Technical package

Community outreach mental health services

Promoting person-centred and rights-based approaches





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Community outreach 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)

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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however, in all countries, whether low-, medium- or high-income, the collective response has been constrained by outdated legal and policy frameworks, and lack of resources.

The COVID-19 pandemic has further highlighted the inadequate and outdated nature of mental health systems and services worldwide.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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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 poorquality 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.

a Strategies to end seclusion and restraint. WHO QualityRights Specialized training. Course guide. Geneva: World Health Organization; 2019 (<u>https://apps.who.int/iris/bitstream/handle/10665/329605/97892</u> <u>41516754-eng.pdf</u>).



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 personcentred, 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 recoverybased 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 communitybased 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:



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 personcentred 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 personcentred 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 faithbased 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.



Introduction

Community outreach services deliver care and support to the population in their homes or other settings, such as public spaces or on the streets. Community outreach services often constitute mobile teams comprising health and social workers and community members.

The support options provided through community outreach are varied. As shown in this technical package, services can provide emotional support and counselling as well as support for medication, to perform daily activities and meet basic needs (supported living), or enable people to make informed decisions concerning treatment and other aspects of their lives. Community outreach services can support people to gain or regain a sense of control over their lives and recovery journeys. They also play a crucial role in connecting people to existing services in the community and provide support in navigating health and social care systems. Additionally, community outreach services often provide information about mental health, and can engage in mental health prevention and promotion initiatives.

Versatile, dynamic and flexible, some outreach services provide mental health services to marginalized populations that would not otherwise have access to them. Several community outreach services showcased in this technical package cater specifically to homeless or rural populations, for example.

The examples of good practice provided in this technical package, show how people delivering outreach services emphasize the importance of respecting individuals' rights to legal capacity. This means that the people using the service are in control and supported to make their own decisions about where the service will take place, when, what will be included in the service and other aspects. Facilitating individuals' paths to recovery and independent living is a priority.

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.



Community outreach mental health services – description and analysis

2.1 **Atmiyata** Gujarat, India



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COMMUNITY OUTREACH MENTAL HEALTH SERVICES – DESCRIPTION AND ANALYSIS

Primary classification: Community outreach

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:
Vertex Published literature Grey literature None
Financing:
State health sector State social sector Health insurance
Donor funding Out-of-pocket payment

Context

Atmiyata^b (1) is a primary care, community outreach service delivered to communities in the Mehsana district of Gujarat, a state in Western India. Gujarat has a population of 60 million (2). Mehsana is a mainly rural district in the northern part of the state, with a population of 1.52 million people and 645 villages, divided into 10 sub-districts or blocks (3). With 53% of the population employed in the agricultural sector, with just under half of Mehsana's rural population has a low standard of living according to the Standard of Living Index (4).

Mehsana has 56 Primary Health Centres (PHCs), 11 Community Health Centres (CHCs), and one district hospital with two full-time psychiatrists in its workforce. Mehsana's District Mental Health Programme (DMHP) employs a psychiatrist, a psychologist, a psychiatric social worker and four nurses. DMHP also provides an information, education, and communication programme. As well as running an outpatient clinic at Mehsana District Hospital, these mental health professionals provide outreach outpatient clinic services every month at four CHCs and three sub-district hospitals in the district for 3–4 hours at a time.

Atmiyata identifies and supports people in distress within rural communities. The service works in collaboration with Mehsana's district health programme which is run by the Government of Gujarat's Department of Health and Family Welfare. It is supported by the NGO Altruist and the TRIMBOS Institute in the Netherlands. The collaboration between Atmiyata and the DMHP has established a clear referral pathway. Atmiyata volunteers assist individuals, their caregivers, and families if they wish to access the DMHP or the psychiatric services at the district hospital. If individuals in distress directly approach specialized mental health services, the volunteer is not included in the discussions with mental health professionals.

b *Atmiyata* means empathy or shared compassion in Marathi, the local language in the Indian state of Maharashtra, where this programme was first used.

Atmiyata, therefore, uses existing resources within communities to strengthen links between them and the public health system. It does this by developing working relationships and referral pathways, linking rural communities with district-level and rural hospitals, primary health care centres and nongovernmental organizations.

A relatively new service, Atmiyata has been implemented successfully in Gujarat and Maharashtra^c demonstrating its potential for successful transfer to other parts of India.

Description of the service

Atmiyata supports those experiencing distress. The service is built upon the principles of empathy and volunteerism, providing a scalable and sustainable path to mental health care in low-resource settings (5).

The service is delivered by two tiers of community volunteers. The first, Atmiyata Mitras, are trained to identify individuals who may be experiencing distress. They come from different castes and religious backgrounds within their villages. The second, Atmiyata Champions, are well-known and approachable members of the community (including former teachers or community leaders) who have leadership and communication skills. Champions are trained to identify and provide structured counselling (6,7) to individuals experiencing significant distress, including those referred by Mitras. Although there are many social barriers based on gender, caste and religion, the Mitras and Champions work to ensure that the service is available to everyone in the village.

Interventions follow a stepped care and support approach. Community-based volunteers are trained, mentored and supervised to conduct four activities; to identify people experiencing distress and provide 4–6 sessions of evidence-based counselling; to refer individuals who may be experiencing a severe mental health condition to public health services when required; to raise awareness by showing films on a smartphone about the social determinants of mental health among community members; and to enable access to social care benefits and increase financial stability.

Evidence-based counselling sessions

Atmiyata Champions use their knowledge of the community to approach people in distress. They also rely on Atmiyata Mitras within the community to refer people from different parts of the village. During a first meeting with an individual who might require help, Champions begin the conversation by asking how the person is feeling, and that they have noticed the person has seemed distressed. They introduce themselves as Atmiyata Champions who can assist the individual in working through their distress, with skills they have been trained to use.

Once a Champion has built rapport and developed a sense of trust, and if the individual wishes to proceed with the conversation, consent is obtained for another meeting. The two agree on the next place and time to meet. The location is usually somewhere private, where the person feels comfortable; it might be their house or farmland, somewhere outside the workplace, or the discussion may take place during a walk. When people feel comfortable enough to share their experiences of distress, Champions introduce structured sessions. They reassure the individual that confidentiality and consent will be respected at every meeting. This process is flexible and varies from person to person. For some, one visit is enough to establish trust and rapport. For others, more than one interaction may be required.

c Maharashtra's programme has now been scaled up to 100 villages in a new district with Mahila Arthik Vikas Mahamandal (MAVIM), the Government of Maharashtra's State Women's Development Corporation.

Technical package

The most important aim is to ensure the individual is in control. They decide whether to continue with the sessions or to stop and resume them later. If someone refuses to engage with the Champion, their preference is respected and they will not be forced to meet again.

During the second meeting, the Champion discusses and explores the distress the person is experiencing and possible reasons in more detail. At a third meeting, the Champion may apply several behaviour activation techniques including activity scheduling (AS) and problem-solving (PS), depending on the goals set by the individual.

During behaviour activation, the Champion works with an individual to create an activity schedule that will assist them to reduce their distress. The Champion might ask the person to chart their present activity schedule, explore activities they have been avoiding due to their distress, reflect on activities that previously kept them well, and schedule pleasurable and valuable activities that allow the individual to resume day-to-day routines (8). For example, an individual may decide to return to activities that worked well for them in the past, such as meeting friends and family, getting back to their earlier work schedule, and meeting with informal groups. The Champion encourages the person to reflect on their emotions and mood, and what activities worked well in order to update their activity schedule on an ongoing basis.

When applying the problem-solving technique, the Champion helps an individual work through the practical steps to achieve their goals and thus reduce their distress. This could include help finding a job, reducing conflict at home, or assisting family members.

Champions are trained to deliver 4–6 sessions of counselling over a period of 6–12 weeks, with no predefined time between sessions. Each session lasts 20–40 minutes based on mutual agreement. The last session is used to reflect on changes that have taken place in the participant's life, which interventions helped them, and how the person could use their skills the next time they are in distress.

The Champions encourage the use of the evidence-based techniques that are reviewed throughout their ongoing engagement. However, they must leave space for flexibility and creativity and ensure the person retains control of the process. If the person is not benefitting from the sessions, or if the process is upsetting for them, they can choose to revise their strategy or even discontinue the sessions. The Champion will provide support even if a person does not wish to follow their activity schedule and problem-solving plans.

Champions may encounter more challenging issues, such as domestic violence and substance use. While the Champion may not be able to solve causes of distress, they aim to assist with increasing the person's own capacity to seek change and progress, reduce their distress, and increase peer support.

In domestic violence cases, the Champion not only provides support and reassurance but works to understand more about the problem. The Champion will work with the woman to set goals for their sessions together, help achieve her goals (such as finding employment) and increase her confidence to address the violence in the home. In addition, Champions follow a protocol for referrals to other support services in the community, such as crisis helpline numbers, shelters, and skills development centres. If required, they explain how to contact the police and request other kinds of assistance. The service will not intervene without the individual's consent, however, and the Champion never makes a decision for the woman.

Community Facilitators (CFs), who supervise and mentor Champions, are trained to; conduct quality assurance assessments of the sessions; to be aware of the power dynamics between the Champion and the individual; and to ensure the participant's will and preferences are being respected and that the goals are set by the person in distress themselves. CFs address any concerns during fortnightly meetings with Champions.

Referral to specialized services

The sessions are intended for people experiencing distress or with mild to moderate mental health problems. In other cases, including severe acute mental health conditions, addiction, suicidal ideation, or suicide attempts, the Champion makes a referral to a psychiatrist at the district mental health service, the district hospital or one of the CHC mental health clinics. If the person and their families wish to seek specialized mental health care, the Champion can provide information about nearby services – including opening hours and contact numbers. The Champion will never break confidentiality by speaking directly to specialized mental health professionals without the individual's consent. The person is not forced to take up a referral; the decision is left entirely to the individual and their family members. CFs can assist with referrals, although information they receive is de-identified. The Champion will discuss challenges faced while making a referral, with their CF. A CF might help by modelling a conversation through role-play. However, if consent is received, they may also speak to the individual directly while the Champion observes.

Showing and discussing films based on the social determinants of mental health

The Champions show four 10-minute films, dubbed in Gujarati, to people in their villages. These films are intended to spark discussions amongst small groups of people, three or four at a time, in community meeting places, such as within a temple or a farm. The films tackle social issues commonly experienced, such as unemployment, family conflict, domestic violence, and alcoholism, and their impact upon mental health. People viewing the films might be undergoing distress or know somebody who is and refer them to the service. Films are aimed at community members and are not used for training or therapy.

Enable access to social care benefits

Champions can help individuals in distress and their families access several government-based social benefits including widows' pensions, rural employment grants, disability benefits and other financial assistance for people with disabilities, social security for those working in the informal sector, and disability certificates. Champions can identify whether individuals are eligible for these schemes, and help them to access the correct documentation, such as identification cards and bank account details. Champions may help to fill in and submit forms to the local authority or track the progress of applications until benefits are received. Champions can also help people to access government paid-work schemes.

Atmiyata Champions are identified by CFs, who typically have a Master's degree in social work or a related field, are based locally, and are aware of community dynamics. CFs may visit a village several times to become familiar with its structure, map community groups, such as farmers' clubs, and interact with community health workers and the village head. This is how they identify candidates most suitable to become an Atmiyata Champion. The CFs interact with both groups and individuals in the village to approach potential volunteers, using a checklist that identifies the skillset required to become a Champion. Candidates are carefully considered, to ensure an equitable distribution of Champions in
terms of caste, gender, religion, age and other factors, so that the service is available to all members of the community. The CF explains the role of a Champion to potential candidates, checks their time commitment and willingness to become a volunteer. The candidate is then invited to attend a training course. When trained, the CF meets the Champion twice a month in the village: once individually, and once as a group of 3–4 Champions. During such meetings, the Champion's work is reviewed, challenges discussed, and solutions suggested. In addition, Champions and CFs speak over the telephone when additional support is required.

Each CF supports 40–50 Champions, so that there is one CF per 1000 population. Each Champion supports 4–5 Mitras. CFs are in turn recruited and trained by Project Managers (PMs), who each support seven or eight CFs.

Training, for both Mitras and Champions, comprises practice sessions, role-playing and discussions. Mitras receive four hours of training from a Champion based in the same village. They are trained to understand the signs and symptoms of distress, as well as how to make a referral to a Champion. Champions are also trained at a central location in the block or village area. Their training focuses on understanding the service, the need for mental health care, signs and symptoms of distress, evidence-based techniques, and protocols and procedures. PMs and CFs receive 55 hours of training over five weeks, with additional 8-hour sessions if they wish to become master-trainers. The methodology underpinning the training is interactive, reflective and participatory.

Additionally, half-day refresher training sessions for Champions are held every four months. These provide an opportunity for Champions to learn from their peers and develop new techniques to help reach more people in their villages and improve counselling skills.

Core principles and values underlying the service

Respect for legal capacity

Atmiyata's activities are based on the distress model, rather than an illness-focused model, because it is more acceptable and feasible for use within the community. The distress model informs the approach and care delivered by the Champions; they are trained to work only in accordance with the will and preferences of the person receiving services. All activities are based on informed consent, which is taken at the start of each session. Training equips the Champions with the skills to seek consent; this is monitored by the CFs during their visits. The individual has the right to withdraw from support provided by Champion; sessions can be discontinued at any time. The Champion can discuss any difficulties faced during the sessions with their mentor although the identity of the person in distress is not disclosed in discussions. The Champions use de-identified data when documenting their work. Similarly, only when Mitras refer individuals in distress, is the identity of the person disclosed to the Champion. The Champion will only suggest seeking specialized services if it is needed and does not approach professionals directly.

Non-coercive practices

Interventions provided by Atmiyata Champions address both social and mental health care needs based on non-coercive principles. They include evidence-based low-intensity counselling techniques such as active listening, problem solving and activity scheduling *(9)*.

Community inclusion

The service is based in the village, within the community. Counselling sessions are held in community venues where the person feels comfortable, for example in their home, in the fields, at their workplace or in a cafe. The service works through existing village networks; it does not attempt to establish new ones. Support to access disability, unemployment and other resources that reduce poverty, including government paid-work schemes, also serve to promote the inclusion of an individual within the community.

Participation

While having lived experience is not a mandatory requirement to be a Champion, personal experiences of distress often motivate people to become volunteers. Where appropriate, Champions do share their lived experience with the people they work with. This can provide hope and assistance in a similar way to peer support. Champions are guided by mentors on how to do this in a positive way.

Recovery approach

The Atmiyata service promotes recovery-oriented care focused on empathy, hope and support to those facing distress. Champions are encouraged to share their personal experiences and how they overcame their distress during counselling sessions. Sharing experiences builds trust, reassurance and inspires hope. Counselling sessions increase the person's capacity to respond to their distress, thereby gaining control over their lives. The support delivered by Atmiyata is designed to build on a Strengths Perspective that encourages a person to lead an independent life, participate in community activities, and be considered an equal member of their community.

Service evaluation

The Gujarati Atmiyata service was evaluated using a stepped wedge cluster randomized controlled trial (SWCRCT) which spanned 645 villages in Mehsana District, with a rural adult population of 1.52 million. The primary outcome of the SWCRCT was an improvement in general health, measured using the GHQ-12 *(10)* at a 3-month follow-up. Secondary outcomes measured using a variety of scales including quality of life, symptom improvement, social functioning, and depression symptoms *(11-15)*.

Results showed recovery rates, for people experiencing distress, were clinically and statistically higher in people receiving the Atmiyata service In addition, improvements in depression, anxiety, and overall symptoms of mental distress were seen at the end of three and eight months. Moreover, significant improvements in functioning, social participation and quality of life were reported at the end of eight months. Overall, results suggest that the Atmiyata service has led to vast improvements in quality of life and disability levels as well as in symptoms related to mental health conditions *(16)*. The results of the Atmiyata evaluation in Mehsana reinforce earlier findings from a proof-of-concept study undertaken in Peth Block, Nashik District in Maharashtra in 2013–2015 *(1)*.

Costs and cost comparisons

Atmiyata was initially funded by Grand Challenges Canada but is now financed by Mariwala Health Initiative until March 2022 (1, 17). The budget supports the salaries of staff members, such as CFs and PMs. Costs also include capacity-building training for staff, smartphones for the Champions, and travel and administrative costs to ensure the effective implementation and quality assurance of the service.



All services are delivered to the end user locally and free of charge and the work of Champions and Mitras is voluntary and unpaid. Travel and other expenses are covered, however.

The total annual cost of delivering the Atmiyata programme to 500 villages, covering a million adults, was US\$ 120,000 in 2019. The service reached 12 758 people experiencing distress or symptoms related to mental health conditions between 2019 and 2020 ([Kalha J], [Indian Law Society], unpublished data, [2021]). This annual cost does not include smartphones provided to the Champions (mobile phones are expected to work for two years and then replaced, therefore are not included in the annual cost).

Challenges and solutions

Building support and engagement from the wider community

Lack of support from government officials and the general public was a major problem.

Several strategies were employed to overcome this obstacle. Meetings were held with local and state government officials to explain the content of the intervention and its possible advantages. Meetings were also held with village level stakeholders to explain the intervention and to form alliances and build trust. The service also worked with other community-based organizations to map the villages and to understand how they functioned and build support

Overcoming discrimination related to caste, class and gender

A significant challenge was the effect of caste, class, gender and other issues, which created barriers to delivering a truly equitable intervention. Communities too lacked the confidence to become involved in co-designing the service.

The service collaborated with organizations engaged with inter-sectoral issues such as caste and gender discrimination; it embarked on sensitizing them to the rights of people with mental health conditions and psychosocial disabilities. It worked to engage with marginalized and vulnerable groups and get them involved in co-designing the service.

Funding challenges

The service faced significant funding challenges. Grant-based funding was restrictive and did not allow the service to expand. To remedy the situation, the service actively engaged with a wider range of funding organizations which were able to provide more long term funding and allow for the expansion of the service.

Building an effective workforce

Recruiting local staff was sometimes problematic because educational qualifications, and even past work experience, did not prove to be a good indicator of how well the person could engage with mental health work or adhere to the values and principles of the service. Some of the material used in training was not appropriate from a learning perspective.

After recruitment, staff were provided with plenty of input from managers of the service. They were provided supervision, monitoring and quality assurance that enabled the staff to deliver appropriate interventions, regardless of previous educational level or lack of experience. In addition, the training

format and materials were changed to better suit the needs of new recruits. Training became less theory-based and more participatory, involving role-play and skill-based exercises.

Key considerations for different contexts

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

- planning ahead and imagining what an expanded service might look like and what it would need in terms of finance and staff;
- developing standard protocols so that what is learnt through experience is not lost;
- considering outcome indices most meaningful for the people using the service (such as participation in their community and quality of life) and not simply levels of symptom reduction;
- using 'evidence-based' techniques, but being prepared to adapt them for the local context;
- closely collaborating with existing public health and social services, support and resources;
- building a strong evaluation that can be used to generate confidence about the impact of the service and lead to more sustainable funding; and
- considering schemes that involve both volunteering and rewards, and that sit well with local social and cultural traditions.

Additional information and resources:

Website

https://cmhlp.org/projects/atmiyata

Videos:

Atmiyata: A rural and community led mental health and social care model <u>https://twitter.com/CMHLPIndia/status/1300301510190927872</u>

What is the role of an Atymiyata Champion? <u>https://twitter.com/CMHLPIndia/status/1331822246575280128</u>

Madina Ben, Atmiyata Champion, Mehsana, Gujarat <u>https://www.youtube.com/watch?v=2Rlter_9Mpl</u>

Dr Animesh Patel, District Senior Psychiatrist, speaks about Atmiyata's Impact <u>https://www.youtube.com/watch?v=V2w-PkbJxxA</u>

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2.2 **Friendship Bench** Zimbabwe



Primary classification: : Community outreach Other classifications: Community outreach Community mental health centre Peer support Hospital-based service Crisis 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

Zimbabwe is a low-income country in sub-Saharan Africa with a population of 13 million. Most people live in rural areas *(18)*. The capital city, Harare, has a population of 1.6 million.

There are four tertiary psychiatric units in Zimbabwe, two forensic mental health units as well as beds reserved for people with mental health conditions and psychosocial disabilities in four of the seven provincial general hospitals *(18)*. An NGO, the Zimbabwe National Association of Mental Health (ZIMNAMH), operates six residential psychiatric rehabilitation centres and half-way homes *(19)*. ZIMNAMH is also involved in advocacy and education. Many people with mental health conditions and psychosocial disabilities in Zimbabwe consult with traditional or faith healers *(20)*.

Many health professionals have left the country, presenting real challenges as Zimbabwe seeks to move towards community-based mental health provision. The Friendship Bench (FB), which was initiated in 2006 in Harare, works with non-professional lay counsellors aims to overcome this brain-drain problem. It provides a short-term form of problem-solving therapy (PST) to people with common mental health conditions at a primary care level. In the Shona language, used by most of Zimbabwe's population, such conditions are known as *kufungisisa*, which translates as, thinking too much.

Since its initiation in Zimbabwe, FB concept is now being implemented in other low-income settings. Projects in sub-Saharan Africa include in Malawi, Kenya and Zanzibar) *(21, 22)*. It has also been introduced in two low-income communities in the Bronx and Harlem, New York City *(23)*. FB is mentioned in the UN's Global Action Plan on Sustainable Development Goals (SDGs); it is a recommended intervention for mental health care *(24)* within SDG 3.4.

Technical package

Description of the service

The Friendship Bench (FB) offers empathy, local community and cultural knowledge, skills, and formal problem-solving techniques (25) to people experiencing significant emotional distress.

The service is offered free of charge and is usually delivered outside a primary care centre on a wooden bench. The name Friendship Bench derives from a term *chigaro chekupanamazano*, translated as, bench to sit on to exchange ideas *(26)*. People can either self-refer or be referred by professionals from schools, the police or the primary health care clinic. Information about mental health issues and Friendship Bench services are provided during morning talks at the clinic or directly from FB counsellors or other clinic staff.

The service is provided by Lay Health Workers (LHWs), local women employed by local health authorities. They are assigned to the Friendship Bench initiative as part of their regular work; their tasks usually involve health-promoting activities such as vaccination campaigns and disease-outbreak awareness work.

Steeped in Shona language and culture, the women have extensive knowledge of the local economy and social networks; they can use Shona proverbs in a skilful way in their work (25, 26). They live in the same community as the people who use the service, often meeting them in informal settings outside therapy sessions and use these encounters to provide encouragement (25). The cultural embeddedness of the service, specifically through its work with these women, has made a major contribution to its sustainability (27).

Once trained, these LHWs carry out their work in a flexible way and often perform home visits where they spend time in prayer with clients and their families; on average each prayer lasts 15.30 minutes and is delivered by a LHW together with the family. The use of prayer in gatherings, particularly related to health, is a common practice in Zimbabwe' (28); the aim of the prayer is to comfort the sick and the family.

That most FB LHWs are older women, is an extremely important part of the service. In Zimbabwe, older persons are seen as important guardians of the community and therefore respected. With an average age of 58, they are referred to as grandmother health providers (*ambuya utano*) or grandmothers (*28*). They may have lived through difficulties in their own lives and bring a great deal of empathy to their work (*25*). The women often use their own life experiences in work with FB clients, creating conditions where people feel comfortable telling their stories too.

LHWs receive eight days of training in symptom recognition, the use of screening tools, psychoeducation and problem-solving therapy (PST) *(28)*. While FB training consists of a manual that provides guidance on how to implement the therapy, there is a strong focus on gaining experience under the supervision of trainers. Trainees practice counselling skills in small groups, often role-playing in front of the whole class. There is plenty of practice to help build the counsellor's confidence. In the clinics, the LHWs support one another; more experienced colleagues advise and guide the less experienced. The LHWs meet weekly to discuss their cases together and continue to receive support from the Friendship Bench training team via telephone or physical visits.

Problem-solving therapy is delivered to clients over six or more sessions. A Shona Symptom Questionnaire *(29)* is used to identify those who might benefit from the therapy. The decision to use Shona in this screening questionnaire and in PST was made after discussion with the LHWs. Indeed, using Shona has

made it easier to deliver PST and contributed to the therapy's acceptance and continued use in primary care facilities *(30)*.

PST has three main elements:

- Opening up the mind (*Kuvhura pfungwa*): an exploration of the client's situation. The client is asked to tell, "their story". The LHW and the client together make a list of the problems and difficulties the client faces. From this list, the client chooses a problem to work on. Take, for example, 19-year-old Tatenda, who is distressed because he must pay the equivalent of US\$ 20 in school fees.
- Uplifting (*Kuzimudzira*): developing a solution-focused action plan. Using the same example, Tatenda decides to approach an uncle who has helped him before, to ask for a loan. He will explain the situation, how much money he needs and how he intends to repay the loan. With help from the LHW, Tatenda works out that he can pay his uncle back by offering to work at the uncle's small farm during weekends. He plans to visit the uncle when he is at home on a Saturday afternoon. Additionally, Tatenda can walk to the uncle's house and therefore does not need money for transport.
- Strengthening (*Kusimbisisa*): the client receives support and is invited to return for a follow-up visit and further sessions. Although Friendship Bench was set up initially to offer just six sessions of counselling, the service has evolved. Many informal sessions continue because LHWs tend to meet their clients in the community and continue to support them.

The intervention is usually initiated at the primary health care clinic, on one of the benches. However, sessions can take place at the client's or LHW's home or outside, at the market or by the public borehole. Usually at least one session of the therapy takes place at the client's home and more frequently if requested (*26*). As well as individual sessions, clients are supported by text messages and telephone calls to reinforce the problem-solving therapy approach (*31*). Depending on the size of the clinic, up to 25 people can be seen per day.

FB clients working on problem-solving techniques are also invited to join a peer support group, called Holding hands together (*Circle kubatana tose*). Here, peers can share experiences in a safe space at weekly meetings. These groups are led by women who have already used Friendship Bench services and received some group management training (*31*). Sometimes, while sharing personal experiences, the women crochet Zeebags, bags from recycled plastic, they can sell. This activity brings an incomegenerating dimension to the project (*26*). People can attend this group for as long as they wish.

FB has also begun to collaborate with established organizations in Zimbabwe. These include Zvandiri *(32)*, an indigenous Zimbabwean NGO working to support young people with an HIV diagnosis; Solidarmed *(33)*, a Swiss NGO that partners with local NGOs in five African countries, and works on improvements in rural primary health care; and the Centre for Sexual Health and HIV/AIDS Research Zimbabwe (CeSHHAR Zimbabwe), which supports research and other interventions in the area of HIV and sexual health *(34)*.

Core principles and values underlying the service

Respect for legal capacity

Using the Friendship Bench service is strictly voluntary. It is targeted at people experiencing distress in the form of anxiety or depression. The aim is to empower the person attending by supporting them to find ways to overcome their problems, make decisions, and take actions on issues that are troubling them.

Technical package

Non-coercive practices

The FB staff do not use coercive practices. Work is carried out entirely on a voluntary and consensual basis. Staff members do not organize for clients to be admitted to public mental health services on an involuntary basis. However, if a person is identified as being high-risk, the counsellor will refer them to a professional, such as the sister in charge of the primary health care clinic, who may decide to refer the person to an inpatient unit.

Participation

The peer support groups bring participants with lived experience together. They are able to support one another and create a sense of solidarity. The leaders are not specifically trained peer-support workers. Importantly, these groups create further opportunities to help people problem-solve, as peers can make suggestions. The peer support groups operate both in primary health clinics and the community. The income-generating dimension also gives attendees a practical focus, as many face serious financial challenges.

Community inclusion

The service is embedded deep within the community in terms of location, links to community resources, and the current lay counsellors, who have lived locally for at least 15 years. Moreover, counsellors are appointed through a selection process that takes place at community gatherings comprising key stakeholders. These include church leaders, the police, head teachers, and other community leaders (*26*).

The problem-solving therapy is often enhanced by an activity-scheduling component. Here, people are encouraged to schedule activities meaningful to them and that make their lives more rewarding. Additionally, some people with mental health conditions in financial need have been referred to local community income-generating projects. In Harare, for example, those have included peanut buttermaking and recycling *(28)*.

Recovery Approach

Shona words and idioms are used in discussions about problems that clients of the service experience. The Shona Symptom Questionnaire (SSQ), used as a screening tool, therefore offers reassurance to the client that their experiences are recognized and experienced by others. Psychiatric diagnoses are not made by LHWs. Neither does the service provide medication or other forms of medical treatment. The aim of the service is to help people set goals for themselves and find ways of achieving these goals. The intervention aims to empower people to become strong problem-solvers, who can go on to make a difference in their communities.

Service Evaluation

FB is currently offered in three Zimbabwean cities as well as in 25 clinics in two rural areas as part of regular primary health care work. Overall, FB is available at 70 primary health care clinics in the country *(27)*. Since its scale up in 2016, FB has offered support to 50 000 people.

An early study showed that the basic FB approach was successful *(28)*; there was a reduction in Shona Symptom Questionnaire scores after 3–6 sessions of the intervention. The survey was based on 320 people who completed the therapy, over 50% of whom were HIV positive.

Subsequently, the FB has been evaluated using a cluster randomized controlled trial *(31)*. Here, 573 people were randomized to the FB intervention or a control group which received enhanced usual care, consisting of psychoeducation about symptoms, medication if indicated, and/or referral to a psychiatric facility. The control group participants also received two or three supportive text messages or telephone calls, the last of which reminded them to attend a six-month assessment. FB clients also attended a six-month assessment. Those who had received sessions through the Friendship Bench and accessed the peer support group showed greater improvements in mental health according to the Shona Symptom Questionnaire than the group which had received enhanced usual care.

Of the specific elements that comprise the Friendship Bench intervention — empathy, local cultural knowledge, group peer support with income-generation, and formal problem-solving techniques — the importance of the first two elements emerged in a qualitative study *(26)*. However, the cluster randomized controlled study could not measure the relative importance of each element, as it did not control for them *(31)*.

The counsellors also report a high degree of work satisfaction; they speak about feeling a strong sense of personal reward and satisfaction by being agents of change. Training in mental health and PST has also helped them cope better with their own lives and assist their own family members. These personal benefits for lay health workers may have helped to keep them motivated, despite receiving very little remuneration for their work *(26)*.

Costs and cost comparisons

The FB service forms part of Zimbabwe's primary health care provision. Therefore, counsellors are employed by local health authorities and receive a monthly salary. A first FB session has been costed at US\$ 5, according to 2019 data. Costs include group sensitization to the programme, individual screening, health care centre staff time, lay health worker time, and any materials necessary for the implementation of the programme. The service is free of charge for clients registered with the primary health care centre. Anyone with an address and an identification document may register. People without these can still receive FB services in the community; the grandmothers can be approached informally in the community and make themselves available.

The importance of the FB programme has been recognized; in 2019 it became part of the Zimbabwean national mental health strategy, driven by the Ministry of Health and Child Care *(18)*. Therefore, FB services will become part of every public health care clinic country-wide within the next few years and funded by the cities and districts.

Community health workers, who work for health departments, will be trained to become lay counsellors. Training will take place through the Friendship Bench Trust, an organization that supports FB activities by funding training materials and provides the material to make the benches. The Trust is financed by private donors and research grants. Training covers counselling skills, mental health literacy, HIV, management of suicidal ideation, self-care and group support.

Challenges and solutions

Moving from hospital-based psychiatric care towards community-based counselling

Psychiatric mental health provision in Zimbabwe tended to be simply medication and psychiatric hospital referral. An alternative to treatment as usual was poorly understood and as a result there was resistance from primary care providers and mental health professionals; moving to community-based counselling was problematic. The use of grandmothers as lay counsellors in the service was also seen as unprofessional and unethical. In addition, there was significant stigma around mental health conditions in the community.

To overcome these obstacles, active collaborative efforts were made to partner with the local work health authorities and to strengthen the existing services. The service initiated awareness campaigns in the community about the service, its benefits and mental health more generally.

Funding challenges

Lack of funding during the first four years was compounded by Zimbabwe's financial instability. Finding funds to run the service, therefore, was a major challenge.

A proof-of-concept research study successfully demonstrated the benefits of the intervention. This led to donor funding for the service. Attracting donor funding allowed the organization to employ a strong team of professionals committed to expanding the programme too.

Competing priorities

The success of the organization meant it grew and developed very quickly. As a result, a challenge has been the competing duties of the people who deliver the counselling. In addition, outbreaks of illness disrupted the service and, therefore, the health care staff supporting the service. The service was as a result forced to be flexible in response to external challenges. For example, it began to deliver counselling by phone as a result of the COVID-19 pandemic.

Tackling wider socio-economic issues

While problem-solving therapy is helpful for many people, it cannot be expected to impact the major socio-economic challenges that people face; poverty, HIV infection and domestic violence cannot be solved by therapy. This has been a major challenge. Health workers said such situations frequently caused their clients to feel pessimistic and worthless, discouraging them from attending further sessions *(26)*. The service therefore introduced an income generation component, built in peer support and supported people to address family and other interpersonal conflicts.

Key considerations for different contexts

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

- recruiting local people as lay counsellors; this may be more cost-effective and culturally acceptable;
- ensuring adequate staffing for implementation;
- using a participatory approach and engaging with beneficiaries to learn about their perspective on the programme and their needs.
- ensuring adequate transport for people to attend sessions and institutional support;
- learning clients' perspectives on the programme and their needs;
- conducting rigorous scientific evaluation, which requires ongoing capacity building of the team and links with established research institutes;
- publishing rigorous scientific evaluations in peer-reviewed journals to help increase the credibility of the work and secure donor funding and support; and
- drawing on the expertise of a communications expert with media skills to help disseminate research results to policy makers, the wider public and to the international medical and scientific community.

Additional information and resources:

Website:

www.friendshipbenchzimbabwe.org

Videos:

The Friendship Bench: grandmothers boost mental health in Zimbabwe <u>https://www.youtube.com/watch?v=qfSTUHCNocl</u>

Why I train grandmothers to treat depression | Dixon Chibanda. <u>https://www.youtube.com/watch?v=Cprp_EjVtwA</u>

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2.3 **Home Focus** West Cork, Ireland



Primary classification: Community outreach



Context

While Ireland is a high-income country, there are significant levels of poverty and disadvantage in some depopulated, and increasingly marginalized rural areas (*35*). In recent decades the provision of public services, including health services, has tended to follow population trends and is now concentrated in urban areas (*36*).

With a widely dispersed population of 55 000 and because of outward migration, the catchment area of West Cork has the highest percentage of the elderly of any Irish catchment area *(37)*. The transport infrastructure is underdeveloped which has made it difficult for people, particular those who do not own a vehicle or are unable to drive, to access services in the towns.

West Cork's public mental health service is organized by the West Cork Mental Health Service (WCMHS), part of Ireland's national health service, the Health Service Executive (HSE). The adult mental health component of WCMHS is based at the Centre for Mental Health Care and Recovery in Bantry General Hospital. There are 18 inpatient beds here, which serve all adult mental health needs, such as mental health emergencies, elderly care and detoxification. The service also runs weekly outpatient clinics in six towns and three small community mental health teams that are organized geographically. There are several long-term residential units in the catchment area and two resource centres based in the largest towns. The adult mental health service does not have a community-based crisis service, such as a home treatment team, nor a separate mental health rehabilitation team. Child and adolescent mental health services are provided by a separate group.

As a result, WCMHS has worked creatively with local and national NGOs and other partners to develop a range of interventions guided by a recovery philosophy and the active promotion of peer-support *(38)*.

West Cork was one of the services involved in Advancing Recovery Ireland, an HSE-led initiative aimed at bringing about the organizational and cultural change necessary to support services become more recovery-oriented. An Open Dialogue programme has also been running in West Cork for a number of years, two Hearing Voices groups and a wide range of initiatives based on the creative arts (39, 40).

West Cork Home Focus was created in 2006 specifically to respond to the needs of a dispersed population living in a rural area with poor transport infrastructure. It is a joint initiative between WCMHS and a group of partner organizations involving services that are delivered by people with lived experience alongside professionals in mental health work and with expertise in vocational training. Home Focus complements WCMHS-run services. Although funded by HSE, the initiative is managed, on a day-to-day basis, by an NGO, the National Learning Network (NLN), which is part of the REHAB group *(41)*. This is the only service of this kind run by NLN and the only service of its kind in Ireland.

Description of the Service

The aim of Home Focus is to help individuals and families in the West Cork area enhance their mental health and wellbeing; promote independent living skills; increase levels of connection to their own communities; facilitate access to training, education and employment opportunities; and enable planning for the future. Home Focus combines initiatives that support individuals and families both at home and the community. The interventions are not diagnosis-led but are suited to the individual's needs and circumstances. The service works specifically with a recovery philosophy and places emphasis on giving people time, as well as being practical, reliable and flexible. It also recognizes the importance of peer-support.

Home Focus is provided by a small team that combines professional and peer-based expertise. It comprises a full-time Community Mental Health Nurse (CMHN), two part-time Rehabilitative Training Instructors, a part-time Recovery Support Worker, and a full-time Recovery and Development Advocate. The CMHN is a trained practitioner who provides specific mental health support to individuals, as well as working with families and other support networks; the CMHN has knowledge and expertise in psychotropic medications but does not prescribe. The Rehabilitative Training Instructors provide support in employment and training. They are also trained in Wellness Recovery Action Planning (WRAP) a programme designed to support people to overcome mental health challenges and to fulfil their life dreams and goals *(42)*. The Recovery Support Worker has been trained in recovery-oriented, person-centred approaches to therapy and dialogical approaches, including Open Dialogue and Hearing Voices. As well as offering individual support, this Recovery Support Worker co-facilitates the two Hearing Voices groups in West Cork.

The post of Recovery and Development Advocate was specifically set up for a person with lived experience. The advocate has undergone training in WRAP as well as Peer Leadership, conducted by the Kerry Peer Support Network *(43)*. As well as working with individuals and families alongside the rest of the team, there is also a community development dimension to their work. The advocate works with 49 North Street (see below), local resource centres and community initiatives, such as Clonakilty Wellness month. The advocate is currently establishing peer support groups in areas of West Cork including Skibbereen, Bantry and Clonakilty.

While team members have specific skills in mental health, much Home Focus work is often generic in nature. The team is available to work in flexible and creative ways with people using the service.

Team members regularly attend multi-disciplinary meetings of the three WCMHS community mental health teams. This means that Home Focus is fully integrated with the local adult mental health service. All referrals to the Home Focus team are made from these community teams. Active liaison with NGOs, voluntary, and community support services also encourages collaborative support.

Anyone interested and willing to join the service, and who fulfills one or more of the following criteria is accepted:

- a history of frequent/ unplanned admissions to psychiatric in-patient services (two or more admissions in the previous 12 months);
- a recent acute mental health episode;
- social isolation and significantly impaired ability to function in their own community;
- patterns of sporadic engagement with services; or
- difficulties attending or accessing mental health or disability services such as psychiatric clinic appointments, visits to the CMHN, or training centres.

The Home Focus service is not set up to support people whose main problems are with substance use, nor those accessing other NLN training courses. However, there is a commitment to flexibility and each person is assessed on an individual basis. People are eligible if they have been involved with mental health services. If someone is not accepted by the Home Focus service they will continue to receive support from their community mental health team. To date, no one has ever been asked to leave the Home Focus service. Participants wanting to withdraw from the service are referred back to their community mental health team. Self-referrals are not accepted, but people can ask their community mental health team to be referred to the service.

Home Focus services are available from 09:00–17:00, five days a week, and the service has supported individuals for between three and 18 months. The team is funded to work with up to 34 people and takes approximately 23 new people per year *(44)*. The frequency of individual follow-ups and support depends entirely on individual need. Team members are valued because they are reliable and able to spend time with users of the service. One person said, "I just can't stress how important that is, to know that I have that connection there you know, and to know that they are good to their word and they will be up and they will talk to you, and they'll spend two or three hours if necessary and things get sorted out. So the issues I had on Monday, when I wanted to speak to the psychiatrist, I don't feel it's so urgent today." *(44)*

Interventions include:

- individual and family mental health work, delivered from a strengths-based approach;
- encouragement with the development of coping strategies, literacy, social skills, setting goals, resolving conflicts, and managing stress;
- support and advice around medication management and, where necessary, liaising between the person and their prescribing psychiatrist about any proposed changes to medication;
- · help with access to education and training opportunities, including home-based training;
- practical help and advice about community integration, social activities and leisure pursuits;

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COMMUNITY OUTREACH MENTAL HEALTH SERVICES – DESCRIPTION AND ANALYSIS

- help to attend peer-support groups, including Alcoholics Anonymous (45); GROW, a community-based organization that provides a 12-step approach to recovery (46); Shine, an Irish NGO that supports individuals with mental health conditions and their families (47); local Hearing Voices groups.
- support to attend appointments with social welfare, GP, the housing office, and other services;
- support with applications for grants, housing support, job opportunities, training, employment, tenancy agreements, and benefits;
- connecting people with local arts and cultural activities in the West Cork area, including work to develop the 49 North Street initiative (see below); and
- connecting people with community-based activities such as walking and gardening groups.

Community Development: The Wellbeing Network and 49 North Street:

In recent years, the HSE, WCMHS and NLN have created a Wellbeing Network, a collaboration with West Cork's creative community of artists and musicians, offering various physical and mental health initiatives *(48)*. The Wellbeing Network encourages inclusive community projects that promote wellbeing. It is open to everyone in the community *(49)*.

The Home Focus team, particularly the Recovery Development Advocate, collaborates with this creative community to create an inclusive area where people with mental health conditions and psychosocial disabilities can engage in communal artistic and therapeutic projects alongside others. An example is the 49 North Street project (50), a space where learning, therapeutic activities, creative expression and diversity can flourish. The project's philosophy is centred on taking risks, building on people's strengths, and working together to create a community where recovery and well-being thrive. Current activities include a community choir, a rock band, a music and story-telling workshop, meditation, walking and gardening groups, an art workshop, an Irish language workshop and a Gamelan orchestra (51). These activities are open to all but are particularly welcoming to people with mental health conditions. In addition, one of the peer support groups being developed by the Recovery and Development Advocate from the Home Focus team is also based at 49 North Street.

The Recovery and Development Advocate has been particularly active in creating a wealth of other initiatives, aimed at community inclusion. The annual Skibbereen Arts festival and the Taste of West Cork Food Festival now incorporate a mental health dimension and actively seek to remove the barriers that might prevent people with mental health conditions and psychosocial disabilities from becoming involved *(52)*.

Core Principles and Values underlying the service

Respect for legal capacity

The service is committed to supporting people to make personal choices and decisions. The team signs a charter of rights and responsibilities with every service user. It includes a statement, "that people using the service are involved in all decision making about their futures." It adds that service users will always be, "helped to make informed choices," in regard to treatments and interventions.

Everyone using the service prepares an Individual Action Plan (IAP), which includes their personal goals and priorities, with the support of a team member. The IAP helps the individual articulate their wishes, including the services they would like to receive and what should happen during crises. WRAP

crisis plans (42) are also used in this regard. While advance directives are not yet legally binding in Ireland, IAP and WRAP crisis plans are respected and enforced by the service in West Cork. The IAP is reviewed every six months.

Non-coercive practices

Any involvement with the Home Focus team is done so on a voluntary basis. There is no sanction for those who fail to attend, neither are there stipulations on adherence to medication. People are supported, whether they wish to take medication, consider other options, advocate for a review of their medication plan, or require help to taper medication, when this is planned. Similarly, there is no insistence that a person engage with any other services such as psychotherapy, occupational therapy or social work.

The Home Focus team works to manage any potential conflict situations and is trained to use various de-escalation techniques and approaches including SafeTalk *(53)*, Assist *(54)* and WRAP. The team's can-do philosophy and support of service users in endeavours of their choosing tries to avoid the build-up of frustration and distress. However, on occasion, people using the service have been admitted to hospital on an involuntary basis. Decisions about involuntary admissions are not made by the Home Focus team but by the person's family, GP and a psychiatrist from the hospital in Bantry.

Community Inclusion

The whole Home Focus programme is aimed at community inclusion. People who use the service are supported to engage with activities in their community, such as training, work, cultural pursuits, and leisure and health activities, such as walking and swimming. They are assisted with planning their own budgets and applying for benefits when appropriate.

Assistance to find alternative housing is provided where necessary. Support is also given in relation to education, training, employment and social activities, in line with the wishes of each individual.

There are active efforts to connect people with their families and communities. The Home Focus team seeks to assist each person to broaden their social network. The aim of the team is to withdraw gradually as the person gains confidence, independence, and becomes increasingly integrated into the community.

The service regularly liaises with Cork County Council as well as with community-based organizations such as Community Resource Centres, Cork Mental Health Foundation, GROW *(46)*, The Clonakilty Wellness Group, Novas *(55)* and Social Farming *(56)*. The 49 North Street project is essentially a community inclusion initiative aimed at removing barriers for people with mental health conditions, allowing them to engage in creative activities, community events and festivals.

Participation

The Home Focus team's Recovery and Development Advocate is a person with lived experience. This person has participated in an 8-week training programme on Peer Facilitation and is now one of the organizers of peer-support groups in West Cork. Several people from West Cork with lived experience underwent this Peer Facilitation training programme and meet regularly to support one another and plan for the future. The Recovery and Development Advocate also spends some of their time with people using the Home Focus service, works flexibly and also uses insights from their own experience.

Technical package

There is a specific collaboration between the Home Focus team and the two Hearing Voices groups

One of the partner organizations involved in setting up the Home Focus service was the Irish Advocacy Network, set up, managed and delivered by people with lived experience. There is peer representation at all management levels in the WCMHS and, accordingly, peer input to the management of the Home Focus service.

Recovery Approach

The service works with an explicit recovery orientation. It focuses on the strengths of the individual and seeks to develop a recovery plan based on the individual's hopes for the future. The team prioritizes the establishment of respectful, supportive relationships and works in a flexible way. All activities of the programme are designed to promote connectedness, hope, identity, meaningful roles and empowerment (CHIME) *(57)*.

The team uses the WRAP planning method to help people using the service plan their recovery journey. The Recovery and Development Advocate is also tasked with creating and supporting a wide range of community initiatives that can be helpful to people on their recovery journeys.

Service evaluation

A qualitative evaluation of the service was carried out by researchers at the Department of Applied Social Studies at University College Cork (UCC) in 2008 (44). As well as 14 participants, staff members and others were interviewed to assess the impact of the intervention on individuals who used the service, service providers and the wider community.

The impact on the participants was substantial. Themes identified in the qualitative interviews included, inspiring hope, being treated with respect, being listened to, being valued, having choices, time and availability of staff, consistency of staff and continuity of care.

Importantly, 89% of those interviewed reported improvements in their personal and social functioning particularly decision-making, sleep, improved interactions with family and social networks, and improved social skills; 72% reported improved social engagement, such as beginning to access personal and public transport or participate in local sporting activities; 71% reported improved independent living. For example, they reported moving to independent housing, having more confidence when shopping, and improved awareness of rights and entitlements. Better mental health was reported by 69%; they were less paranoid, reported less suicidal ideation, had better understanding of their medication, and an improved ability to communicate about their mental health issues. Finally, 40% reported better links with community groups and support organizations. The researchers found that participants particularly valued the time the team spent with them, their flexibility and the practical support that they delivered.

The Home Focus staff members also appreciated the freedom to work in an individualized and recoveryfocused manner. One said, "People with the same diagnosis on paper will have totally different recovery journeys...and for some people it may be appropriate for them to address past issues whereas for other people that could be the absolute worst thing for them to do, and I think it's again the nature and flexibility of the project that can address some of that." *(44)*. Additionally, researchers said the partnership between state-run services, NGOs, and advocacy organizations had a very positive impact on the relationships between the different services.

The service was reviewed by the Inspectorate of Mental Health Services in 2011. It described the Home Focus team as, "innovative in its composition and service delivery." In addition, it said that a unique feature of the service was the, "capacity to deliver a truly recovery-oriented service and not just pay lip-service to the notion. The inter-agency team had a flexibility and capacity to respond over a range of psychosocial domains and to deliver person-centred care. This flexibility was not limited by the confines of professional role, diagnostic-related interventions or balkanized agency working' *(37)*.

The service has achieved national recognition as an example of good practice. Its peer-support element has stood as a positive example for other services *(58)*.

Costs and cost comparisons

The service is fully state funded through the HSE and costs approximately $\in 260,000$ (US\$ 313,394^d) per annum ($\in 7,600$ or US\$ 9,162 per person per year^d). This fee covers payroll and other employer expenses, training course fees, training materials, IT and software licenses, community subsidies, mileage and car allowances, to cover the large catchment area, as well as general administration and operational costs. There are no costs to the individuals using the service and no payments required from insurance agencies.

Challenges and solutions

Financial challenges

The end of the initial pilot project phase coincided with onset of economic crash in 2008. That brought major challenges around funding. To overcome this major obstacle, perseverance and belief in the approach led to sustained, and ultimately successful, efforts to persuade management to continue funding. Having an independent evaluation of the pilot period was crucial in securing ongoing management support. Local community and political support and collaboration between the HSE and the NLN was critical to the service's survival through a period of national austerity, when many other services were cut.

Building confidence in the recovery approach

Significant numbers of staff in the existing mental health services, and some people who used these services, were reluctant to embrace the recovery approach.

A large non-hierarchical steering group, which included the staff members, allowed early challenges to be overcome. Not only that, but the service embarked on active relationship building with existing services including people delivering government and NGO services in the area. The team attended local mental health multi-disciplinary teams (MDTs) meetings, received referrals from them and provided direct feedback to them. The service also worked closely with other initiatives, such as West Cork Open Dialogue and the local Hearing Voices groups, that also work with a recovery approach. This added to the credibility of the approach and helped to build a strong coalition in the area working towards sustaining it.

d Conversion as of March 2021.

Technical package

Overcoming infrastructure challenges

A major obstacle was the logistics of providing a service over a very large area with poor infrastructure. The poor quality of rural roads and limited public transport infrastructure were and have been ongoing issues. To address this, the service built links with local transport initiatives, such as West Cork Rural Transport. It also sought to share transport with other organizations too.

Key considerations for different contexts

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

- having regular team meetings to support the staff in staying well and true to the ethos and ideals of the service;
- using the CHIME framework to conceptualize outcomes when evaluation on a 'value-for-money' basis is difficult in person-centred service;
- using the model of a flexible outreach team, by combining mental health and vocational training elements;
- being creative and open to collaboration with other organizations and community groups to reach individuals and families who are in need.
- having a team member with lived experience has been a major advantage as it validates the recovery orientation and authenticates the team's work with peers and local peer-led initiative; and
- conducting reflective team practice and regular team meetings supports the staff in staying well and true to the ethos and ideals of the service.

Additional information and resources:

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2.4 **Naya Daur** West Bengal, India



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Primary classification: Community outreach

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

Kolkata is the capital of the state of West Bengal in north-east India. The population of Kolkata's metropolitan area is over 14 million, with a high population density (59). Kolkata's mental health services are available through two psychiatric hospitals and six teaching hospitals. The NGO sector also delivers mental health services (60). There are no government outreach programmes and the onus is placed on the individual and their family to access mental health interventions (59). There are estimated to be 70 000 homeless people in the city with a significant proportion experiencing mental health conditions.

Iswar Sankalpa is an NGO based in the city. Formed in 2007, it aims to provide services to the homeless population with long-term mental health conditions and psychosocial disabilities *(61)*. Its outreach programme, Naya Daur, which translates as New Age, was its first and remains, its flagship project. Iswar Sankalpa has since developed a range of other services in conjunction with Kolkata Police, the Kolkata Municipal Corporation, the West Bengal Department of Health and Family and the Department of Social Welfare. These services include a drop-in centre and an emergency response unit. Iswar Sankalpa also opened Sarbari, a shelter for homeless women with mental health conditions and psychosocial disabilities with Kolkata Municipal Corporation in 2010, and in 2015, began Marudyan, a shelter for men with mental health conditions and psychosocial disabilities. In 2018, Naya Daur was further expanded to 20 new districts in Kolkata with cooperation from local authorities.

Naya Daur may not be part of the formal mental health system, but works very closely with the governmental public health system, municipal authorities and the Kolkata police and court system (62). For example, it has even negotiated a designated drop-in space for clients within the Hastings Police Station, helping to improve the care offered to homeless people with mental health conditions and psychosocial disabilities, as well as to maintain their autonomy.

Description of the Service

The core goal of Naya Daur is to provide community-based support, treatment and care for homeless people with mental health conditions or psychosocial disabilities, in order to increase their inclusion in the community. Its strong guiding principle is that no one should be forced to move from the neighbourhood in which they live, to receive treatment. All efforts are made to build meaningful relationships with community members, avoid the seclusion and ill-treatment of people with mental health conditions or psychosocial disabilities and support them to live meaningful and dignified lives.

Currently Naya Daur provides services to 60 municipal wards of Kolkata with a multidisciplinary team comprising 10 social workers, two psychiatrists, two counsellors, one coordinator, and support officers as well as a driver. By August 2020, Naya Daur had provided services to over 3000 homeless people with mental health conditions or psychosocial disabilities *(62, 63)*.

Homeless people with a mental health condition or psychosocial disability are generally accepted onto the programme. However, there are some exceptions, including highly mobile individuals who do not have a fixed neighbourhood; people who exhibit violent or aggressive behaviour; those who have a serious health condition and cannot be supported in the community (these may include those with physical illnesses, such infections that require hospital care); and those who refuse all services offered by Naya Daur for more than three months.

Naya Daur's multi-disciplinary team works to engage and build rapport with homeless adults between 16 and 80 years of age. This engagement, with the consent of the homeless person, focuses on relationship-building and can take many months. The team provides regular check-ups, physical and mental health care, clothes, food, access to entitlements, and visits by counsellors and social workers. Homeless clients within the organization's catchment area, who appear to have or express a need for mental health support and may benefit from Naya Daur's services, are identified by outreach field workers in consultation with mental health professionals.

With the client's consent, rapport is built through conversation, provision of food, personal hygiene services and medical attention, if necessary *(64)*. Within two weeks, and after giving their consent to receive Naya Daur's services, new clients are offered a comprehensive mental health assessment by the organization's psychiatrist. This takes place in the area where the person lives. Rehabilitation and recovery activities are also commenced, including recovery goal-setting and social inclusion interventions. Medication options are also discussed and prescribed, but only if the person wishes to take medication. In some situations, however, hospitalization is negotiated with the client. For example, the client may be harming themselves or others, require urgent medical attention, use dangerous substances, or there has been no improvement with community support. Often, hospitalization will happen with the support of community members the person is familiar with. The experience of Naya Daur staff is that involuntary admissions can be avoided through open discussion and giving people space.

Community volunteers are vital to Naya Daur. They live in the same neighbourhood and are recruited to support the homeless client, alongside the team. These volunteers do not receive payment. Usually volunteers have small vending carts, eateries or shops on the streets of Kolkata and limited educational qualifications. The community volunteers are usually people who already know the person; often they have been concerned about the person but did not know how to help.

With Naya Daur's involvement such volunteers feel more confident about offering practical and personal support. Responsibility for providing support, however, is jointly shared between the multi-disciplinary team, the client, and community volunteers Community volunteers are trained and supervised by outreach workers in taking on caregiving roles. Training includes meeting clients' basic needs, psychoeducation, medication administration, accompanying the client to access public health services and facilitating their social integration through the offer of shelter or employment. Mostly the training takes place where the client and volunteer are located, through dialogue and discussion. The volunteer is helped to respond appropriately to behaviour that may be difficult to understand and to practice patience in communication. Community volunteers are also invited to meetings with other caregivers, to encourage peer support *(64)*.

Access to day centres and activities are available to interested clients; supported employment is encouraged, including employment by community volunteers, and a reunion with the client's family is explored, with both parties' consent. If they request, clients may also be referred to Sarbari and Marudyan, temporary shelters provided to homeless people with mental health conditions or psychosocial disabilities. Basic services including food, water, clothes, hygiene materials and a space to sleep. Diverse biopsychosocial interventions are available too. Sheltered care is routinely offered to female clients who may be at increased risk of abuse and gender-based violence in the community. This risk is continually assessed and acted upon, based on the clients' and caregivers' feedback on any threats to their safety and wellbeing.

In parallel, the team conducts monthly awareness workshops on mental health and homelessness to address stigma and sensitize the community to the challenges faced by many people in their everyday lives. The awareness camps take place in local clubs near to locations where Naya Daur's clients reside.

Staff members at Naya Daur are subject to rigorous orientation and training sessions, according to a defined Standard Operating Procedure *(64)*. They shadow existing staff on field visits and receive detailed practical training on the various steps of the intervention. These include building empathy, signs, symptoms, attending skills and psychosocial intervention, client-centred practice, medication and side-effects, addressing challenges and mitigation strategies, leadership skills training for networking and building stakeholder relationships, non-violent communication, team-building, and mindfulness skills. Community caregivers, in addition to ongoing training and support, undergo an annual training on potential client identification, handling carer stress and building awareness in the community on the need to support homeless people with mental health conditions and psychosocial disabilities *(65)*. Planned additions to staff training include physical health check-up skills, stakeholder mapping and volunteer strategies.

Core principles and values underlying the service

Respect for legal capacity

The central premise of Naya Daur is the autonomy of the client; service delivery is entirely governed by a person's will and preferences. People who decide to use the service do not need to leave their home on the street to receive care and support. If they are vulnerable and require urgent care, they are asked if they would like to go to a shelter, which is a separate programme, or, if necessary, to the hospital. If they disagree, they are not forced, and negotiation continues in acute cases. The clients decide for themselves the pace of recovery, if they want to interact with the programme's social worker and receive

help. The client's choice is central to all decisions and interventions offered, from accepting food and taking medicines to the degree and manner of interaction with the team, sharing information about families and whether to take employment.

Staff are oriented, trained and reviewed by senior staff every quarter specifically on supporting clients to exercise their legal capacity. Client comments, statements and interactions are extensively documented. Individual care plans (ICPs) are drafted in conjunction with the client, who is supported to make every decision through a process of informed consent by the staff. ICPs are based on the clients' personal goals and revisited every quarter to assess progress made. The goals and plan can be changed if required. The staff understand that clients may be unable to make certain decisions at a certain time, thus they continually check with clients about any changes in preferences and communicate client decisions to all stakeholders. The multidisciplinary team holds case conferences, quarterly reviews and annual needs assessments for each client. Here, a clients' recorded will and preferences are incorporated into their treatment and support plan.

There is currently no formal policy for crisis situations or situations where there may be impaired decision-making; staff make use of a client's non-verbal cues and body language, as well as caregivers' knowledge, to infer the best interpretation of a person's will and preferences. Crisis situations are carefully documented and reviewed. They are always discussed with the person and used as a learning opportunity on how to better face a future crisis. There are plans to record advance directives from all clients to ensure compliance with India's Mental Health Care Act.

Non-coercive practices

A basic philosophy of the programme is to provide care and support within the community. Even the psychiatrist visits the clients on the streets. A slow process of building a trust-based relationship of care and understanding is established. This enables the homeless person to respond to the social worker at their own pace. Clients can disengage or withdraw consent at any time, by walking away. The client is enrolled into the programme only after they give their consent, communicating their wishes either verbally or nonverbally – sometimes the latter is necessary because of language or dialect issues, and depending on the severity of physical or mental health conditions.

Referrals to services that may use coercive practices – including hospitals – and involuntary admissions are minimized. The situation is explained to clients beforehand. The team teaches non-coercive practices to community caregivers and impresses on them the importance of not resorting to coercion, through awareness-raising camps and one-on-one psychoeducation and supervision. Caregiver support is supervised and monitored to ensure the client's safety.

In awareness camps, the difficulties faced by homeless people with mental health conditions are explored with the wider community. The hope is that such camps lead to more understanding, so that members of the community do not use force against the person. Additionally, the social worker draws on the homeless person's social networks and support within the community, such as care givers, to prevent coercion and gain information regarding the client's history and health. Recently, a caregiver negotiated with the railway police force to prevent a client being involuntarily admitted to hospital. Another actively intervened to prevent physical violence by a group of men during the night.

Community Inclusion

Potential caregivers from the community are identified to coordinate the care and support provided through Naya Daur. When a homeless person is willing and feels able to work, people from the community employ them in shops and small businesses. Field outreach workers and counsellors continue to visit the clients and caregivers every month to support them and resolve any practical issues and they may be experiencing.

If the client has become homeless a long distance from their original residence, a family reunion can be facilitated with the mutual consent of the client and their family members. The final stages of intervention at Naya Daur involve building alliances with the community caregivers, and handing over the role of providing daily and social support for the clients from the outreach workers to volunteers. In addition, a network of care is built around clients that promotes coordination between health services, local officials, law enforcement, NGOs, caregivers and community members.

Naya Daur also assists and advocates for clients' entitlements, including benefits, and healthcare. It forms direct links with the community through awareness programmes held at municipal health units, schools, colleges and local youth clubs. These serve to sensitize community members about the conditions of homeless persons, psychosocial disability and mental health in general.

Participation

Plenty of Naya Daur's former clients take on peer support roles or even become carers for new clients. Clients' voices and feedback are informally incorporated in service design and implementation. However, the service does not yet have formal mechanisms, schemes or policies for the inclusion of clients as employees or incorporating clients' feedback in the development or implementation of the service.

Recovery approach

The holistic recovery approach followed by Naya Daur puts the person at the centre of the care process; it focuses on their social recovery alongside symptoms that they may be experiencing. Homeless people with mental health conditions and psychosocial disabilities are supported in all areas of their life. Daily communication with the client is goal-oriented in the way that it seeks to motivate the client to take decisions regarding their well-being, regain control of their life and develop hope for the future. The team adopts a strengths perspective with clients, and all interactions are geared towards helping them identify existing resources – whether physical or social – as well as the strengths and resources that they can continue to build upon. Counsellors and caregivers, with training, visit almost daily and provide motivational and supportive counselling. They tend to use considered self-disclosure, which means sharing their personal experiences, struggles and triumphs where appropriate. This kindles hope, increases self-acceptance, and helps clients move towards their life goals. The process of obtaining entitlements, re-establishing social and family connections and securing a livelihood in the community, enables clients to reintegrate into community life.

Service Evaluation

A review of Naya Daur from 2007-2011, conducted by Iswar Sankalpa, contains case studies of rehabilitated clients and service statistics *(62)*. No formal client feedback survey or evaluation has been conducted, however statistics are available on clients served, reintegrated and for whom homes were

found. During this period, the service provided food to 1015 clients, clothing and hygiene services to 765, medical care to 615, and homes for 69 people. From 2011 until August 2020, the service was in contact with 2003 homeless people, of which 65% were diagnosed with a mental health condition; the majority had psychosis. Medicines and counselling services were provided to 1122 clients. Additionally, 197 people were supported into housing. On average 90–100 street clients are supported by community member carers every year ([Das Roy S], [Iswar Sankalpa], unpublished data, [2021]). To date, Naya Daur has built a care circle comprising 250 community caregivers, a number it strives to expand.

Costs and cost comparisons

Naya Daur costs 107 rupees (\mathfrak{F}) per person per day (approximately US\$ 1.50 per day^e or around US\$ 45 per month) compared to US\$ 60 per person per month for shelters run by Iswar Sankalpa (*66*) and US\$ 150 per person per month for more highly-priced institutional support at privately-run centres. All cost estimates include food, medicines, treatment, hygiene materials, clothes, manpower, and overheads (*67*) ([Das Roy S], [Iswar Sankalpa], personal communication, [2020]).

Costs of this service were lower, because instead of traditional mental health resources such as psychiatrists, psychologists and hospitals, the outreach model provided a service staffed primarily by social workers, provides care to clients where they live, and skills up community members in the basics of daily support for the clients. In Naya Daur, even very poor street traders found it rewarding to contribute their time to support others in their community. Helping to develop a horizontal community has meant that some project costs were lowered. Furthermore, the service minimizes the need for, and cost of, a formal reintegration or vocational programme compared to shelter services.

The clients of Naya Daur do not pay for services provided by the organization. However, when clients begin to earn money and can meet their own basic needs like food, hygiene material, clothes, the support provided by the organization is reduced. Over 60 clients have gained access to government entitlements since 2015.

The cost comparisons show that this form of community-based support is less cost intensive and a more acceptable approach to supporting homeless people with psychosocial disabilities. The service is currently funded by the following private sources; the Hope Foundation, Azim Premji Philanthropic Initiatives and Tides Foundation.

Challenges and solutions

Lack of awareness concerning homelessness

A major challenge was that the authorities did not recognize that a homeless population with mental health problems and psychosocial disabilities even existed. No one knew the extent of the problem because no data had been collected. No government department took responsibility for this population either; the social welfare department believed people with mental health conditions did not fall under its remit and the health department stated that if a person could not give their own name, that of their father or husband, or an address, they could not receive treatment from the health services.

Several strategies were pursued to overcome these problems. A point-to-point survey was carried out in 144 wards of the city of Kolkata to identify homeless people with mental health conditions; 466

e Conversion as of February 2021.

Technical package

people were identified. In addition, a provision, within the 1987 Mental Health Act was discovered, stating that the police are responsible for this population. Thus, the service began to work with the Commissioner of Police. It requested permission from the city's mayor to set up a women's night shelter. Concurrently, the Indian Supreme Court mandated the creation of night shelters in every city in the country. The mayor agreed and the first Special Shelter for Homeless People with Psychosocial Disabilities was opened in 2010.

Overcoming suspicion in the community

Members of the community were dubious and even suspicious of the service and questioned its intentions. They queried the medicines that were given to people. Other people wanted homeless people with mental health conditions removed from the streets and put into institutions.

The service tackled these concerns patiently using communication and education. Its work with community stakeholders eventually paid off. Involving a medical practitioner to explain the role of medication was important too. Nurturing a spirit of philanthropy amongst people who made a living on the street was also vital for the project's success.

Securing financing

Funding the service remains a continuing challenge. To help overcome this obstacle, requests for donations such as food, clothing, medicines are made directly to the community.

Supporting people to remain connected

A major challenge was that after receiving input successfully from Naya Daur, beneficiaries often became disconnected from the service. Some people became better able to travel around and then disappeared altogether. While some remembered their homes and went back to their families, others were rounded in various city efforts to 'clear the streets'. Additionally, there were service users who improved, became able to work but used the money they earned to purchase alcohol and street drugs; this negatively impacted their ability to receive support from the service.

In an effort to maintain contact, beneficiaries who use the service are supported to talk about their families; the service seeks to reunite them in a planned way if possible. Often, they are asked to stay for a few nights in one of the shelters to help them to improve their domestic abilities and to make sure that any planned meeting with family members actually takes place. It also actively counsels people about the risks of using alcohol and street drugs.

Key considerations for other contexts

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

- recognizing that such a programme, which works with homeless people with mental health conditions, cannot be managed in a top-down manner, like an outpatient clinic;
- allowing the service to develop at its own pace, and in tandem with the local socio-cultural environment;
- demonstrating to the community that people with long term mental health conditions and psychosocial disabilities living on the streets can recover with the right kind of support and minimal resources. This helps to address stigma, and combats myths that people cannot recover and builds hope;

- involving all stakeholders in the care regime is the core practice. This ensures sustainability by building a proxy family around the homeless;
- promoting "equity in philanthropy" so that everyone can contribute; and
- focusing evaluations on functional, rather than clinical, recovery goes some way to combatting stigma, as the community can see that people do well when they are given support.

Additional information and resources:

Website: https://isankalpa.org/

Videos:

Community of Care: The Ashoka Fellow Bringing Mental Healthcare To Kolkata's Homeless <u>https://www.ashoka.org/en-IN/story/community-care-ashoka-fellow-bringing-mental-healthcare-kolkata%E2%80%99s-homeless</u>

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2.5 **Personal Ombudsman** Sweden



Primary classification: Community outreach

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:
Vertex Published literature Grey literature None
Financing:
State health sector State social sector Health insurance
Donor funding Out-of-pocket payment

Context

The Personal Ombudsman (PO) system was established in Sweden in 2000. A high-income country with a population of around 10.3 million, Sweden has a highly developed mental health system with an annual budget of US\$ 6.74 billion in 2017 (10% of the overall health budget)*(68, 69)*.

In 1995, the Swedish government introduced The Psychiatric Care Reform legislation, to improve the quality of life and living conditions of those with mental health conditions and psychosocial disabilities. Specifically, it aimed to improve their participation in the community, access to care, and social support. The committee preparing the reform identified a need for an advocate type role, with clearly defined responsibilities to draw attention to the needs of the individual and coordinate support for that person (70, 71). In response, ten Personal Ombudsperson service pilot projects took place between 1995 and 1998. In response to a pilot PO project evaluation, which showed both good qualitative and quantitative outcomes, including a significant reduction in the need for inpatient care, the Government earmarked funds in 2000 to establish permanent independent PO systems (70-72). The PO was consequently introduced as a newly-recognized social profession and has become an established part of most Swedish municipalities' social services. The introduction of the PO system in Sweden coincided with a general shift from hospitalization to community care, including in budget allocation. With the passing of legislation in 1995, 15% of the mental health budget (an annual budget of US\$ 1.5 billion of which 75% went to inpatient care) was transferred to the municipalities for community alternatives to hospitalization (73).

By 2018, the service had 336 POs reaching 9517 users, with the service provided in 87% of the country's 290 municipalities (74). PO services in Sweden are primarily provided by the municipality, although independent of the municipality's main health and social welfare system. Other non-government stakeholders, including user organizations, may also provide PO services (71). Sweden



has six independent PO organizations, two of which are led by user organizations. These organizations can be contracted by a municipality to provide a PO service. PO services are partly financed by the government via Sweden's National Board of Social Affairs and county administrative boards (70, 75).

The PO service is a practical example of supported decision-making that has successfully transferred across Sweden. Similar PO models are developing in the UK *(76)*, Finland *(77, 78)* and Norway *(79)*. While these PO services are not exact replicas of the Swedish system, they follow similar principles.

Description of the service

The PO role

The role of the PO is to help individuals who access the PO service, known as clients, live actively and autonomously. The PO may help clients with a range of issues: family matters, health care, housing, finances, community integration and accessing support, services or employment. How this is achieved will reflect the needs and preferences of the client, where they live (for example, urban versus rural settings) and the care, support and services that are available to them. Additionally, the PO works to ensure that authorities collaborate with each other so that a client's needs can be better met (74). However, a key principle of the PO role is that any assistance or support the PO provides is with the full input and consent of the client.

POs have a variety of backgrounds, including professional and lived experience. They will undergo training to become a PO, although the way in which they do their job does not follow a strict format, allowing greater flexibility and creativity in how best to support a client. This is an approach that works particularly well with clients.

To work successfully with a client, the PO must establish a relationship of trust at the outset. By listening to and working with the client, the PO can help them identify what they want or need. Together, they can set out a roadmap to achieve these goals. The initial introductory phase, where a client learns more about the PO and their role, is regarded as essential because clients may have become accustomed to assuming passive roles with people they see as being in authority. They may be more used to, for example, substitute decision-making, involuntary treatment or hospitalization. Therefore, space and time is given to the client, enabling them to understand and trust how different the PO role is.

The PO relationship has been described as a type of professional friendship. While the professional element involves the providing and sharing of skills, knowledge, and support, the relationship also reflects the power balance, availability and reciprocity more associated with a friendship (75). Building the initial trustful relationship may take a long time, sometimes several months, but is key to the PO service and proves especially successful in supporting people that are usually hard to reach.

The role of the PO is different from that of case managers seen in other contexts; the PO service is independent of health and social services and the client chooses to work with a PO for example. Importantly, any assistance the PO provides is done so with the full input and consent of the client concerned. This is a key principle and widely-recognised feature of the PO-client relationship. In addition, the client's experiences, needs and wishes are the focus, not their diagnosis or treatment. The client, not the PO nor any other third party, dictates the order and urgency with which issues are addressed. The PO does not act as an authority figure in relation to the client. Nor is the PO responsible for any adherence to medical treatment. The role of the PO is not to step in and solve problems for

the client, but to support them to become more confident in themselves and their own abilities, thus achieving better control and power to solve their own problems in everyday life. Particular effort is made to reduce any potential power imbalance between POs and their clients. For example, POs might choose not to work from formal premises, offices or government authority spaces, working instead from home. They may schedule meetings at the client's home or in neutral spaces such as cafes or other public spaces. The PO is typically available to the client during standard office hours but can be available after hours if needed.

Who can access the service?

The PO service is available to adults, 18 years of age or older, with severe psychosocial disabilities that typically require long-term care and support to access accommodation, rehabilitation and employment. Clients are expected to need long-term contact with health and social services and other relevant authorities. Six main groups are eligible to access support through the service (80, 81).

They include people who:

- have failed to contact authorities or have withdrawn from government services. These individuals may be isolated in their living arrangements or communities;
- receive some assistance, although insufficient to meet their needs;
- receive assistance that does not meet their needs;
- receive assistance that is uncoordinated;
- feel that authority interventions are too extensive or are no longer needed (for example, guardianship); and
- public systems have thus far been unable to assist.

When the demand for POs exceeds staffing levels, municipalities typically prioritize potential clients if they:

- have children at home who are at risk of ill-health;
- are young adults;
- risk being evicted from their home or are homeless;
- are considered a suicide risk; or
- lack any form of support or social network (74).

Different methods are used to make the community aware of PO services. Many PO services distribute information leaflets in public places, such as shops, health centres, churches, and pharmacies. PO services may also visit hospitals and mental health services, for example, to speak to both service users and staff at inpatient mental health facilities. Information on the services is also shared via word-of-mouth; through other clients, or when individuals use particular services (72).

There is no formal referral process. Rather, the aim is to ensure there are as many ways to access a PO as simply as possible; clients can request a PO directly, through their health or social service, service user organization, a relative, or friend. POs can actively reach out to potential clients. As PO services are not regulated by law in Sweden, there is no formal application process required to work with a PO.

Once contact is made, the service will call the individual to provide more information and to get a better understanding of whether the person meets the criteria that will make them eligible for a PO. A PO will



then meet with the person for an informal discussion at a place where they feel comfortable, such as at a café or in their own home. Here, they can then discuss specific challenges the person faces, as well as hopes, goals and the kind of support that person would like from a PO. This meeting is also an opportunity for the PO to provide more information on their role and the ways they can support clients. Through discussion, the PO is able to confirm whether the person meets the criteria for the PO service, and additionally, if the person has a difficult or unmanageable life situation. There may be other issues the PO can support the person with, and this may take some time to determine. This first meeting also allows the individual to decide whether they still wish to work with a PO. Client preferences, for example, for a male or female PO, are accommodated where possible. If a person requests a PO but is refused – perhaps because they do not meet the service's criteria – they are directed to the municipality for support.

Once there is a mutual agreement, the client and PO will begin to work together. Some services may use a form of written agreement that describes how the client and PO will then collaborate – in terms of goals, tasks, and responsibilities of both client and PO. Most services do not, however. They try to avoid administration because it may be off-putting to some prospective clients. Any paperwork developed by the PO and the client, for example action plans, may be kept either by the client or stored securely by the PO. Neither family members, health and social service professionals nor the courts can request this paperwork.

A client can end their use of the PO service at any time; there is no set amount of time an individual can work with a PO. As the client and PO work together and evaluate their progress, they may come to an agreement to end their collaboration. Terminating the relationship may include referring the client to other services or support if required. The length of time a PO and client work together varies greatly. Durations of one month to eight years have been reported, however the average length is 12–18 months. A relationship can also be concluded at the request of the PO. A client can continue to work with a new PO if needed and this change is managed sensitively.

The PO

Many POs are trained social workers, lawyers or have a background in medicine, nursing, psychology or psychotherapy. The majority have experience of working with people with mental health conditions and psychosocial disabilities (72) and individuals with lived experience may also work as POs.

New POs undertake an initial training delivered over the internet, followed by a 3-day taught course. Additional educational opportunities are provided in diverse subjects including physical and mental health, mental health first aid, suicide prevention, migration and mental health, gambling, and family honour-related violence. Responsibility for providing education over and above the basic training lies with each PO service provider and so additional training provided to POs will vary. POs also have the opportunity to learn through the sharing of experiences at regional network meetings (74). At a local level, POs also have the opportunity to speak with experienced colleagues on a more regular basis – every other week or month – to discuss everyday work, difficult situations and potential solutions.

POs can have anything between 13 and 20 clients at the same time, though most have 13-15 *(72)*. A PO professional body, *Yrkesföreningen för personligt ombud Sverige* (YPOS), was established in 2005 to support the role of the PO and its development.

PO Management body

The PO Management body is made up of representatives from the municipality, county council primary care and psychiatry, the employment service and social insurance office. It is recommended that service user and family organizations also participate. POs can report system errors, barriers and deficiencies to the management body, via the relevant member *(70)*. The body is also responsible for receiving client complaints. POs may work alone or in groups under the overarching PO management body. An essential aspect of the success of the PO service in Sweden is the buy-in at all levels of the system. This ensures that the PO can successfully navigate and engage with authorities in support of their client. It also ensures that system failures or deficiencies can be raised, so that remedies can be addressed.

Core principles and values underlying the service

Respect for legal capacity

The basic premise underlying the PO role is respect for the legal capacity of the client. Only the individual can request a PO. They cannot be involuntarily assigned a PO at the request of family, friends, public authorities, or the courts. Individuals who are under involuntary treatment or hospitalization can request a PO, either by contacting the PO service directly or with the help of a friend or family member. The individual, who becomes a client once assigned a PO, can choose to end the relationship at any time. A client can ask for a different PO if they are unhappy with the current one and if the service has more than one PO available. The client can also make a complaint to the manager of the PO service, the social welfare manager in the municipality or the PO management body.

The PO will only act with the consent of and as directed by the client, even if the PO disagrees with them. The PO will also support the client in exercising their legal capacity when other authority figures challenge it. Such a situation may arise when individuals decide to change their living situation; they may want to live independently, to move from supported living arrangements or to challenge guardianship status. In this context, the PO not only supports the client to exercise their own legal capacity but importantly, for their legal capacity to be recognized in the wider system. The PO never acts as an authority figure towards the client, only as a support.

If a client is unhappy living under a guardianship arrangement, the PO can try to support the client in finding a solution. This may involve supporting the client to discuss problems with the arrangement directly with the guardian, make a complaint or argue for a change of guardian. POs can also help a client apply for a guardian if this is what the client wants. If a client is assigned a new guardian, the PO can support the relationship at the beginning to ensure that it is working well. They may end the PO service if appropriate.

The introductory phase of the PO relationship with the client is essential to promoting legal capacity. The PO service emphasizes the importance of establishing a relationship of trust between the PO and the client; individuals require sufficient time to build trust with their PO before working on articulating needs and a way forward. The service recognizes the need for individuals to be supported in learning how to identify and articulate their needs, something of particular importance where individuals may have been disempowered from doing so in the past, for example, because of perceptions of their disability or treatment. This process underpins the legal capacity of the client by empowering them to know what they want and then supporting them to ask for it.
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The PO role recognizes the potential power imbalance between a client and a PO, particularly in the early stages. Working and meeting arrangements are kept as informal as possible, therefore. While there is no formal requirement for POs to have legal training, legal capacity is covered in the introductory course for new POs.

Non-coercive practices

The use of force or coercion goes against the purpose and principles of the PO service. Neither are used by the PO. A PO can only support a client to participate in various services, including medical treatment; they cannot insist or force the client. If the client experiences a crisis or a psychotic episode, the PO will try to guide the person to the right services. A client's preferences, should a crisis occur, can be discussed in advance and reflected in their agreement with the PO. If a client is placed under involuntary admission or treatment, the PO will remain in contact and continue to support the client. The PO might monitor how an individual's rights are being respected during this time, help the client to express their will and preferences, continue to empower, and help the client focus on the future and continued recovery. On the other hand, work with the PO may also be put temporarily on hold depending on the client's health.

If the PO believes a client's behaviour is a serious risk to themselves or others, the PO will make a formal notification of concern to social services or other relevant authority. Depending on the situation, the PO will discuss the concern with the client before making contact with authorities. If a child is at risk, there is no obligation to discuss or inform the client first. The PO will usually inform the client if they make a report. POs normally discuss these potential courses of action with their clients when they first make contact.

Community inclusion

A key aim of the PO service is to support clients to be active participants in and leaders of their own lives. This includes as much inclusion and participation in the community as a client desires. The PO works with the client to identify barriers or conflicts that may be preventing them from feeling included in their community as well as potential solutions. A PO can also support a client if they experience any difficulties or conflict as part of living in the community. For example, they may support the client in learning how to handle conflict situations, provide information on available mediation services, or support the client to move to a different community. Based on the needs and wants identified by the client as they work with their PO, the PO will support the client's link with community services, organizations and activities. The PO will also report barriers and deficiencies identified in the community that need to be addressed to the PO management body.

Participation

The PO service encourages the engagement and contribution of clients, user and family organizations both in the PO management body and as a wider stakeholder. They are seen to have a key advisory role in identifying and addressing barriers that prevent individuals from accessing care, support and services available in the community. Addressing these barriers is a key objective in meeting the PO clients' long-term needs. User organizations may also share service evaluation reports directly with the National Board of Health and Welfare. PO Skane, a user organization-led PO service in Sweden, carries out regular client satisfaction surveys which are then used to inform POs and their practices, and the development of the overall PO programme.

Recovery approach

The relationship between the client and the PO is essential to the recovery process. A primary function of the PO is to support people to gain confidence and skills to take control over their everyday life. As the client gains greater influence and power over their own situation, the possibility of recovery increases. POs receive training in recovery to support them in their role (70, 80).

The PO service takes a person-centred approach to working with clients and the care, support and services they receive. Recovery is not viewed in terms of recovery from mental ill-health but the creation of new goals and having a new meaning to life. It is not seen as a linear process, but one that requires attempting different solutions or paths. Each may take different lengths of time and support depending on the client's needs *(80)*.

Service Evaluation

The system is evaluated on an ongoing basis. Both quantitative and qualitative evaluation data is available on the effectiveness and efficiency of the PO service. A 2010 qualitative study by Berggren and Gunnarsson (75) followed 23 individuals who were supported by a PO for at least six months and showed that people using PO services valued their relationship with the PO as a friendship-like professional support. There were common themes identified in the interviews with service users; they felt that the PO helped them, "take power over their own lives, adding resources, lessening distress and promoting well-being". The PO was reported to inspire hope in seemingly hopeless situations and help them raise their own voices and empower them to make their own decisions in life. The study reported that support by a PO, "enhances recovery processes and lessens the impact of social exclusion". A limitation to this study, however, is the inclusion criteria, which only assesses support by a PO for at least six months. Typically, individuals dissatisfied with the PO service leave the service quite quickly and would not have been included in this study. Due to the minimal documentation used by the PO service, including individuals who have withdrawn from PO support, evaluating the service was said to be difficult.

A 2007 quantitative study investigated changes during a 6-year follow-up period (82); it looked specifically at the symptoms, need for care, psychosocial function, quality of life and social network of a PO client group. Of the original 176 clients who participated in the original study, 92 past and current clients took part in the follow-up. This was considered a reasonable representation of the original study sample. Client satisfaction with the PO service was reported as high; clients had fewer psychiatric symptoms, a better subjective quality of life, an increased social network and were more satisfied with this network. Clients who had left the PO service at the time of the study reported significantly fewer symptoms than current clients, a better overall quality of life, psychosocial functioning, and social network. They used less inpatient psychiatric care.

Similar results were seen in a series of internal studies on the effectiveness and efficiency of PO services when conducted by the Swedish National Board of Health and Welfare. In 2005, one study showed that the PO service brings considerable socio-economic benefits since individuals using PO support require less care and their psychosocial situation improves (70, 83). Once a person

receives support from a PO, it has been shown that, "a radical shift takes place away from passive and expensive help such as psychiatric care and income support towards more active help such as rehabilitation, employment, psychotherapy, a contact person, assistance, home help services and so on" (70). Furthermore, studies revealed increasing numbers of individuals with a PO who had obtained meaningful employment, more social contacts, less symptoms related to mental health conditions and many reported that they were receiving the kind of care, support, and help they wanted. Another study showed that clients experienced a greater degree of empowerment and became part of a strong social network. The National Board of Health and Welfare therefore concludes that, "since the help provided [...] better corresponds to the client's needs, and is coordinated, it benefits the recovery process and boosts the individual's quality of life".

A more recent 2014 report found an increase in municipal interventions, such as housing support and home care, indicating that the PO service is successful in supporting individuals to access the support and services they need and want (72). Clients were better off financially, once engaged with a PO; many were able to address debt settlement and income issues. Some clients also reported improved social networks through reduced isolation and improved contacts with family, work or school. Health care costs increased in the first three years but returned to pre-PO levels thereafter.

Costs and cost comparisons

The PO system is firmly established throughout Sweden. The Swedish government has committed to funding PO services indefinitely; in 2013, a new regulation entered into force in Sweden that established permanent funding for the system *(70, 72)*. However, PO services are only partly financed by the government, via Sweden's National Board of Health and Welfare. It increased the overall funding available for PO services from around 100 million Swedish Krona (kr) (approximately US\$ 12 million)^f in 2019 to kr 130 million (approximately US\$ 15.5 million)^f in 2020 ([Bengtsson A], [Socialstyrelsen], personal communication, [2020]).

The PO service in Sweden has also reported socio-economic benefits; it reduced government costs by approximately kr 700,000 (approximately US\$ 83, 760)^f per client over a 5-year period, representing savings equivalent to 17 times the costs *(70, 83)*.

Funding is made available to municipalities through a state grant as a fixed amount per PO employed by the municipality. In addition to this grant, municipalities cover part of the PO salary and additional costs, such as transport and expenses. The remaining costs are covered by each of Sweden's 21 county administrative boards, however this varies significantly between counties (Sweden's constitution provides for local self-government at municipality and county level). The services are free of charge to the client.

Challenges and solutions

Lack of recognition and building trust

In some communities, both professionals and service users were unaware of how a PO service could support people. As a result, it was sometimes difficult to secure clients. Commissioners thought there was little demand for the service as a result.

f Conversion as of February 2021.

Extensive engagement with all stakeholders and building the profile of the service has therefore been essential to overcome these challenges. One method of building trust in the PO role with individuals, family members and professionals was visiting locations; here POs could meet potential users of the service to let them know what it provides.

A particular challenge was the way the role was viewed by some professionals. Many did not appreciate or respect the PO profession and others were even suspicious and opposed it. Some staff within the health and social protection system perceived that POs were working against them, because the job of a PO is to favour the client. Much effort was put into explaining, in advance, why the PO must always be on the client's side. Finally, commissioners at the municipalities were informed that establishing this new service is a process and an absence of immediate interest did not necessarily mean there was no need for a PO service.

Managing gaps in provision within mental health and social services

A key element of the PO role is to document and report shortages or deficiencies in the mental health and social protection system. It was a challenge, therefore, to ensure those responsible for welfare system provision responded to reports and made the necessary changes.

One solution for many POs was to stay in contact with and learn from others in their profession. They could therefore learn various ways to address challenges, such as conflicts with other services or how to report shortages in a way that encouraged people to pay attention. It was also recognized that POs should not work in isolation despite their independence. Indeed, the formation of the YPOS professional body was instrumental in helping POs successfully navigate and engage with authorities in support of their clients. System failures or deficiencies could therefore be raised with the appropriate authorities and a remedy expected. Crucially, the PO system was designed so that, when problems could not be addressed at a local level, for example, POs were able to use channels at regional or national level.

Maintaining the purpose and values of the PO role

A complicating factor throughout the PO system in Sweden was the variation between services offered within and across different municipalities. One solution was to ensure POs were provided with regular supervision and training to support them in their role. Having a YPOS, a professional representative body to organize conferences, provide support and information to POs, and link with government organizations, was crucial. There was also strong engagement with organizations of persons with psychosocial disability and associated movements and family organizations. Finally, by reviewing and updating service policies and practices, YPOS helped POs keep up to date with societal changes and new research and practices while retaining the core principles of the PO role.

Building a sustainable service

The PO state grant did not increase for many years after the establishment of the PO service. Also, it was not mandatory for municipalities, to fund PO services. Funding shortages at the municipality level meant PO services could be reduced or shut down, during a recession for example. This risked leaving clients unsupported and POs unemployed.



Due to the success of the PO role, as provided by evaluations, the government recognized the importance of the service. In December 2019, the Swedish government increased the PO state grant for 2020, 2021 and 2022.

Key considerations for different contexts

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

- recognizing and formalizing the role of the PO to ensure system level buy-in and overall sustainability;
- ensuring the formal independence of the role of the PO;
- respecting confidentiality, for example, not talking about a client if they are not there and not sharing client information with other professionals;
- informing other professionals about the PO service and develop good working relationships at the outset;
- reviewing existing policies, standards and regulations to help shift power from a service-led to a userled service;
- limiting the service to the intended population group to make it more sustainable;
- ensuring POs network with each other, have regular supervision and training;
- establishing a professional representative body to support POs;
- providing several avenues to address shortages the PO identifies; and
- surveying clients' perspectives on the service, find different ways for people to provide feedback, for example through text message.

Additional information and resources:

Websites:

<u>https://kunskapsguiden.se/omraden-och-teman/psykisk-ohalsa/personligt-ombud/</u> (in Swedish) <u>https://personligtombud.se</u> (in Swedish)

Videos:

Paving the way to recovery - the Personal Ombudsman System https://www.youtube.com/watch?v=xqma4wK8sC0

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Moving forward: from concept to good practice community outreach 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 community mental health outreach 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 community outreach mental health services:

- 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 (<u>https://www.who.int/publications/i/item/who-qualityrights-guidance-and-training-tools</u>) 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.

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- Are you aiming to transform an existing community outreach service or set up a new one?
- Where will the community outreach service be delivered (for example, in the home, at a public space, on the street or other setting)?
- Will your outreach service be stand-alone or part of another service (for example, part of a hospital service or community mental health centre)?
- Who are the beneficiaries of the service: will anyone be excluded? How will the service be accessed?
- What treatments and interventions are you planning to provide? Options may include:
 - » assessments of support needs and diagnosis if agreed by the person
 - » counselling
 - » behavioural activation including problem solving and activity scheduling
 - » personal support services for example:
 - » focused support for decision-making
 - » supported living (for example, support to perform daily activities and meet basic needs)
 - » assisting people to connect with and navigate existing community services and resources
 - » support to end guardianship or involuntary orders
 - » administrative support (including accessing grants, housing support, social benefits and job opportunities)
 - » person-centred recovery planning
 - » psychotropic and other medication (including, prescribing medication, as well as support for withdrawing safely from medication)
 - » transitional support for people returning to their home and community
 - » dialogue/meetings with families, friends and supporters (with the agreement of the person using the service)
 - » other.
- How will your service promote access to other community-based services and support? For example:
 - » psychotherapy, e.g. Cognitive Behavioural Therapy
 - » individual and group based supportive counselling/ therapy
 - » peer support
 - » other.
- How will your service assess, provide for or refer people for any physical health conditions they may have?
- What will be the interrelationship between this service and other services, supports and resources in the community, including upward and downward referral systems?

- What human resources will be required (such as doctors including psychiatrists, general practitioners and others, psychologists, nurses, social workers, peer support workers, occupational therapists, outreach workers, community/lay workers, and administrative staff, etc.) and what sort of skills and training will be required for them to provide quality and evidence-based services in line with human rights?
- What strategies and training are you planning to put in place to realize legal capacity, noncoercive practices, participation, community inclusion and recovery orientation^g?

Legal capacity

- How will the service ensure that mechanisms for supported decision-making are in place so that decisions are made based on the will and preference of the person?
- How will the service approach informed consent by service users in relation to treatment decisions?
- How will the service ensure that people are:
 - » able to make informed decisions and choices among different options for their treatment and care; and
 - » provided with all critical information relating to medication, including its efficacy and any potential negative effects?
- What processes will the service put in place to systematically support people to develop advance plans?
- What kind of mechanisms will the service put in place to ensure that people can make a complaint if they need to?
- How will the service facilitate access to legal advice and representation by its users who may need this type of service (e.g. pro bono legal representation)?

Non-coercive practices

- How will the service ensure the systematic training of all staff on non-coercive responses and de-escalation of tense and conflictual situations?
- How will the service support people to write individualized plans to explore and respond to sensitivities and signs of distress?

Participation

- How will people with lived experience be made an integral part of the service team as staff, volunteers or consultants?
- How will people with lived experience be represented in the high-level decision-making in your service?
- How will the service systematically collect feedback from service users and integrate this into your service?

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

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Community inclusion

- How will the service support people to find work and income generation opportunities, 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 communitybased 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.?
- 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 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.
 - » Will the service seek to understand the social dynamics of the local community and map the frequent problems that most impact people's lives and mental health (for example, police violence, threats related to drug trafficking, and economic hardship)?

- **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.

Technical package

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