic drugs at the centre of treatment responses whereas psychosocial interventions, psychological interventions and peer support should also be explored and offered in the context of a person-centred, recovery and rights-based approach. These changes will require significant shifts in the knowledge, competencies and skills of the health and social services workforce.

More broadly, efforts are also required to create inclusive societies and communities where diversity is accepted, and the human rights of all people are respected and promoted. Changing negative attitudes and discriminatory practices is essential not just within health and social care settings, but also within the community as a whole. Campaigns raising awareness of the rights of people with lived experience are critical in this respect, and civil society groups can play a key strategic role in advocacy.

Further, as mental health research has been dominated by the biomedical paradigm in recent decades, there is a paucity of research examining human rights-based approaches in mental health. A significant increase in investment is needed worldwide in studies examining rights-based approaches, assessing comparative costs of service provision and evaluating their recovery outcomes in comparison to biomedical-based approaches. Such a reorientation of research priorities will create a solid foundation for a truly rights-based approach to mental health and social protection systems and services.

Finally, development of a human rights agenda and recovery approach cannot be attained without the active participation of individuals with mental health conditions and psychosocial disabilities. People with lived experience are experts and necessary partners to advocate for the respect of their rights, but also for the development of services and opportunities that are most responsive to their actual needs.

Countries with a strong and sustained political commitment to continuous development of community-based mental health services that respect human rights and adopt a recovery approach will vastly improve not only the lives of people with mental health conditions and psychosocial disabilities, but also their families, communities and societies as a whole.

What is the WHO QualityRights initiative?

WHO QualityRights is an initiative which aims to improve the quality of care and support in mental health and social services and to promote the human rights of people with psychosocial, intellectual or cognitive disabilities throughout the world. QualityRights uses a participatory approach to achieve the following objectives:

1

Build capacity to combat stigma and discrimination, and to promote human rights and recovery.

- WHO QualityRights face to face training modules
- WHO QualityRights e-training on mental health and disability: Eliminating stigma and promoting human rights

2

Improve the quality of care and human rights conditions in mental health and social services.

- WHO QualityRights assessment toolkit
- WHO QualityRights module on transforming services & promoting rights

3

Create community-based and recovery-oriented services that respect and promote human rights.

- WHO guidance and technical packages on community mental health services: Promoting person-centred and rights-based approaches
- WHO QualityRights guidance module one-to-one peer support by and for people with lived experience
- WHO QualityRights guidance module on peer support groups by and for people with lived experience
- WHO QualityRights person-centred recovery planning for mental health and well-being self-help tool

4

Support the development of a civil society movement to conduct advocacy and influence policy-making.

- WHO QualityRights guidance module on advocacy for mental health, disability and human rights
- WHO QualityRights guidance module on civil society organizations to promote human rights in mental health and related areas

5

Reform national policies and legislation in line with the Convention on the Rights of Persons with Disabilities and other international human rights standards.

- WHO guidance currently under development

For more information visit the WHO QualityRights website

About the WHO Guidance and technical packages on community mental health services

The purpose of these documents is to provide information and guidance to all stakeholders who wish to develop or transform their mental health system and services. The guidance provides in-depth information on the elements that contribute towards the development of good practice services that meet international human rights standards and that promote a person-centred, recovery approach. This approach refers to mental health services that operate without coercion, that are responsive to people's needs, support recovery and promote autonomy and inclusion, and that involve people with lived experience in the development, delivery and monitoring of services.

There are many services in countries around the world that operate within a recovery framework and have human rights principles at their core – but they remain at the margins and many stakeholders including policy makers, health professionals, people using services and others, are not aware of them.

The services featured in these documents are not being endorsed by WHO but have been selected because they provide concrete examples of what has been achieved in very different contexts across the world. They are not the only ones that are working within a recovery and human rights agenda but have been selected also because they have been evaluated, and illustrate the wide range of services that can be implemented.

Showing that innovative types of services exist and that they are effective is key to supporting policy makers and other key actors to develop new services or transform existing services in compliance with human rights standards, making them an integral part of Universal Health Coverage (UHC).

This document also aims to highlight the fact that an individual mental health service on its own, even if it produces good outcomes, is not sufficient to meet all the support needs of the many people with mental conditions and psychosocial disabilities. For this, it is essential that different types of community-based mental health services work together to provide for all the different needs people may have including crisis support, ongoing treatment and care, community living and inclusion.

In addition, mental health services need to interface with other sectors including social protection, housing, employment and education to ensure that the people they support have the right to full community inclusion.

The WHO guidance and technical packages comprise a set of documents including:

- ***Guidance on community mental health services: Promoting person-centred and rights-based approaches –*** This comprehensive document contains a detailed description of person-centred, recovery and human rights-based approaches in mental health. It provides summary examples of good practice services around the world that promote human rights and recovery, and it describes the steps needed to move towards holistic service provision, taking into account housing, education, employment and social benefits. The document also contains examples of comprehensive, integrated networks of services and support, and provides guidance and action steps to introduce, integrate and scale up good practice mental health services within health and social care systems in countries to promote UHC and protect and promote human rights.

- ***Seven supporting technical packages on community mental health services: Promoting person-centred and rights-based approaches –*** The technical packages each focus on a specific category of mental health service and are linked to the overall guidance document. The different types of services addressed include: mental health crisis services, hospital-based mental health services, community mental health centres, peer support mental health services, community outreach mental health services, supported living services for mental health, and networks of mental health services. Each package features detailed examples of corresponding good practice services which are described in depth to provide a comprehensive understanding of the service, how it operates and how it adheres to human rights standards. Each service description also identifies challenges faced by the service, solutions that have been found and key considerations for implementation in different contexts. Finally, at the end of each technical package, all the information and learning from the showcased services is transformed into practical guidance and a series of action steps to move forward from concept to the implementation of a good practice pilot or demonstration service.

Specifically, the technical packages:

- showcase, in detail, a number of mental health services from different countries that provide services and support in line with international human rights standards and recovery principles;
- outline in detail how the good practice services operate in order to respect international human rights standards of legal capacity, non-coercive practices, community inclusion, participation and the recovery approach;
- outline the positive outcomes that can be achieved for people using good practice mental health services;
- show cost comparisons of the good practice mental health services in contrast with comparable mainstream services;
- discuss the challenges encountered with the establishment and operation of the services and the solutions put in place to overcome those challenges; and
- present a series of action steps towards the development of a good practice service that is person-centred and respects and promotes human rights and recovery, and that is relevant to the local social and economic context.

It is important to acknowledge that no service fits perfectly and uniquely under one category, since they undertake a multitude of functions that touch upon one or more of the other categories. This is reflected in categorizations given at the beginning of each mental health service description.

These documents specifically focus on services for adults with mental health conditions and psychosocial disabilities. They do not include services specifically for people with cognitive or physical disabilities, neurological conditions or substance misuse, nor do they cover highly specialized services, for example, those that address eating disorders. Other areas not covered include e-interventions, telephone services (such as hotlines), prevention, promotion and early intervention programmes, tool-specific services (for example, advance planning), training and advocacy. These guidance documents also do not focus on services delivered in non-specialized health settings, although many of the lessons learned from the services in this document also apply to these settings.

How to use the documents

Guidance on community mental health services: Promoting person-centred and rights-based approaches is the main reference document for all stakeholders. Readers interested in a particular category of mental health service may refer to the corresponding technical package which provides more detail and specific guidance for setting up a new service within the local context. However, each technical package should be read in conjunction with the broader Guidance on community mental health services document, which provides the detail required to also integrate services into the health and social sector systems of a country.

These documents are designed for:

- relevant ministries (including health and social protection) and policymakers;
- managers of general health, mental health and social services;
- mental health and other health and community practitioners such as doctors, nurses, psychiatrists psychologists, peer supporters, occupational therapists, social workers, community support workers, personal assistants, or traditional and faith based healers;
- people with mental health conditions and psychosocial disabilities;
- people who are using or who have previously used mental health and social services;
- nongovernmental organizations (NGOs), and others working in the areas of mental health, human rights or other relevant areas such as organizations of persons with disabilities, organizations of users/survivors of psychiatry, advocacy organizations, and associations of traditional and faith-based healers;
- families, support persons and other care partners; and
- other relevant organizations and stakeholders such as advocates, lawyers and legal aid organizations, academics, university students, community and spiritual leaders.

A note on terminology

The terms “persons with mental health conditions and psychosocial disabilities” as well “persons using mental health services” or “service users” are used throughout this guidance and accompanying technical packages.

We acknowledge that language and terminology reflects the evolving conceptualization of disability and that different terms will be used by different people across different contexts over time. People must be able to decide on the vocabulary, idioms and descriptions of their experience, situation or distress. For example, in relation to the field of mental health, some people use terms such as “people with a psychiatric diagnosis”, “people with mental disorders” or “mental illnesses”, “people with mental health conditions”, “consumers”, “service users” or “psychiatric survivors”. Others find some or all these terms stigmatizing or use different expressions to refer to their emotions, experiences or distress.

The term “psychosocial disability” has been adopted to include people who have received a mental health-related diagnosis or who self-identify with this term. The use of the term “disability” is important in this context because it highlights the significant barriers that hinder the full and effective participation in society of people with actual or perceived impairments and the fact that they are protected under the CRPD.

The term “mental health condition” is used in a similar way as the term physical health condition. A person with a mental health condition may or may not have received a formal diagnosis but nevertheless identifies as experiencing or having experienced mental health issues or challenges. The term has been adopted in this guidance to ensure that health, mental health, social care and other professionals working in mental health services, who may not be familiar with the term ‘psychosocial disability’, nevertheless understand that the values, rights and principles outlined in the documents apply to the people that they encounter and serve.

Not all people who self-identify with the above terms face stigma, discrimination or human rights violations. a user of mental health services may not have a mental health condition and some persons with mental health conditions may face no restrictions or barriers to their full participation in society.

The terminology adopted in this guidance has been selected for the sake of inclusiveness. It is an individual choice to self-identify with certain expressions or concepts, but human rights still apply to everyone, everywhere. Above all, a diagnosis or disability should never define a person. We are all individuals, with a unique social context, personality, autonomy, dreams, goals and aspirations and relationships with others.

1.

Introduction

Peer support mental health services consist of one-to-one or group support sessions provided by people with lived experience to others who wish to benefit from their experience and support. The aim is to support people on the issues they consider important to their own lives and recovery, in a way that is free from judgment and assumptions.

As experts by experience, peers are able to uniquely connect with, and relate to individuals going through a challenging time because of their first-hand knowledge and experience. As such, they serve as compassionate listeners, educators, coaches, advocates, partners and mentors. The services highlighted in the following section are managed and run by people who are experts by experience. Participation in peer support is always based on choice and informed consent, and people receiving peer support are under no obligation to continue the support that was offered, allowing the person to make the choice based on their will, preference and self-identified needs.

The ways in which peer support services are structured and organized varies widely depending on their context. These services also vary in terms of the scope of activities provided, ranging from emotional support, helping people understand their experiences, supporting people to access social benefits and other opportunities, and activities aimed at promoting people's social inclusion, through to advocacy and awareness raising work. In general, peer support services facilitate the creation of social support networks that may not have been possible otherwise.

Peer support is reported to be a central pillar in many peoples' recovery. It is based on the important premise that the meaning of recovery can be different for everyone and that people can benefit tremendously from the sharing of experiences, being listened to and respected, being supported to find meaning in their experiences and a path to recovery that works for them, ultimately enabling them to lead a fulfilling and satisfying life. While the many peer support services being provided around the world place importance on promoting hope, sharing of experiences and empowerment, the examples of good practice services showcased in this document also take active steps to avoid coercive practices and to ensure that the legal capacity of people participating in peer support is respected.

The services described in this technical package were chosen following an extensive search and screening of services identified through literature reviews, a comprehensive internet search, an e-consultation and with input from existing WHO networks and collaborators. A detailed description of the methodology is provided in the annex of *Guidance on community mental health services: Promoting person-centred and rights-based approaches*. The selection process was based on the five human rights and recovery criteria, namely: respect for legal capacity, non-coercive practices, participation, community inclusion, and the recovery approach. Services from low-income contexts and under-represented geographical regions were prioritized where possible and/or appropriate, as well as services with evaluation data. One of the key challenges identified in reviewing the services was the lack of robust evaluation data. This challenge was encountered across all service categories. The need for greater investment in evaluating services is one of the recommendations made in the section on guidance and action steps in *Guidance on community mental health services: Promoting person-centred and rights-based approaches*. The services described in this technical package are not intended to be interpreted as best practice, but rather to illustrate what can be done and to demonstrate the wider potential of community-based mental health services that promote a person-centred, rights-based, recovery approach.

Providing community-based mental health services that adhere to human rights principles represents considerable shifts in practice for all countries and sets very high standards in contexts where insufficient human and financial resources are being invested in mental health. Some low-income countries may assume that the examples from high-income countries are not appropriate or useful, and equally, for high-income countries looking at the examples showcased from low-income countries. New types of services and practices may also generate a range of questions, challenges, and concerns from different stakeholders, be it policy makers, professionals, families and carers or individuals who use mental health services. The intention of this guidance is not to suggest that these services be replicated in their entirety, but rather to take and learn from those principles and practices that are relevant and transferrable to one's own context in providing community-based mental health services that are person-centred and promote human rights and recovery.

2.

Peer support mental health services – description and analysis

2.1

Hearing Voices Support Groups

Primary classification: **Peer support**

Other classifications:

☐ Community mental health centre ☐ Community outreach ☐ Peer support
☐ Crisis service ☐ Hospital-based service ☐ Supported living service

Availability in different locations:

☑ Yes ☐ No

Evidence:

☑ Published literature ☑ Grey literature ☐ None

Financing:

☐ State health sector ☐ State social sector ☐ Health insurance
☐ Donor funding ☐ Out-of-pocket payment ☑ Other[b]

Context

Hearing voices is an experience that frequently brings individuals into contact with mental health services. While many people who experience distressing voices find some relief through the suppression of their voices by anti-psychotic medication, others are not helped by this approach *(1, 2)*. In addition, many people experience their voices as potentially meaningful, even if confusing and distressing, and wish to understand where these voices come from *(3-5)*.

The Hearing Voices Movement (HVM) began in the Netherlands in the late 1980s and emerged from a collaboration between a Dutch psychiatrist, a researcher, and a voice hearer, along with many other individuals with lived experience of voice hearing *(6)*. Rather than trying to suppress voices with medication, the HVM believed that a more helpful strategy for many voice hearers was to change their relationship with their voices. This involved an exploration of the nature of the voices and what they might mean, in the context of group meetings with other people who had similar experiences.

The movement has now spread across the world *(7)* with national networks in 30 countries *(8)*. The worldwide network of Hearing Voices Groups called Intervoice supports the International Hearing Voices Movement through "connecting people, sharing ideas, distributing information, highlighting innovative initiatives, encouraging high quality respectful research and promoting its values across the world" *(9)*. Some groups have been co-founded by professionals and operate as part of, or closely aligned with, existing mental health services. Others have been organized by people who hear voices themselves and are resolutely independent of health services *(8)*.

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[b] Funding for Hearing Voices Groups can come from different sources depending on the group, including donor funding, some small amounts of out-of-pocket funding or funding from health services.

While the HVM and individual Hearing Voices Groups (HVGs) incorporate and celebrate a diverse range of perspectives, several core principles guide both the peer groups and the movement that has emerged around them *(7)*:

> *Normalization* – hearing voices is a normal part of human experience: In HVGs, voices are not regarded as being necessarily pathological, but as a meaningful and interpretable response to social, emotional or interpersonal challenges. The potential for hearing voices is understood to exist in all of us. This does not undermine the fact many people may hear voices that they find to be distressing and debilitating.
>
> *Diversity of explanation* – different understandings of voices are welcomed: HVGs welcome a diversity of ideas in relation to the origins and significance of voice-hearing *(10)*. These include biological, psychological and spiritual understandings *(11)*.
>
> Voice-hearers are encouraged to develop their own understanding: HVGs encourage people to take ownership of their own voices, and to work out their own understanding of these. A basic function of the HVG is to provide a safe space in which this can happen *(12)*.
>
> *Voice hearing can be best explained by reference to life events and interpersonal narratives:* Overwhelming life events that disempower a person are often reported to underlie the development of voices. Many people have written and spoken about the role of traumatic events in the genesis of these experiences *(13)*, and there is empirical evidence to support this association *(14)*. In fact, there is growing evidence of the role of childhood trauma in the origins of psychotic experience more generally *(15, 16)*. Frequently, the words, identity of the voices, or the timing of their onset, correspond to aspects of early childhood events *(5)*. HVGs encourage a careful articulation and interpretation of each individual's voice-hearing experiences. There is resistance to the use of psychiatric labels and medicalized explanations, even when these incorporate references to trauma. Instead, insights from HVGs, and the HVM more generally, "guide understandings of health as a fundamentally social, cultural, and political process" *(1)*.
>
> *Working towards acceptance of voices is often a better strategy than trying to suppress or eliminate them:* An acceptance of the voices implies a corresponding acknowledgement of the subjective reality of the person involved, even if this is painful and/or conflicted. Romme and Escher *(17)* suggested that voices are often both the "problem" and the "solution"; that is, while they may involve an attack on the identity of the person, they are often also a way of preserving this identity by "articulating and embodying emotional pain" *(7)*. HVGs work to help people reorient themselves in relation to their voices and rebuild their relationships with them.
>
> *Peer support and collaboration is empowering:* Voice hearing is very often considered "taboo" *(12)*, and finding solidarity with others can offer reassurance and a sense of safety. Sharing the experience of voice hearing with others who have had similar experiences can be powerfully validating and even liberating for many people. Such mutual listening and learning among peers allows people to be exposed to different ways of thinking about voices and learn new strategies to cope with them.

Hearing Voices Groups are organized into local and national networks that offer support, advice and guidance for new groups, and many have their own websites with information available to anyone seeking help or advice. Conferences take place regularly. The groups support one another without a hierarchical structure, which may explain the success of long-standing networks such as the one in the UK. The movement is strongest in the UK, with over 180 groups hosted in a wide range of settings including child and adolescent mental health services, prisons, inpatient units and in the voluntary sector. In London, a city-wide project called Voice Collective supports young people (aged 12-18 years) who hear voices *(18)* and is run by the organization Mind *(19)*. While HVGs have been slower to take root in the USA, 121 groups in 25 states are currently listed in the US Hearing Voices Network database, and these numbers have been increasing every year *(20)*. In Australia, each state has its own HVG network, with 23 groups in Sydney and the State of New South Wales *(21)*. In Hong Kong, five NGOs are running HVGs and the organization New Life *(22)* has six groups running in its centres and houses.

Description of the Service

Hearing voices group meetings typically do not follow a standard format, unlike more structured peer-support approaches such as that of Alcoholics Anonymous (AA). Instead, local groups are encouraged to develop independently. Some HVGs have been set up by individuals or groups of individuals who hear voices, while others have been initiated by professionals working on their own or in partnership with a voice hearer.

HVGs welcome people who have experiences other than voice hearing *(12)* – some groups are open to people who have visions or other experiences that would be typically regarded as "psychotic", while others are open to people who experience any form of mental distress *(8)*. Some HVGs only accept those with personal experience, while others involve professionals, and some involve family members. A small number of HVGs are women-only, other groups exist for young people *(18)*, and still others for members of specific cultural communities.

Group meetings are held in various venues including community facilities such as libraries, peer organization offices, adult education or arts centres; and others are held in mental health settings. HVGs also exist prisons and inpatient psychiatric units *(23)*. Most meet on a weekly or fortnightly basis as open groups, in which new members can join at any time and people come and go as their needs change. Attendance is informal and not time-limited *(24, 25)*. Some groups simply organize informal discussions, while others invite guest speakers, and in the USA some HVGs arrange group outings or activities *(8)*.

Group meetings are guided by two facilitators whose role is to act as enablers, allowing members to gain support from the group while keeping the discussion focused and maintaining "ground rules". They introduce the HVN ethos as stated in its charter, manage the logistics of meetings and aim to provide some structure to the group meeting, but do not act as therapists. Well-established groups work with a pool of facilitators, providing them with flexibility and support *(26)*. Facilitators come from different backgrounds but usually include at least one person with lived experience of voices or visions.

Facilitators are trained to enable a diversity of perspectives to be equally valued in group meetings, and to model acceptance and non-judgmental curiosity toward the complexities of psychological experience *(10, 25)*. There is no expectation for members to conform to any particular explanatory framework such as psychological, biomedical, spiritual or paranormal. *(24)*. Crucially, voices are not regarded as necessarily pathological. While some people experience them as such, the group helps to make them less so. By establishing an intentionally non-judgmental attitude *(10)* HVGs aim to represent a safe space, where people can deal with emotionally painful experiences and memories *(27)*. If conflict occurs in a group meeting there is a collaborative effort to deal with this. One person gave this example from an American group: 'Recently someone in the online group was screaming, and it was very disruptive. But instead of asking him to leave, people focused on what it was like for him to be having that experience, and the situation calmed down' *(10)*.

To encourage such curiosity about voice-hearing, many groups use voice profiling *(10)*. A full picture of a person's voices may be created by the members asking each other questions regarding what the voices say, the tone they use, how many different voices there are, whether they are male or female, whether they have changed over time, whether there are certain situations when they're most likely to appear, how the person feels when hearing the voices, and what purpose they think they serve. *(5, 25).* The aim of this questioning is to help a person to "know" the voices better and to feel less intimidated by them, making sense of experiences that have often been confusing or terrifying.

Many people find the experience of other people asking questions about their voices to be enabling. In this supportive context a person may be able to identify the circumstances most likely to trigger the voices, giving them more control over the experience. One person said that attending an HVG had helped her to develop a vocabulary to describe her own experiences *(25)*. This transformation and the processes involved are explained by a three-phase model developed by Hornstein, Putnam and Branitsky *(2020) (10)*.

Some HVGs also engage in activities other than peer support, such as providing consultation and advice to other organizations including government-provided services and NGOs. This serves an educational purpose, helping to reduce stigma and promote acceptance of people who hear voices. In the USA, there are now several online HVGs run by the Western Mass Recovery Learning Community, now known as the Wildflower Alliance *(28)*. The same organization also provides a support group for family and friends of people who hear voices *(29)*.

Core principles and values underlying the service

Respect for legal capacity

Hearing voices groups operate on a purely voluntary basis. They are never imposed on a person and never work to undermine a person's legal capacity. They do not incorporate any mechanism by which a person would be referred to a service that could undermine their legal capacity. The ultimate aim of HVGs is to empower people in relation to the voices they hear and the mental health services they encounter, so that they are in control of their lives and the decisions that affect them. They do so by providing a forum for dialogue about experiences and treatment options. HVGs aim to strengthen the voice hearer's ability to articulate their own understanding of their voices, and to make more informed decisions about whether to take medication and whether to engage in psychotherapy.

Alternatives to coercive practices

All attendance at HVGs is voluntary, and there are no coercive practices. Hearing voices groups do not refer people for treatment elsewhere against their will or to services where coercion may be used.

Community inclusion

HVG meetings are held primarily in community settings rather than mental health settings, hosted by NGOs, or as stand-alone groups. Some groups undertake external activities in the community, such as providing consultation to other organizations or arranging inclusive activities, such as hiking trips *(8)*.

HVGs are focused on providing a safe place for people to engage differently with their experiences. While individuals may receive advice and suggestions in group meetings, the groups are not involved directly in finding work, education or housing for attendees.

Participation

The spirit and structure of the groups and the wider movement is one of peer participation and support. HVGs are made up of people with lived experience of voice hearing. Most groups are organized by peers who have received training to be facilitators. While many groups are facilitated by trained peer supporters rather than professionals, this differs substantially within and across countries.

Recovery approach

The core principles of the HVGs are closely allied with the recovery approach. The five key CHIME[c] processes identified in the literature on recovery *(30)* are discussed extensively in the HVM and in research reports on HVGs *(27)*. HVGs work to help individuals develop their own framework of understanding, set their own goals and objectives in relation to their voices, and generate hope through the medium of peer support. There is an avoidance of medicalizing terminology such as 'auditory hallucinations', 'delusions' and 'symptoms'. Further, many members of HVGs argue that their voices are a core part of their personality, not a symptom of illness from which they need to recover.

Service Evaluation

Research on HVGs is constrained by the fact that groups work to individual agendas and do not have a manualized structure, thus cannot easily be studied in a randomized controlled trial format. Studies that measure clinically defined outcomes (such as symptom rating scales) may miss some of the most important benefits of this work, such as achieving the meaningful goals that people have set for themselves *(31)*. Further, when hearing voices is approached as a potentially positive phenomenon, the benefits cannot be captured by standard clinical rating scales *(32)*. In fact, some HVGs see themselves primarily as social groups in which important transformative work can take place, rather than as traditional therapy groups *(33)*.

Nevertheless, a research literature has emerged around HVGs that has explored their impact on attendees and the processes they involve. One UK study that used both quantitative and qualitative methods found that duration of hospital admissions, as well as voice frequency and power, decreased significantly after attendance at a HVG *(34)*. In addition, studies have shown that people have been able to find support that was often unavailable elsewhere, and have felt heard within the groups *(24)*. These factors appeared to improve both social and emotional outcomes, including greater self-esteem *(21, 24, 35)*, improved social functioning *(24)*, better ability to cope *(21, 24)*, increased hopefulness *(21, 24)*, feeling less isolated, and strengthened bonds with friends and family *(24)*. People have also reported a better understanding of their voice experiences and an increased ability to share this relationship with their voices with others *(21, 35, 36)*: "I have an understanding of what my voices are and where they come from and I've been able to cope with them better, and as I've got better in myself and they've reduced then that's made life a lot better, because I don't have these voices all the time" *(27)*.

The theme of people finding acceptance comes through in all the studies of HVGs *(37)*, and in several studies people described a sense of solidarity; they found that the group provided a secure base to

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[c] Connectedness, hope, identity, meaning in life and empowerment.

explore their feelings, and acted as a catalyst for change *(27, 37)*. In the words of one respondent: "It was the veil being lifted because I'd heard somebody actually voice these feelings and I sort of thought … I know it's abnormal but equally there sort of seems to be a normality about it"*(37)*.

There is evidence that the benefits of attending HVGs happen in a phased manner. To date, the largest qualitative study undertaken of HVGs is that reported by Hornstein et al in the USA *(10)*. The researchers found that people initially engage in a process of discovery regarding other voice hearers and different ways of understanding voices. The HVG then enables them to explore ways of reframing their experience so that they can be make sense of it. Eventually, the group serves as a laboratory for change in relationships outside the group *(10)*.

While many people who attend HVGs continue to use psychiatric medication *(24)*, in the study by Hornstein et al., some members reported "more limited and targeted use of medication, or tapering off it entirely" *(10)*. Some respondents also reported a reduced need for hospital or crisis services.

Some studies reported that respondents found some group meetings "unsettling" at times and that there was sometimes a "kick back from the voices" *(38)*. The largest quantitative study to date was reported by Longden et al *(24)*, who sent a 45-item questionnaire to 62 groups affiliated with the English HVN. Around a third of the participants reported finding group meetings "distressing" at times. However, these negative experiences did not impact on the benefits of attending. In fact, the researchers speculated that it might have been the very fact that people were able to talk about distressing material, without being judged or "pathologized" that was beneficial.

Costs and cost comparisons

HVGs can operate with little or no funding *(26)*. Some groups are supported by mental health services and others by NGOs, while yet others are standalone. The only costs involved are the rent of a weekly meeting space and a possible fee for the facilitator. Most HVGs are free to the people who attend; however there is a small membership fee for attendance at groups in Japan *(39)*.

Challenges and solutions

Changing attitudes and reliance on the biomedical model

Changing staff attitudes in mental health services can be difficult and professional staff can be reluctant to adopt the HVM approach. Because HVGs work with the idea that voices can be understood in different ways and because they acknowledge that anti-psychotic drugs are not always helpful, professionals who are focused primarily on the biomedical model can experience HVGs as challenging. There can be a lack of understanding on the part of mental health service management and difficulty in accepting the need for change.

HVGs have addressed these issues by through transparency and inclusivity, inviting professionals from different disciplines to be involved, starting with small pilot groups and gathering evidence on outcomes. Many groups have chosen to develop independently, in most cases, launched by voice-hearers or professionals who have been inspired by the hearing voices approach. Often an initial public meeting is held to launch an HVG. To preserve their own identity as independent of psychiatry and mental health services, the English Hearing Voices Network has produced a charter for groups that are affiliated to it *(33)*, and HVN-USA has revised and expanded this charter to include the newest developments in HVGs *(40)*. Some voice-hearers and professionals provide training in setting up and running HVGs. The English network offers specific advice about setting up groups on its website *(26)*, and HVN-USA provides information on organizations offering facilitator training.

Broadening geographic reach

Most HVGs were originally established in high-income countries: in Europe, the USA, Canada, Australia, New Zealand, Japan and Hong Kong. The HVG approach is spread by people who hear voices themselves, or by individual professionals who are interested in this way of working, but it is not promoted by mainstream services, nor is it on any list of government priorities. Different social and cultural world views clearly shape the way that voices are experienced and interpreted, and therefore the ways that people react to them *(41)*. Local understandings of the nature of mind, bodies, spirits, the natural world, and the interaction of these factors with one another influence the way in which people experience and make sense of voice hearing *(42)*. The fact that the central tenets of the HVM approach emphasize this diversity in the voice hearing experience has helped broaden the movement's geographic reach. The establishment of the worldwide network, Intervoice, has helped the movement spread to many countries across the world, with national networks now established in 30 countries *(8)*.

Key considerations for different contexts

Key issues to consider for the establishment or expansion of this service in other contexts include:

- promoting transparency and open dialogue, explaining the purpose, goals and rationale for the Hearing Voices approach;
- building an evidence base by starting with a pilot group;
- inviting professionals from different disciplines to be involved;
- encouraging managers and others to attend training events to become familiar with the approach;
- collecting feedback on the approach from those participating in the groups and systematically building evidence of outcomes;
- ensuring strong leadership overseeing the groups and their implementation; and
- ensuring adherence to the Hearing Voices Movement approach.

Additional information and resources

Website:
http://www.hearing-voices.org/

Videos:
Beyond Possible, How the Hearing Voices Approach Transforms Lives
http://beyondpossiblefilm.info/

Eleanor Longden, The voices in my head, TED2013.
https://www.ted.com/talks/eleanor_longden_the_voices_in_my_head?language=en

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2.2

Nairobi Mind Empowerment Peer Support Group

USP Kenya

Primary classification: : Peer Support

Other classifications:

☐ Community mental health centre ☑ Community outreach ☐ Peer support
Crisis service ☐ Hospital-based service ☐ Supported living service

Availability in different locations:

☑ Yes ☐ No

Evidence:

☐ Published literature ☑ Grey literature ☐ None

Financing:

☐ State health sector ☑ State social sector ☐ Health insurance
☑ Donor funding ☐ Out-of-pocket payment

Context

Users and Survivors of Psychiatry in Kenya (USP-K) is a national membership organization established in Kenya in 2007. It is affiliated with the World Network of Users and Survivors of Psychiatry and is represented on the board of the Pan African Network of People with Psychosocial Disabilities *(43, 44)*. The primary objective of USP-K is to promote and advocate for the rights of persons with psychosocial disabilities and mental health conditions, enabling them to live and work as productive members of society. The organization is peer managed and peer led *(44)*.

USP-K provides peer support groups in Kenya as one of its core activities, with the aim of providing support, building capacity and leading social change to promote greater inclusion at national and community level *(43, 45)*. USP-K established its first peer support group in Nairobi in 2012 having secured funding in late 2011 to increase its activities. As a new concept with few alternatives available, the group experienced high levels of interest and attendance from the beginning, with on average, 20-35 people attending each meeting. Individuals with lived experience and family members each accounted for 50% of the group, and women and men represented 60% and 40% of attendees respectively. The individuals who attended had a broad range of backgrounds including young people from the local university, young professionals, businesspeople and individuals from the informal settlements in Nairobi.

Since its inception, a further 12 support groups have since been established across six counties in Kenya, with two groups in Nairobi. Peer support groups are initiated by individuals who identify a need or interest in establishing a group, or where individuals have to travel long distances to attend a group, their local hospital, which may be in a rural location, may request a group to be set up locally. USP-K has also established a referral system so that mental health professionals can refer individuals to the peer support groups. USP-K provides the initial seed funding to support new groups in getting started. This may be used for example, to hold their initial meeting to adopt the group's constitution and to elect the chairperson, secretary and treasurer of the group by the group members. USP-K then supports groups to access government funding opportunities available at community level (both disability-specific and general), which can be used to support the ongoing operation of the group and/or its members, for example through grants for peer support group activities addressing stigma and discrimination, economic empowerment opportunities, women or youth-specific funds *(46)*. However, each group must have its own bank account and also fundraise independently. USP-K also provides technical support to the groups through training on topics including human rights, self-advocacy, crisis response strategies and sustainable livelihoods.

New groups are established with the support and collaboration of key partners at the grassroots level including county governments (departments of social services and health), community health workers and volunteers, social workers, and local administrative authorities. Support groups are formally registered with the Ministry of Labour and Social Protection and with the National Council for Persons with Disabilities. Each group is responsible for renewing their certificate from the Ministry of Labour and Social Protection each year, which involves submitting details of the chairperson, secretary, treasurer and members and a simple annual report. Members can choose to have their details excluded from this reporting process if they wish. There is also a registration renewal fee of approximately US$ 10.

USP-K also has a virtual support group using WhatsApp messenger used by approximately 125 members *(47)*. USP-K peer support groups are community-based and operate independently of Kenya's mental health system. The groups are not linked with any mental health institution.

To give more a more detailed understanding of USP-K peer support groups, the USP-K Nairobi Mind Empowerment Peer Support Group was selected to showcase primarily due to the availability of supporting evaluation data. This example provides insight into the functioning of USP-K support groups in Kenya generally.

Description of the service

USP-K peer support groups bring together individuals who self-identify as users of mental health services, survivors of psychiatry, people with mental health problems or people with psychosocial disabilities. Any individual with lived experience may join a group. Caregivers may also join; however, groups aim to restrict the number of family members in attendance and may suggest that family members start their own support group. The National Council for Disabilities and the Ministry of Labour and Social Protection stipulate that a minimum of 70% of members of a peer support group must have lived experience. The remaining 30% may then be caregivers. This 70 : 30 ratio is consistent with the composition of the Nairobi peer support group.

The peer support groups provide a space to come together within a human rights and social framework promoting non-discrimination, full and effective participation and inclusion, respect for inherent dignity, individual autonomy including the freedom to make one's own choices and mistakes, and gender equality.

Meetings are generally structured in three to four parts:

1. informal session offering peer support and psychosocial support;
2. structured session dealing with group advocacy objectives;

3. break-out sessions if necessary, for example, to address gender-sensitive issues; and
4. guest attendees, for example professionals, may be invited to the group at the request of group members.

The USP-K model allows for adaptation of peer support group meetings to best meet members' needs. This may be as simple as allowing meetings to run over time to allow members to discuss and share what they need to, the use of breakout sessions to reflect sensitivities within the group as they arise, or giving specific suggestions to peers when requested rather than adhering to the normal model of avoiding prescriptive discussions. As an example, the rural Kenya support groups incorporate additional elements that are pertinent to members beyond sharing experiences, for example through discussing livelihoods *(47)*. Consistency in attending peer support group meetings is encouraged to help build close relationships between members, support personal growth and to provide a diversity of perspectives at each meeting. Members receive training on the Convention of the Rights of Persons with Disabilities (CRPD) and the Sustainable Development Goals (SDGs), offered twice annually, as well as regular training during the meetings on key aspects of human rights and how they apply to everyday life.

The USP-K Nairobi Mind Empowerment Peer Support Group meetings bring together on average 25 participants. The meetings are informal, and individuals can join and leave the group without notice. No forms are used, and meeting attendance sheets are voluntary. No one is required or forced to speak when they attend. Meetings are held once a month, and normally take place in the Central Business District in Nairobi rather than on hospital grounds in an effort to minimize power imbalances *(47)*. The location is convenient for most people living in the Nairobi Metropolitan Area.

The group is advertised in different ways, and knowledge of the group often spreads by word of mouth. USP-K also advertises the peer support groups, for example through sharing information on the group when providing training to service providers and local administrators, or through their advocacy work which includes articles in newspapers and spotlights on television programmes.

Member-led peer support groups

USP-K peer support groups are led and managed by members. The peer facilitator is appointed directly by the members of the group and receives training from USP-K on meeting facilitation and technical aspects including the CRPD. During meetings, members share experiences and encourage each other to try different strategies or approaches for coping or for decision-making *(47)*. Learning, asking questions and self-reflection are all encouraged. The facilitator works to reflect and meet the needs of the members and the group dynamics. This may include encouraging members to develop and see a new narrative of themselves beyond a diagnosis, encouraging contributions to ensure balance and representation in a discussion, diffusing conflict if necessary but also supporting members to address conflict that may arise between them. Building relationships is seen as encouraging a sense of solidarity and replacing individual isolation. The facilitator also works to build connections between members who can be of support to each other outside group meetings, or between caregivers, or if requested between members and mental health professionals who have received USP-K training on dignity and human rights.

If a member is having difficulties, the facilitator follows up outside the group meetings with the individual, their family or community, and ensures they have the support they need. Peer facilitators may also link with other formal community workers such as community health volunteers and social workers, as part of the community support network. For example, if a social worker learns of an individual who is being abused in the home, for example, tied to a tree, the social worker may contact the peer facilitator to determine actions to be taken. If a person does not wish to go to hospital, the relevant person in the community network may contact the peer facilitator for assistance to identify and support the individual's preferred solution. However, any such actions are only undertaken with the knowledge and consent of the individual.

Peer support groups have a chairperson, treasurer and secretary and three committee members who are all elected annually by the group members. These roles are established by the group's constitution, provided by the Ministry of Labour and Social Protection. The chairperson is responsible for overall coordination, fundraising, advocacy and representing the group particularly at the local level. The secretary is responsible for documenting the group proceedings in a confidential manner, focusing on broad needs such as access to medication or issues concerning violence. The treasurer is responsible for fundraising, collection of monthly member contributions and financial records. Group members decide jointly on a feasible monthly, non-mandatory contribution for members, used to create a common fund known as a welfare fund. A percentage of this fund is reserved to address specific challenges or individual requests – for example lack of medication, support to fund a funeral or wedding, or reimbursement for travel related to an advocacy meeting.

The peer support group has a separate dispute resolution committee whose members are nominated by fellow peer support group members. This committee helps navigate difficult situations, conflicts or complaints in relation to the group itself, or externally such as difficulties between a member and their family, or issues of abuse or neglect. In the case of the latter, the dispute resolution committee attempts to help resolve the situation. This committee can also support members who may wish to change their circumstances, for example, to live independently or return to work.

Supporting role of USP-K

USP-K has four part-time staff members, and two full-time volunteers. Two USP-K members normally attend each peer support group meeting to welcome new members and introduce them to how the meeting works. They act as a resource, providing information on disability and mental health, or advice if members are having difficulties accessing financial supports. They can steer discussions if needed, including bringing the discussion back to a human rights approach and the social model of disability. The USP-K staff members help build trust in the group and the confidentiality of the space.

USP-K volunteers also provide support outside of the peer support group meeting, which may include hospital visits, making referrals or helping members in their daily lives. Members can make contact if in a crisis by phone, through the virtual support group on WhatsApp or if in Nairobi, at the USP-K offices. Staff and members of the group who attend training or conferences, for example on human rights, also share their learning with the peer support group.

USP-K virtual peer support group

The virtual USP-K Peer Support WhatsApp group was established to reflect that not all people may be comfortable with or physically able to attend face-to-face peer support group meetings. The group is open to anyone in Kenya who wishes to join and individuals do not need to be a member of a USP-K peer support group to join. While in the face-to-face meetings, people discuss more in-depth subjects, personal details and emotional content, leading towards a psycho-emotional support group dynamic, the WhatsApp group is more of a social support group.

When the group was first established, members advertised the group through word of mouth. The group remains informal and allows people to share their experiences on a wide range of topics or issues. People are encouraged to provide information regarding support persons in case they are in a crisis situation or distressed so that the group is able to identify when someone is in crisis and who might be able to respond and provide support. Members are also encouraged to set up a support system in the places where they live. The administrators of the WhatsApp group are responsible for reaching out to the relevant support person if necessary. If an individual joins the group but finds it difficult to engage or get the support they need because of the open and virtual nature of the group discussion, they can also reach out directly to the administrator or another member to have a separate discussion. If a member posts something that has the potential to negatively impact the group, they may be temporarily excluded but with continued alternative support. Administrators may also exclude individuals who try to participate in a way that is against the rules, for example, if professionals try to use the group to solicit new clients. At the time of writing, there were 125 members in the WhatsApp group.

Core principles and values underlying the service

Respect for legal capacity

A key objective of the USP-K Nairobi Mind Empowerment peer support group is to support individuals in exercising their legal capacity. By adopting a human rights approach, the peer support group supports individuals to exercise their right to make their own decisions and to have those decisions respected by others.

When an individual has a decision to make that they choose to bring to the group, the other members are encouraged to share their individual experiences, learning and knowledge of the topic. The group uses an “inform rather than prescribe” approach, to avoid power imbalances. The individual is empowered to use the information provided in their own way *(47)*, which may include making a decision that is different to what the rest of the group might have suggested. USP-K facilitators help ensure this dynamic is respected. A wide variety of decisions may be brought to the peer support group including decisions concerning employment, living arrangements, relocating, heath care options and treatments and family planning. A 2016 USP-K report *(47)* identified a direct link between peer support and exercising legal capacity in that, for example, the group may provide information and share experiences of different medical treatments to assist a peer in deciding on the right choice for them, and understanding what their rights are, how to communicate their choice and have that choice respected.

The peer support group also supports members to exercise their legal capacity through promoting and respecting the “dignity of risk”, that is, to have the same right as anyone else to make mistakes *(47)*. As such, decisions made without the support or input of the group are given equal respect as those made with the support of the group.

The group also discusses and helps members to develop informal advance directives (advance directives are not recognized by Kenyan law) which could take a variety of formats such as a written document, having a dedicated person who knows their wishes in a time of crisis or identifying emergency contacts to which a prepared “help text” message could be sent.

Alternatives to coercive practices

USP-K Nairobi Mind Empowerment peer support group actively works to promote non-coercive practices. The group actively identifies, maps out and promotes the use of social capital to de-escalate crises in place of coercive methods, using peer facilitators, social workers and community-based workers. Similar work is done with members' families on the human rights-based approach to mental health, how to identify a crisis and how to leverage social capital.

If a person experiences a crisis during a meeting, the peer facilitator leads the support response for that person. This may include speaking with the person to try and establish what they might find helpful, respecting preferences they have previously expressed and linking with the person's chosen support person or people (members of the group are advised to nominate three support people of their choice). The peer facilitator provides support in accordance with the person's preferences where possible, however, in an emergency situation such as attempted suicide, the risks to the individual are addressed first and then at the earliest possible opportunity, the person's wishes are respected. Members of the group can provide a form of collective support to the individual if so wished and possible, along with any mental health professionals invited to the group. The group may also be able to reach out to professionals on the USP-K database which lists professionals who have received training by USP-K on human rights and mental health.

USP-K also trains local police and administrators in using social capital if an individual is in crisis, in consultation with the relevant local USP-K peer support group. If a member wishes to stop taking medication, the group supports the member to identify their reasons, explore whether they can discuss and address the decision with a medical professional, understand the impact of not taking medication, and understand how to responsibly stop medication with appropriate planning and support in place.

Community inclusion

USP-K Nairobi Mind Empowerment peer support group actively works towards full and effective participation and inclusion of individuals with psychosocial disabilities in the community. USP-K supports individuals with aspects such as social protection, accessing tax exemptions and economic empowerment programmes. The group helps members to register as having a disability, including filling out the form, booking an appointment for an assessment or any other action required. Once successfully registered, information is provided concerning disability benefits and other funding opportunities that the person may now be able to access. These could include education grants, trade tool grants and waivers on local markets operations fees for those in informal employment *(46)*.

The group also takes a human rights approach to overcoming barriers to community inclusion. USP-K peer support groups are recognized by local administrative authorities, which facilitates community engagement and inclusion. In Nairobi, for example, the peer support group is recognized by the county government and local national government administrative units, such as the Chief, Sub-Chief and District Commissioners,[d] and other strategic partners including development and human rights organizations such as the Red Cross, CBM, and Sight Saver Programme. These linkages help to ensure that these groups are aware of individuals in their community with psychosocial disabilities and the importance of including them in their work and decision-making. By linking with the group's social capital (peer facilitators, social workers, community-based workers), community support systems available to members are strengthened. The peer support group also continuously engages with families in

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[d] National government roles at county level.

recognition of their role as the natural form of support for most people *(47)*. This engagement includes training programmes to gain knowledge and understanding of mental health and human rights, and reaching out to families if there is an issue for an individual in relation to their family, but only with the consent of the individual. If a person does not want their family involved, but the family is a source of a problem, the group may need to involve local community structures (such as village elders) to assist, again, only with the consent of the individual.

Participation

USP-K peer support groups are led and managed by individuals with lived experience. Each group sets out its own advocacy objectives on a quarterly basis. These objectives are identified based on a discussion between USP-K and members of the group about the pertinent issues affecting members' lives (for example, mental health, discrimination). The group identifies priorities for action and USP-K supports them to develop a simple implementation plan. USP-K provides technical support and finance (if appropriate/available) and reviews progress at the monthly peer support group meetings.

Recovery approach

A 2018 USP-K report found that peer support promoted members' agency and autonomy – key components of recovery. The report found that through the group and peer discussions, members begin to "reclaim their voice and become more assertive" *(47)*. This happens in different ways within the group but is steered using specific approaches by the peer facilitators and older members. Facilitators and peers constructively challenge one another to see themselves beyond their diagnosis and treatment, take their wider life experiences into account, and to see themselves as a person first and foremost. Discussion within a safe and constructive space allows members to regain their voice and to make sense of their experiences, which is particularly important in cases in which individuals have become accustomed to being passive recipients of treatment or support. Through peer support and discussion, members also see how others who may have a similar diagnosis or living situation are in control of their lives and make their own decisions, which can encourage people to see that the same is possible for them. The peer support group encourages peers to "try out new ways of being, to make mistakes if they must, with the knowledge that the understanding and support of peers will be there regardless of the outcome of one's decision" *(47)*.

Service Evaluation

In 2016 USP-K undertook a research project on the role of peer support in exercising legal capacity in Kenya *(47)*. The research was funded by the Open Society Initiative for Eastern Africa. Ten peer support group meetings of the USP-K Nairobi Mind Empowerment group were observed. Persons attending the peer support group meetings had a broad range of mental health conditions. In total, 164 individuals attended the peer support group meetings over the course of the research. A further three focus group discussions were undertaken. Eight interviews were conducted with carers and USP-K staff.

The research found that the USP-K peer support group directly supported members in exercising their legal capacity. The group was also found to promote agency and autonomy of its members, in that members reported returning to education or starting a business as a result of interacting with a peer who had taken similar steps. Further, members were encouraged to challenge relationships which have an unsatisfactory power imbalance, for example where treatment decisions are being made solely by medical professionals rather than in consultation, collaboration and agreement with the individual. One member of a USP-K Peer Support Group stated, "When I don't understand something the doctor says, I ask. When I don't agree with something the doctor proposes, I say "no" and ask for alternatives."

Another way the group promoted agency and autonomy was noted to be through encouraging members to plan for crisis situations. In doing so the members retained control even in a crisis situation, which was seen as one of the ways of "taking one's power back". Members also spoke of increased self and general advocacy describing "situations in which they were able to speak up for themselves where before they would just have been silent." Moreover, the study observed that the group encouraged positive risk taking through sharing relevant personal experiences and information. This may concern changing or ending certain medical treatments that are unsatisfactory to the individual or areas such as livelihoods or family matters.

Costs and cost comparisons

There is no cost for members to attend USP-K peer support groups, however there is a voluntary monthly member contribution to support the wider activities of the group.

Since establishing the first peer support group in Nairobi in 2012, USP-K developed its remaining groups through the support of the Disability Rights Initiative of the Open Society Foundation and the National Council for Persons with Disabilities *(47)*. In 2016, the social sector of the Kenyan government also provided funding to USP-K to support their work. Currently, funding for the USP-K peer support groups is primarily provided by the Open Society Initiative for East Africa (OSIEA) and the National Council for Persons with Disabilities (NCPWD). USP-K receives US$ 30,000 per annum from OSIEA and US$ 26,000 per annum from NCPWD. USP-K staff receive a salary and volunteers receive a monthly stipend.

The annual cost of running the Nairobi Mind Empowerment Peer Support Group is US$ 4,000 per year including venue costs, expenses for peer facilitators and supporting the group in implementing its advocacy objectives. The Nairobi Mind Empowerment Peer Support Group receives its core funding of approximately US$ 4,000 per annum from OSIEA, and a further US$ 2,000 per annum from NCPWD, primarily to support economic empowerment programmes. USP-K also works with NGOs and religious organizations which can also provide support. Other potential funding options available to groups include fundraising from private entities, in particular in areas such as sustainable livelihoods and entrepreneurship. Finally, peer support groups may also be able to apply for financial loans as part of a financial literacy programme provided by banking institutions. Supporting groups and members to secure independent funding opportunities ensures that groups can become financially independent.

Challenges and solutions

Promoting the disability and human rights-oriented model

Until recently in Kenya, people's perspectives and knowledge (including individuals, families, communities and professionals) were based almost exclusively on the biomedical model. The human rights model of mental health was relatively unknown. Acceptance of a human rights-based approach required a fundamental paradigm shift which was accomplished through leveraging existing legal frameworks and extensive engagement with all stakeholders including families, community resources and other human rights actors, to promote law reform and challenge existing laws. Further, USP-K documented, identified and shared existing and new alternatives to the biomedical model, including good practices from within the community, to begin to build up alternative practices. The groups have also provided continuous training on human rights using the CRPD to promote shared understanding of human rights and mental health. This shift took approximately three years to happen. USP-K continues its engagement with the community and community resources on human rights, as well as its advocacy and training efforts.

Establishing the peer support model

Peer support is not recognized under Kenya's mental health act but is anchored in Kenyan law through the CRPD which was ratified by Kenya in 2008 *(47)*. When the first USP-K peer support group was established, peer support was an entirely new concept in Kenya which many people did not recognize or understand. Extensive advocacy and engagement with individuals, families, communities and professionals was required in order to promote understanding of the peer support model. USP-K also documented evidence on the benefits of peer support and established formal government recognition of the groups to access new opportunities for funding.

Sustaining funding

Since the first USP-K peer support group was established in 2012, two peer support groups have had to close. The primary challenge for groups continuing their work is sustainable funding. USP-K is only able to provide financial support to new groups for the first two to three years. Peer support groups have no access to state level funding so must fundraise independently. If unable to do so, the group may not be able to sustain operations. To address this challenge USP-K provides seed funding and supports groups to access various sources of government funding. USP-K further embedded fundraising into the organizational structure for all peer support groups by giving related responsibilities to both the Chairperson and Treasurer for each group.

Accessing sufficient mental health services and supports

An additional challenge for the Kenya Nairobi Mind Empowerment Peer Support Group in its work on community inclusion is the lack of accessible services and supports for individuals with psychosocial disabilities to live as independent members of society. These constraints limit the impact of peer support when a person is ready to become a more active member in their community but is unable to implement this choice due to a lack of practical support such as insufficient state benefits for example, or lack of supported living arrangements. USP-K addresses this issue directly by looking beyond mental health and peer support – it also emphasizes the practical issues affecting a person's life and means to improve their situation, such as livelihoods, employment. However, wider challenges such as poverty, lack of employment and lack of social protection can prevent individuals from fully benefiting from the peer support group's actions in this context, and limit how much the peer support groups can achieve.

Key considerations for different contexts

Key issues to consider for the establishment or expansion of this service in other contexts include:

- understanding and working with the whole system of the communities where people live, including government, families, community actors, religious leaders, etc.;
- considering context-related issues outside the service, such as systematic discrimination, poverty and inequality, and developing practical solutions within those contexts;

- identifying positive aspects upon which to build (legislation, community practices, etc.) and leveraging these strengths to implement change, for example, reflecting these points in trainings and discussions with stakeholders; and
- engaging people of influence who can strongly advocate for evaluation findings and present them to the decision makers who may influence possible funding decisions.

Additional information and resources:

Website:
https://www.uspkenya.org/peer-support-groups/

Contacts:
Michael Njenga, Executive Council Member Africa Disability Forum, Chief Executive Officer, Users and Survivors of Psychiatry in Kenya, Nairobi, Kenya;
Email: michael.njenga@uspkenya.org

2.3

Peer Support South East Ontario (PSSEO) – Transitional Discharge Model

Ontario, Canada

Primary classification: : **Peer Support**

Other classifications:

☐ Community mental health centre ☐ Community outreach ☐ Peer support

Crisis service ☑ Hospital-based service ☐ Supported living service

Availability in different locations:

☑ Yes ☐ No

Evidence:

☑ Published literature ☑ Grey literature ☐ None

Financing:

☑ State health sector ☐ State social sector ☐ Health insurance

☐ Donor funding ☐ Out-of-pocket payment

Context

Peer Support South East Ontario (PSSEO) is a non-profit organization providing different supports and services within South East Ontario, Canada, to people who are living with mental health conditions and/or addictions and seeking peer support as a means of managing and working towards wellbeing and recovery. PSSEO's core purpose is to inspire hope and wellness through "peer support with intention". The organizational values are patience, compassion, empathy, empowerment, encouragement, respect and support *(48)*.

PSSEO, which is funded by the Ontario Ministry of Health and Long Term Care, was established in 2001. Since then, the organization has evolved significantly to meet the needs of people living with addictions and/or mental health conditions and psychosocial disabilities in the South East Ontario region.

Organizationally, PSSEO offers non-clinical service delivery in three distinct programmes:

1. peer support centres offering recovery-focused groups and activities, one-to-one peer support and Wellness Recovery Action Planning *(49)* as well as other services like a lunch programme and access to laundry and computers;
2. a community peer support programme specifically addressing access to peer support for people living in rural or remote communities; and
3. one-to-one peer support as part of the **transitional discharge model** (TDM) to support people transitioning back into their communities following treatment in an inpatient mental health hospital service.

The TDM aims to provide a safety net of relationships to bridge the hospital discharge process into community care. This includes one-to-one peer support and continued hospital support until a therapeutic relationship is established with a community care provider *(50)*. In this model, peer support workers play an important role in providing support and links to community services based on people's expressed needs for support. With this support, people do not have to wait for weeks or months after discharge for community supports to become available. It also helps prevent re-admission to hospital which is most likely to occur within the first year after a person has been discharged *(51, 52)*.

PSSEO is delivering peer support using the TDM at five different hospital sites in South East Ontario.[e] For the purpose of this document, the peer support delivered through TDM at Providence Care Hospital in Kingston will be outlined in detail.

Description of the Service

Providence Care Hospital is a publicly-funded hospital that integrates long-term mental health and psychiatry programmes with physical rehabilitation, palliative care and complex medical management. As part of the TDM at Providence Care, PSSEO offers peer support in four mental health units, each accommodating up to 30 people for inpatient stays. There are two mental health units for adults, one unit for people with acquired brain injuries and one forensic mental health unit. The peer support service consists of weekly peer support groups and, as part of the TDM, one-to-one peer support for people prior to and after leaving the hospital, with the specific aim of supporting people to transition back into the community. Peer workers act as a bridge of support from the point of a person's discharge to their first contact with mental health services in the community or outpatient appointment. They provide further assistance, friendship and support for up to one year after discharge.

The PSSEO peer support is firmly embedded into the daily routine at Providence Care. The same peer worker visits each of the four units on one day every week to meet and engage with people who have recently started to receive treatment and care at the hospital. The peer worker informs newly admitted persons about the peer support services offered by PSSEO, providing information material, contact details and an invitation to participate in the TDM programme and the weekly peer support group being run in the unit where they are staying. The peer support groups are run by the same peer worker every week.

The peer support groups are very popular with an average of 15–20 people for each of the three peer support groups attending each week. The groups are designed to be an open and welcoming space for everyone interested. There is no obligation for a person to attend the groups and people are invited even just to listen and observe. The topics and activities for the peer support groups vary from week to week and participants are invited to contribute topics or issues that they would like to discuss. During the group meetings, the peer worker introduces the one-to-one peer support as part of the TDM and interested participants are invited to schedule a meeting to initiate a matching process with a peer support worker before discharge.

When a person expresses interest, the PSSEO peer worker at Providence Care sets up a meeting with that person to initiate the matching process. There are five one-to-one PSSEO peer workers allocated to Providence Care that people can be matched with based on their background and interests. Once a peer worker has been matched with a person, the ward peer support worker arranges a first meeting in

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[e] Providence Care (Kingston), Kingston Health Sciences Centre (KHSC), Hotel Dieu, Belleville General Hospital and Brockville General Hospital.

a neutral space like a café or a park where the peers can get to know each other. To ensure continued support throughout and directly after the discharge process, this first meeting is ideally held in the week before discharge from hospital or one to two weeks after discharge at the latest. If after the first meeting the match doesn't feel right to the person using the service, they can request to be re-matched with a different PSSEO peer worker.

Where a successful match has been made, the peers arrange weekly one-hour meetings for a period of up to a year. The weekly meetings can be used for whatever the person wants or needs support with, for example bureaucratic tasks, scheduling appointments with community-based services or simply having a conversation at a café or going for a walk together. Peer workers can arrange additional meetings under certain circumstances for example to accompany and support the person for an important doctor's appointment. The peer worker from the hospital unit who organized the original match regularly checks in with the discharged person to see if everything is going well, if they are still happy with the match and to help resolve potential issues.

PSSEO ensures that everyone at the four mental health inpatient units at Providence Care who is interested in receiving peer support, is matched with a peer worker. If an individual is discharged to a different catchment area, PSSEO provides resources for potential peer support services in that area. PSSEO may also work with the person to establish what other resources and community-based services are available in their area should they wish to explore these.

At times of exceptionally high demand, there can be a waiting list of three to four weeks until a person can be matched. In these cases, PSSEO offers the alternative of participating in group meetings at a Peer Support Centre until the individual is matched. If someone is not interested in being matched with a peer worker before discharge but changes their mind later, they can contact PSSEO for up to 30 days after discharge to initiate the matching process. After more than 30 days post discharge, a person would not fall under the TDM peer support programme anymore and would instead be referred to the PSSEO community Peer Support Centers for further support.

There are very few formal requirements for a person to receive peer support by PSSEO through the TDM. To ensure maximum respect for privacy, PSSEO does not require formal registration involving personal information and medical history and no files are kept for people using the service. However, there are some eligibility criteria to use the TDM one-to-one peer support service. People need to be able to make and maintain their appointments by themselves and for all meetings with peer support worker, they need to be free of alcohol or other substances. A person is free to terminate the relationship with their peer support worker at any time without having to state a reason for this.

Core Principles and Values Underlying the Service

Respect for legal capacity

Supporting people to exercise their right to legal capacity is a key objective of PSSEO peer support. Being matched with a PSSEO peer support worker is strictly voluntary, based on a person's own recovery goals and would not be imposed on a person by hospital staff, PSSEO or other agencies under any circumstances. The same is true for all other peer support programmes run by PSSEO.

After discharge from hospital, peer workers actively support people to make informed decisions and choices about different treatment, care and support options by exploring the possibilities together with the person, weighing pros and cons and making sure a person has access to and understands all the information needed to make a decision on the basis of full informed consent. If an individual wishes to receive any kind of support in the area of mental health, addiction, social services or other areas, the peer worker facilitates contact with the appropriate services, agencies and/or organizations as required.

PSSEO peer workers are trained to actively support people to develop advance plans as part of the Wellness Recovery Action Planning (WRAP) *(53)* to prepare for potential crises in the future. These plans include the kinds of treatment, care and support a person does or does not want during a crisis, medications they do or do not want to take and who in their support network they do or do not wish to be in contact with during a crisis. PSSEO peer workers are encouraged to discuss the advantages of completing an advance plan with individuals; however, a person is completely free to decide whether they wish to develop an advance plan or not, or if they only wish to recognize and develop certain sections of an advance plan.

Once a person has finalized an advance plan, PSSEO peer workers encourage them to share it with whomever they wish, including friends and family members or with inpatient services where a person is likely to go to in a crisis, to help ensure that their will and preferences are respected during a future crisis situation.

Alternatives to coercive practices

Receiving PSSEO peer support is completely voluntary and no coercive practices are ever used by PSSEO staff or the community services and supports to which PSSEO facilitates access. All PSSEO peer workers are thoroughly trained in de-escalation techniques and are therefore able to respond to tense situations in a calming and reassuring manner.

Under exceptional circumstances, for example if a person acts violently towards others and/or is harming themselves, PSSEO calls the responsible crisis service who might refer the person to a hospital where coercive practices may be used. In these cases, the PSSEO peer worker tries to accompany the individual to the hospital and stay with the person during the admission process to provide support and continue to make efforts to de-escalate the situation.

At Providence Care hospital all staff are committed to preventing the use of coercive practices, however coercion is used in situations of actual harm to self and/or others if other means of de-escalation have failed. Efforts are made by PSSEO to stimulate discussions around avoiding coercive measures by engaging in different working groups and councils that advise hospital management decisions. PSSEO peer workers also facilitate access to complaint mechanisms including the “patient advocacy group” at Providence Care in case a person has experienced a coercive measure such as seclusion or physical, mechanical or chemical restraint.

Community inclusion

Peer support provided by PSSEO as part of the TDM is specifically dedicated to facilitating the transition of an individual back into the community after discharge from hospital. The service aims to make sure that a person is not left alone after an inpatient stay but is rather supported to access appropriate services and supports by a peer who might have previously been in a similar situation.

PSSEO has established, long-standing relationships with many agencies and organizations in the South East Ontario region that provide services and supports to individuals living with mental health conditions and/or addiction(s). Once a peer worker is matched with an individual, they get to know each other, discuss the individual's support needs and wishes, and the peer worker introduces the person to available community-based services that could be a good fit. PSSEO does not have a pre-designated referral policy and individuals are at all times free to decide which services they are interested in. Although PSSEO's focus lies primarily in facilitating access to community-based mental health and/or addiction services, the peer workers can also support people to gain access to housing, education or social protection benefits if this is the person's wish.

Participation

All of PSSEO's peer workers have lived experience and are certified in the practices and delivery of peer support as per the OPDI Peer Support Core Essentials Program *(54)*. Furthermore, the majority of staff members are certified WRAP Facilitators through the Copeland Centre for Wellness and Recovery. Furthermore, PSSEO has people with lived experience within their management group which ensures that the perspective of lived experience is reflected throughout the service including in decisions about funding and budget allocation, service development and implementation. Further, satisfaction surveys are conducted within a minimum of a two-year timeframe for all programmes run by PSSEO including the TDM at Providence Care. The results of these surveys are used to improve and adapt the services provided by PSSEO as appropriate.

Recovery approach

The core principles of PSSEO peer support are closely aligned with the recovery approach. PSSEO peer workers work with individuals to develop their own framework, goals and wishes for their personal recovery journey and to identify which services and supports might be helpful for them as in individual. PSSEO emphasizes the importance of seeing an individual as a whole person and avoiding medicalizing terminology and a focus on diagnoses and other clinical characteristics. In the peer support groups at Providence Care as well as during the one-to-one peer support after discharge, the focus lies on strengthening autonomy and empowerment of the individual. This is done by establishing with the peer what recovery means to them and working alongside to support, advocate and provide hope.

Service Evaluation

During the fiscal year 2017–2018, 119 individuals received peer support by PSSEO peer workers as part of the TDM at Providence Care, amounting to 2182 visits and 1068 service hours. In 2018–2019, the number of individuals using the peer support services at Providence Care increased to 127, amounting to a total of 2765 visits and 940 service hours. For 2019–2020 the numbers further increased to 138 individuals, 3061 visits and 1263 service hours.

Analyses of quality improvement surveys on the peer support delivered by PSSEO as part of TDM at Providence Care, including questionnaires, interviews and testimonials, showed high levels of satisfaction with the services among people using the services and among staff members *(55)*.

In a 2019 study, 92% of individuals using the PSSEO peer support services at Providence Care reported a positive experience and high levels of satisfaction with the services provided. For example, people using the service experienced the support by peer workers as empowering and as a key positive factor in their recovery journey during the inpatient hospital stay and beyond. People using the service felt understood, listened to and supported by the peer worker. Furthermore, individuals found the peer support to be crucially helpful with managing day-to-day tasks and re-establishing daily routines out of hospital. When asked what could be done to improve the service, many people wished for more hours with their peer support worker, more frequent weekly visits/meetings and an extension of the programme to offer long-term peer support for more than one year *(55)*.

In the words of one client who summarized her experience with peer support offered through TDM at Providence care:

“My time in the hospital was a very difficult time and my Peer Support worker was very helpful. I was coming off a lot of medication and I was having a lot of struggles. There was a situation on the ward that became very hard and overwhelming for me to deal with. I felt that I couldn’t do it alone. I had my Peer Support worker right from the start, she was awesome. She helped me write letters and she attended all the meetings that I had to attend over the months that it took and she was with me supporting me every time. With her support she made me feel like I meant something and my voice needed to be heard.”

In the conducted surveys, staff members at Providence Care equally reported that “having peer support on the units not only provides more holistic care but is an invaluable service” and that the peer support work “is an essential part of the care and recovery of patients”.

The Senior Director of Hospital Mental Health at Providence Care describes his experience with the PSSEO peer support workers as follows:

“Since inception, only one client who was matched with a peer in the community was readmitted to hospital. That admission was for a period of nine days versus our average length of stay at 30 to 90 days (…) Anecdotal feedback from discharged clients who are connected to Peer Support in the community is extremely positive. The clinical teams in the Adult Mental Health programme at Providence Care believe that having peer support on the units not only provides more holistic care but is an invaluable service.”

In addition to the survey data outlined above, studies evaluating the overall TDM including peer support at different hospital sites have shown that service users’ quality of life improved and that average length of stay was reduced *(50, 56-58)*. For example, a 2013 study evaluating the TDM on 10 hospital wards in Ontario, including Providence Care, found that the average length of stay could be reduced from 74.2 days before the program had started to 56.9 and 64.4 days, at 4 and 8 months later respectively following implementation *(50)*.

Costs and cost comparisons

The peer support delivered as part of TDM at Providence Care is entirely funded by the Ontario Ministry of Health and Longterm Care. There is no cost involved for individuals to use the peer support services delivered through the TDM by PSSEO. Since the introduction in 2013 of the first TDM peer support programme in one unit at Providence Care, PSSEO received further funding for the peer support programme to expand it to all mental health units (including the Forensic Unit). In addition to Providence Care, PSSEO is now delivering their peer support services as part of the TDM at four other hospital sites in South East Ontario: Kingston Health Sciences Centre (KHSC), Hotel Dieu, Belleville General Hospital and Brockville General Hospital.

In the fiscal years 2017-2018 and 2018–2019, the total cost of the peer support delivered though the TDM at Providence Care was Can$ 53,280 (US$ 42,362)[f]. and Can$ 59,200 (US$ 47,070)[f]. respectively. This cost includes peer supporters salaries, one-to-one service delivery, refreshments for group participants and mileage accrued by peer support staff when traveling between visits. The cost of service delivery per individual for the fiscal years 2017-2018 (119 individuals) and 2018-2019 (127 individuals) was, on average, Can$ 447 (US$ 355)[f]. and Can$ 466 (US$ 370)[f]. respectively.

Studies that found a reduction in average length of stay suggest a substantial cost savings. In 2008, the average cost of one day of hospitalization was estimated at Can$ 800 (US$ 636)[f]. Thus, a reduction of 9.8 days in length of stay per discharge translates to an average savings of Can$ 7,840 per discharge (US$ 6,234)[f] *(50)*.

Challenges and solutions

Overcoming resistance to the peer support model

One of the initial obstacles to formation of the service was weak commitment and the reluctance of management to invest time and resources into a pilot due to uncertainty about its possible future success. To address these issues, as part of a two-year implementation study starting in 2013, PSSEO, began offering peer support services as part of the TDM to persons being discharged from one psychiatric ward at Providence Care. Following the overwhelming positive results of this initial implementation, PSSEO received annualized funding specifically for the TDM by the Ontario Ministry of Health and Longterm Care to continue delivering their peer support services at the hospital. PSSEO has received continuous funding over 19 years for all their peer support programmes by the Ontario Ministry of Health and Long-term Care since its founding year in 2001.

Creating an environment of mutual trust and respect between clinical and non-clinical staff

Another challenge during the early stages of setting up the service was the degree of anxiety from hospital staff that the peer support services would supplant clinical services. At the same time, there was a need to establish and maintain the independence of PSSEO staff, in that they report to PSSEO management rather than hospital management. Both factors created a distinct need to establish and maintain an environment of mutual respect for both the clinical approach of the hospital and the non-clinical approach of peer support. One of the ways the service addressed this was to deliver information sessions to hospital staff on the role and importance of peer support and the transitional peer support service being offered by PSSEO. Another solution was to identify and support “champions” within the hospital who were aware of and believed in the peer support model so they could spread the key message and culture of inclusion among other hospital staff.

Building a knowledge base in an environment of high staff turnover

Misinformation about the role of peer support presents a continuing challenge. This issue is compounded by high staff turnover within the hospital staff which creates gaps in understanding of peer support and the PSSEO service being provided. This high turnover presents a continuous need to communicate and educate internally regarding the role of peer support to address the frequent knowledge gaps on this issue. For this reason, the service prioritizes ongoing communication with hospital staff about the role

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[f] Conversion rate as of March 2021.

of PSSEO, the transitional peer support being provided and the importance of putting people at the centre of decisions and actions.

Supporting staff working in stressful conditions

The service has faced an ongoing challenge of retaining its peer support staff who are often working in an environment that can be stressful and has competing interests. The service management and others in the environment may not understand the wide range of challenges that people living with mental health problems may experience, including peer workers with lived experience. To approach this issue with understanding and sensitivity, the service emphasizes open communication if a member of the peer support team identifies as being unwell, and the person is not judged. PSSEO has a programme-specific management team, Business and Operations Manager and TDM Coordinator to provide flexible support to peer workers needing assistance, according to their wishes and preferences.

Key considerations for different contexts

Key issues to consider for the establishment or expansion of this service in other contexts include:

- conducting qualitative evaluations to capture service users' personal experiences of the service and to implement improvements, acknowledging that recovery is a journey and that service evaluations are a snapshot in time that may not reflect the entirety of the service as a whole or the entirety of people's experiences;
- encouraging participant engagement in evaluations can be difficult as people are often reluctant to provide information about their experiences for different reasons that may include distrust or anger at having had to complete evaluation surveys on multiple occasions for different organizations; and
- maintaining an attitude of growth and adaptation is required from both clinical and non-clinical peer support providers to resolve disagreement or conflict between entities.

Additional Information and Resources:

Website:
https://psseo.ca/

Videos:
https://www.youtube.com/watch?v=q_1qdE6kins&feature=emb_title
http://www.ledbetterfilms.com/our-videos.html

Contact:
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3.

Moving forward: from concept to good practice peer support mental health service

The purpose of this section is to provide readers with some key practical steps and recommendations that will facilitate the process of conceptualizing, planning and piloting a good practice peer support service that aligns with human rights standards. It is not meant as a comprehensive and complete plan for setting up the service since many context-specific factors, including socio-cultural, economic and political factors, play important roles in this process. Further detail on integrating the service into health and social sectors is provided in the guidance and action steps section in *Guidance on community mental health services: Promoting person-centred and rights-based approaches.*

Action steps for setting up or transforming a peer support mental health service:

- **Set up a group of different stakeholders** whose expertise is crucial for setting up or transforming the service in your social, political and economic context. These stakeholders can include but are not limited to:
  - » policymakers and managers from health and social sectors, people with lived experience and their organizations, general health and mental health practitioners and associated organizations, legal experts, politicians, NGOs, OPDs, academic and research representatives and community gatekeepers such as local chiefs, traditional healers, leaders of faith-based organizations, carers and family members.
- **Provide the opportunity for all stakeholders to thoroughly review and discuss the good practice services** outlined in this document to get an in-depth understanding of the respective services. This is an opportunity to identify the values, principles and features of the good practice services that you would like to see incorporated into your country's services given the social, political and economic context.
- **Establish contact with the management or providers of the service(s)** that you are interested in to get information and advice on setting up or transforming a similar service in your context and to understand the nuances of the service. Ask specific questions about how these services operate keeping in mind the local context in which the services would be developed. This can be done via a site visit to the good practice service and/or video conference.
- **Provide training and education on mental health, human rights and recovery** to the groups who will be most relevant for setting up or transforming the service using WHO QualityRights face-to-face training materials (https://www.who.int/publications/i/item/who-qualityrights-guidance-and-training-tools) and e-training platform. Changing the attitudes and mindsets of key stakeholders is crucial to reduce potential resistance to change and to develop attitudes and practices in line with the human rights-based approach to mental health.
- **Research the administrative and legal regulations** concerning setting up or transforming the service.

Questions specific for setting up or transforming peer support services:

- Are you aiming to transform an existing peer support service? Or to set up a new peer support service?
- Will the peer support service be stand-alone or part of another service (for example, part of a hospital service, community mental health centre, or as part of a local community initiative, etc.)?
- Will the peer support service be accessible to anyone with mental health conditions or psychosocial disabilities or will it focus on specific groups (such as individuals with specific mental health experiences or conditions, women, men, older persons, persons who are homeless, persons with substance or alcohol use problems, other minority or marginalized groups, etc.)? Will anyone be excluded from your service?
- What type of peer support service are you planning to provide? Options may include:
  - one-to-one peer support
  - peer support groups - with open/closed membership *(59)*
  - other.
- What format(s) will the peer support take? Options may include:
  - discussion
  - shared activities (such as outings together, painting, attending lectures, etc.)
  - other.
- Where will the peer support meetings take place? Options may include:
  - a designated place (for example, the service will have its own premises where meetings/activities can take place).
  - in the community (for example, hiring meeting rooms, one-to-one meetings in a cafe)
  - at a person's home
  - online
  - other.
- How will your peer support service be accessed? For example:
  - open door policy, anyone can join at any time
  - by referral, and if so, by whom
  - via invitation by an existing member
  - other.
- What will be the interrelationship between this service and other services, supports and resources in the community, including referral systems?
- What will be the areas of focus in your peer support service? Options may include:
  - general peer-to-peer discussion and sharing of experiences
  - support mechanisms during a crisis situation

  - supported decision making
  - transitioning back into the community from hospital
  - providing information and training opportunities, for example on developments in mental health and human rights
  - linking to other community resources, for example:
    - other peer support or peer-led initiatives
    - community inclusion initiatives
    - employment initiatives
    - education initiatives
    - social protection including social protection benefits
    - legal services
    - housing services.
- What elements are needed to support how peer support is provided? For example:
  - the role of facilitator(s) in a group meeting
  - values and ground rules
  - confidentiality
  - the role of a moderator in online forums
  - supporting someone if they are experiencing a crisis situation
  - process for new members to join the service (application process/drop in/etc.)
  - other.
- What human resources will be required (peer supporters, administrative staff, etc.) and what sort of skills and training will be required for them to provide quality and evidence-based service in line with human rights?
- What role (if any) will other professionals (such as doctors including psychiatrists, general practitioners and others, psychologists, nurses, social workers, peer support workers, occupational therapists, outreach workers, community/lay workers, etc.) have in your peer support service? Options may include:
  - invited to speak at the request of members
  - referral mechanisms for members who wish to contact one of these professionals
  - other.
- How will your service assess, provide for or refer people for any physical health conditions they may have?
- What strategies and training are you planning to put in place to realize legal capacity, non-coercive practices, participation, community inclusion and recovery orientation?[g]

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[g] For more information see section 1.3 in *Guidance on community mental health services: Promoting person-centred and rights-based approaches.*

Legal capacity

- How will the service ensure that individuals are attending of their own free will?
- How will the service ensure that each individual's unique experience is respected?
- How will the service ensure that, as part of peer support, any supported decision making is based on the will and preference of the person?
- How will the service provide information on human rights, informed consent, advance planning and legal capacity?
- How will the service facilitate access to legal advice and representation by its users who may need of this type of service, (e.g. pro bono legal representation?
- How will the service support people to end guardianship or involuntary orders?
- How will the service ensure that complaint mechanisms are in place?
- How will the service support people to:
  - » make informed decisions and choices different options for their treatment and care?
  - » access all critical information relating to medication and other treatment including on their efficacy and on any potential side effects?

Non-coercive practices

- How will the service support people who are subject to violence and abuse in services, in the home and in the community?
- How will the service support people to write individualized plans to explore and respond to sensitivities and signs of distress?

Participation

- How will the service ensure that individuals with lived experience are leading all aspects of the service?
- How will the service systematically collect feedback from service users and use this feedback to develop and improve the service?

Community inclusion

- Will the service provide direct support for community inclusion, for example a peer accompanying a person to support them at medical, legal or other appointments?
- Will the service identify spaces in the community that facilitate community inclusion (such as cafes, local groups, other peer support initiatives)?
- How will the service support people to find work and income generation, for example through a transitional employment programme, supported employment programme or through independent employment as appropriate?
- How will the service facilitate access to housing services?
- How will the service facilitate supported education and assistance in accessing community-based education opportunities and resources to continue education?

- How will the service facilitate access to social protection benefits?
- How will the service facilitate access to social and recreational programmes?

■ Recovery

- How will the service ensure that people will be considered in the context of their entire life and experiences and that care and support will not solely focus on treatment, diagnosis and symptom reduction?
- How will the service ensure that the five dimensions of recovery: (1) connectedness, (2) hope and optimism, (3) identity, (4) meaning and purpose and (5) self-empowerment are integral components of service provision?
- How will people be supported to develop recovery plans; that is, to think through and document their hopes, goals, strategies for dealing with challenging situations, managing distress, strategies for keeping well, etc.?

- Will the peer support service provide training and support activities regarding the human rights-based approach in mental health to other stakeholders and in the community?
    - » Will the service provide training and support to organizations in the community, including civil society groups?
    - » Will it provide training and support to staff of other health and social services, including non-specialized health services?

- Awareness-raising and advocacy
    - » Will the service undertake awareness-raising on mental health and human rights, including with families, schools, employers, local organizations and other community settings?
    - » Will the service undertake advocacy actions on mental health and human rights for the rights of people with mental health conditions and psychosocial disabilities and create positive opportunities for individuals to engage in the community with the ultimate aim of creating a community whereby individuals can live autonomously? This includes actions to reduce stigma around mental health and creating positive opportunities for community engagement.

- **Prepare a proposal/concept note** that covers process issues, detailing the steps for setting up the service, the vision and operation of the service network based on the full range of services that will be provided, covering the following:
  - » human resource, training and supervision requirements;
  - » how this service relates to other local mental health and social services;
  - » strategies to ensure that human rights principles of legal capacity, non-coercive practices, community inclusion, and participation will be implemented, along with a recovery approach;
  - » details about the monitoring and evaluation of the service; and
  - » information on costs of the service and how this compares with the previous services in place.
- **Secure the required financial resources** to set up or transform the service, exploring all options including government health and social sectors, health insurance agencies, NGOS, private donors, etc.
- **Set up and provide the service** in accordance with administrative, financial and legal requirements.
- **Monitor and evaluate the service on a continual basis and publish research** using measures of service user satisfaction, quality of life, community inclusion criteria (employment, education, income generation, housing, social protection), recovery, symptom reduction, assessment of quality and human rights conditions (for example, by using the QualityRights assessment toolkit), and rates of coercive practices (involuntary treatment, mechanical, chemical and physical restraints).
- **Establish dialogue and ongoing communication with key stakeholders and members of the public** by holding public forums and hearings with these groups to allow people to openly express their views, ideas, and concerns about the service, and to address these concerns.
- **Advocate and promote the service** with all relevant stakeholder groups (politicians, policy makers, health insurance agencies, media, people with lived experience, families, NGOs, OPDs and the community at large). This also involves actively reaching out through both traditional and social media. Having the successes of the service highlighted publicly can be a good strategy to bring people on board.
- **Put in place the strategies and systems** required to ensure the sustainability of the service.

Further guidance is also available through the following WHO resources:

Peer support groups by and for people with lived experience. WHO QualityRights guidance module. Geneva: World Health Organization; 2019. Licence: CC BY-NC-SA 3.0 IGO.

One-to-one peer support by and for people with lived experience. WHO QualityRights guidance module. Geneva: World Health Organization; 2019. Licence: CC BY-NC-SA 3.0 IGO.

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