Guidance on community mental health services

Promoting person-centred and rights-based approaches



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The accompanying guidance document and technical packages are available here.

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however, in all countries, whether low-, medium- or high-income, the collective response has been constrained by outdated legal and policy frameworks, and lack of resources.

The COVID-19 pandemic has further highlighted the inadequate and outdated nature of mental health systems and services worldwide.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

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:



For more information visit the WHO QualityRights website

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

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

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

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

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

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

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

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

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

1. Overview:

person-centred, recovery and rights-based approaches in mental health

1.1 The global context

Mental health has received increased attention over the last decade from governments, non-governmental organizations and multilateral bodies such as the United Nations (UN) and the World Bank. In 2013 the World Health Assembly endorsed the Comprehensive Mental Health Action Plan 2013–2020. This action plan recognizes the essential role of mental health in achieving health for all people and was extended to 2030 at the Seventy-second World Health Assembly in 2019 (*1*, *2*).

International development agendas also make specific references to mental health, such as the Sustainable Development Goals (SDGs) Target 3.4: "By 2030 reduce by one third premature mortality from non-communicable diseases (NCDs) through prevention and treatment, and promote mental health and well-being", and the resolutions intended to make UHC (3) a reality. As a result, governments are being called upon to prioritize mental health and well-being through their health strategies and plans to expand UHC (4).

This increased visibility for mental health has brought a growing awareness of the many challenges in mental health resulting from decades of low investment, which persist to this day. According to the WHO Mental Health Atlas 2017, globally, the median government expenditure on mental health represents less than 2% of total government health expenditure (5). Allocating enough financial resources to mental health is a necessary precondition for developing quality mental health systems with enough human resources to run the services and provide adequate support to meet people's needs. While many mental health services across the world strive to provide quality care and helpful support for people with mental health conditions and psychosocial disabilities, they often do so in the context of substantial restrictions in human and financial resources, and within the confines of outdated mental health policies and laws.

Increased investment in mental health is clearly needed and more services are required. However, the problems of mental health provision cannot be addressed by simply increasing resources. In fact, in many services across the world, current forms of mental health provision are considered to be part of the problem (6). Indeed, the majority of existing funding continues to be invested in the renovation and expansion of residential psychiatric and social care institutions. In low- and middle-income countries, this represents over 80% of total government expenditure on mental health (5). Mental health systems based on psychiatric and social care institutions are often associated with social exclusion and a wide range of human rights violations (7-10).

Although some countries have taken critical steps towards closing psychiatric and social care institutions, simply moving mental health services out of these settings has not automatically led to dramatic improvements in care. The predominant focus of care in many contexts continues to be on diagnosis, medication and symptom reduction. Critical social determinants that impact on people's mental health such as violence, discrimination, poverty, exclusion, isolation, job insecurity or unemployment, lack of access to housing, social safety nets, and health services, are often overlooked or excluded from mental health concepts and practice. This leads to an over-diagnosis of human distress and over-reliance on psychotropic drugs to the detriment of psychosocial interventions – a phenomenon which has been well documented, particularly in high-income countries (*11-13*). It also creates a situation where a person's mental health is predominantly addressed within health systems, without sufficient interface with the necessary social services and structures to address the abovementioned determinants. As such, this approach therefore is limited in its consideration of a person in the context of their entire

life and experiences. In addition, the stigmatizing attitudes and mindsets that exist among the general population, policy makers and others concerning people with psychosocial disabilities and mental health conditions – for example, that they are at risk of harming themselves or others, or that they need medical treatment to keep them safe – also leads to an over-emphasis on biomedical treatment options and a general acceptance of coercive practices such as involuntary admission and treatment or seclusion and restraint (14, 15).

Reports from high-, middle- and low-income countries around the world also highlight the extensive and wide-ranging violations and discrimination that exist in mental health care settings. These include the use of coercive practices such as forced admission and forced treatment, as well as manual, physical (or mechanical) and chemical restraint and seclusion. In many services, people are often exposed to poor and inhuman living conditions, neglect, and in some cases, physical, emotional and sexual abuse, exacerbated by the power imbalances that exist between health staff and people using the services (7, 16-20).

In the larger community context too, people with mental health conditions experience wide ranging human rights violations. They are excluded from community life, stigmatized and discriminated against in the fields of employment, education, housing and social welfare on the basis of their disability. Many are denied the right to vote, marry and have children. These violations not only prevent people from living the lives they want, but also further marginalize them from society, denying them the opportunity to live and be included in their own communities on an equal basis with everyone else (*21, 22*).

A fundamental shift within the mental health field is required, in order to end this current situation. This means rethinking policies, laws, systems, services and practices across the different sectors which negatively affect people with mental health conditions and psychosocial disabilities, ensuring that human rights underpin all actions in the field of mental health. In the mental health service context specifically, this means a move towards more balanced, person-centred, holistic, and recovery-oriented practices that consider people in the context of their whole lives, respecting their will and preferences in treatment, implementing alternatives to coercion, and promoting people's right to participation and community inclusion.

1.2 Key international human rights standards and the recovery approach

International human rights instruments establish obligations on countries to respect, protect and fulfil fundamental rights and freedoms for all people, and as such they provide a critical framework for ending the current status quo and promoting the rights of people with mental health conditions and psychosocial disabilities. The *Universal Declaration of Human Rights*, proclaimed by the UN in 1948 (23) protects a full range of civil, cultural, economic, political and social rights. Though not legally binding, many of its provisions have become customary international law, which means it can be invoked by national and international legal systems.

The Declaration gave rise to two formal Covenants in 1966, legally binding on States that ratify them: the *International Covenant on Civil and Political Rights (24)*, and the *International Covenant on Economic, Social and Cultural Rights (25)*. Civil and political rights include: the right to liberty; freedom from torture, cruel or degrading treatment; freedom from exploitation, violence or abuse; and the right to equal recognition before the law. Economic, social and cultural rights include: the right to health, housing, food, education, employment, social inclusion and cultural participation.

In 2008, the UN Convention on the Rights of Persons with Disabilities (CRPD) came into force, which undoubtedly marks the most significant contribution to moving the agenda forward and ensuring full respect for the rights of people with mental health conditions and psychosocial disabilities (23). Significantly, the CRPD was drafted with the active input, engagement and participation of persons with disabilities and Organizations of persons with Disabilities (OPDs) thus ensuring that the perspective of those primarily concerned with the issues was reflected in the final document (26). Underscoring the urgent need to establish human rights protections of people with disabilities, the Convention was the fastest-negotiated human rights instrument and one of the most swiftly ratified, with to date, 181 States Parties agreeing to be bound by its provisions.

The CRPD calls for "respect for difference and acceptance of persons with disabilities as part of human diversity and humanity". It prohibits discrimination on the basis of disability of any kind and requires that people with disabilities be able to enjoy all human rights on an equal basis with others. The Convention also acknowledges that disabilities, including psychosocial disabilities, result from "interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".

It also recognizes that these barriers constitute discrimination and sets specific legally binding obligations on government to remove such barriers, in order to ensure that people can enjoy equal rights and opportunities. This means governments must take a full range of measures to ensure that people with mental health conditions and psychosocial disabilities are able to enjoy the same rights as everyone else, are treated equally, and are not discriminated against. Actions to be taken by countries include abolishing discriminatory laws, policies, regulations, customs and practices, and adopting policies, laws and other measures that realize the rights recognized in the Convention.

The Committee on the Rights of Persons with Disabilities is made up of 18 independent experts and was established to monitor implementation of the Convention by the States Parties. The Committee has issued a number of General Comments which outline in more detail the measures to be taken by countries, several of which are particularly pertinent to the mental health care context. They address

the right to legal capacity, the right to live independently and be included in the community, and the right to equality, non-discrimination, and participation (27).

Echoing and reinforcing the rights set out in the CRPD and the accompanying General Comments, are a number of UN resolutions and reports emanating from the UN human rights mechanisms. For example, a series of UN Human Rights Council resolutions have all underscored the importance of a human rights approach in mental health, calling on countries and UN agencies to tackle the "widespread discrimination, stigma, prejudice, violence, social exclusion and segregation, unlawful or arbitrary institutionalization, overmedication and treatment practices [seen in the field of mental health] that fail to respect... autonomy, will and preferences" (28-31).

Additionally, several reports by UN Special Rapporteurs have underscored the need for governments to address human rights in mental health. The former UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (hereafter, Special Rapporteur on the Right to Health) published several reports outlining the right to mental health and highlighting harmful practices in current mental health services, and calling for a significant "paradigm shift" in the field (*15*, *32*). In addition, the former UN Special Rapporteur on the Rights of Persons with Disabilities has underscored the urgent need for countries to adopt effective measures to combat stereotypes, negative attitudes and harmful and coercive practices against persons with psychosocial disabilities, as well as measures to ensure respect for their legal capacity and to promote their full inclusion and participation in the community (*33*, *34*).

Over the last three decades, the emergence of the recovery approach has also been instrumental to promoting human rights in mental health. This approach, which had its roots in the activism of people with lived experience, has received widespread endorsement by WHO Member States within the WHO Comprehensive Mental Health Action Plan. It also aligns with WHO's Framework on integrated people-centred health services which was adopted with overwhelming support by Member States at the World Health Assembly in 2016 (1, 35).

For many people recovery is about regaining control of their identity and life, having hope for their life, and living a life that has meaning for them whether that be through work, relationships, spirituality, community engagement or some or all of these.

The recovery approach aims to address the full range of social determinants that impact on people's mental health, including relationships, education, employment, living conditions, community, spirituality, artistic and intellectual pursuits. It stresses the need to place issues such as connection, meaning and values, centre-stage and to holistically address and challenges the idea that mental health care is just about diagnosis and medication.(36). The meaning of recovery can be different for each person and thus each individual has the opportunity to define what recovery means for them, and what areas of their life they wish to focus on as part of their own recovery journey. The recovery approach, in this way, embodies a complete paradigm shift in the way that many mental health services are conceived and run.

Both the human rights and recovery approach are very much aligned. Both respect people's diversity, experiences and choices and require that people be afforded the same level of dignity and respect on an equal basis with others. Also, both approaches recognize the social and structural determinants of health and promote the fundamental rights to equality, non-discrimination, legal capacity and community inclusion, and have important implications for how mental health services are developed and delivered. Both fundamentally challenge the current status quo in this area.

1.3 Critical areas for mental health services and the rights of people with psychosocial disabilities

The objective of providing better services for people with mental health conditions requires fundamental changes to the way services conceptualize and provide care. The right to health detailed in the CRPD requires that governments provide persons with disabilities with access to quality mental health care services that respect their rights and dignity. This means operationalizing a person-centred, recovery and human rights-based approach, and developing and providing services that people want to use, rather than being coerced to do so. It also means establishing services which promote autonomy, encourage healing, and create a relationship of trust between the person providing and the person receiving the service. In this respect the right to health depends on a number of key human rights principles in the mental health care context, namely, respect for legal capacity, non-coercive practices, participation, community inclusion and the recovery approach.

Respect for legal capacity

Many people with mental health conditions and psychosocial disabilities are denied the right to exercise their legal capacity; that is, the right to make decisions for oneself and to have those decisions respected by others. Based on stigmatizing assumptions about their status – that their decisions are unreasonable or bring negative consequences, or that their decision-making skills are deficient, or that they cannot understand and make decisions for themselves or communicate their will and preferences – it has become acceptable in services in countries throughout the world, for others to step in and make decisions for people with mental health conditions and psychosocial disabilities. In many countries, this is implemented through schemes like guardianship, supervision and surrogacy. and is legitimized by laws and practices. In other cases, this substitute decision-making is practiced more informally in home and family environments, with day-to-day decisions related to a person's life – such as what to wear, who to see, what activities to do, what to eat – being made by family members or others.

Promoting people's autonomy is critical for their mental health and wellbeing and is also a legal requirement according to international human rights law, in particular the CRPD. The Convention requires that States end all systems of substituted decision-making, so that people can make their own formal and informal day-to-day decisions on an equal basis with others. It requires that supported decision-making measures be made available, including in crisis situations, and that others must respect these decisions (*37*, *38*).

Although challenging, it is important for countries to set goals and propose steps to eliminate practices that restrict the right to legal capacity, such as involuntary admission and treatment, and to replace these with practices that align with people's will and preferences, ensuring that their informed consent to mental health care is always sought and that the right to refuse admission and treatment is also respected. This can be achieved in services where people are provided with accurate, comprehensive and accessible information about their care and support for making decisions.

One method of supported decision-making that can be implemented involves the appointment, by the person concerned, of a trusted person or network of people who can provide support in weighing up different options and decisions. The trusted person or group can also help in communicating these decisions and choices to mental health staff or others. If, despite significant efforts, it is not possible
to determine a person's will and preference, then decisions are based on the best interpretation of their will and preferences. Supported decision-making cannot be imposed on anyone as a condition to having their decisions respected.

Another way to implement supported decision-making is through the use of advance plans which comprise statements concerning people's will and preferences in terms of the care and support they receive, among other matters (37, 39). Advance plans enable people to consider and express what they might want to happen in the future if they experience a crisis or distress. The person can specify in what circumstances an advance plan should come into effect and designate in their plan one or more people to help with communication, advocacy or any other kind of support (such as support for decision-making or the tasks of daily living). These plans can also include information on matters such as: treatment, what should happen to their home if they decide to enter a service for a short period of time, who should take care of any personal affairs, and who should be contacted or not contacted.

Respecting people's legal capacity can be complex and challenging in many situations and no countries have become fully aligned with this CRPD requirement as yet. There are many situations where people's will and preferences are unknown, and the use of best interpretation may not in the end actually reflect a person's will and preference. The aim in these situations is to evaluate, learn and change practices to avoid similar situations arising in the future. Detailed information on strategies to promote and protect people's will and preferences, including in challenging situations, is available in the <u>WHO QualityRights</u> training modules and includes: supported decision-making and advance planning (*39*) legal capacity and the right to decide (*38*), freedom from coercion, violence and abuse (*10*), and strategies to end seclusion and restraint (*40*).

Non-coercive practices

Coercive practices refer to the use of forceful persuasion, threat or compulsion to get a person to do something against their will (41). In this way coercive practices also involve the denial of people's right to exercise their legal capacity. In the mental health service context, coercive practices may include for example, involuntary admission, involuntary treatment, the use of seclusion and of physical, mechanical, or chemical restraint.

Many stakeholders are now calling for the elimination of coercive practices and the implementation of alternatives in mental health and related services. The right to Liberty and security of person in the CRPD underscores actions to address coercion by prohibiting the deprivation of liberty based on a person's disability (42). This right significantly challenges services, policy and law in countries that allow involuntary admission on the basis of a diagnosed or perceived condition or disability, even when additional reasons or criteria are given for the detention, such as "a need for treatment", "dangerousness" or "lack of insight" (43).

Several other rights of the CRPD, including Freedom from torture or cruel, inhuman or degrading treatment or punishment and Freedom from exploitation, violence and abuse, also prohibit coercive practices (44). such as forced admission and treatment, seclusion and restraint, as well as the administering of antipsychotic medication, electroconvulsive therapy (ECT) and psychosurgery without informed consent (45-48).

The perceived need for coercion is built into mental health systems, including in professional education and training, and is reinforced through national mental health and other legislation. Coercive practices are pervasive and are increasingly used in services in countries around the world, despite the lack of evidence that they offer any benefits, and the significant evidence that they lead to physical and psychological harm and even death (43, 49-57). People subjected to coercive practices report feelings of dehumanization, disempowerment, being disrespected and disengaged from decisions on issues affecting them (58, 59). Many experience it as a form of trauma or re-traumatization leading to a worsening of their condition and increased experiences of distress (60, 61). Coercive practices also significantly undermine people's confidence and trust in mental health service staff, leading people to avoid seeking care and support as a result (62). The use of coercive practices also has negative consequences on the well-being of the professionals using them (63).

In many instances, coercive practices are justified, by those who use them, on the basis of 'risk' or 'dangerousness'(64), which raises concerns given the potential for bias and subjectivity (65). Other key reasons include the lack of understanding about the negative and detrimental consequences of these practices on people's health, well-being, sense of self and self-worth and on the therapeutic relationship (51), the lack of alternative care and support options, the lack of resources, knowledge and skills to manage challenging situations including crises in a non-confrontational way as well as negative service cultures in which shared values, beliefs, attitudes, rules and practices of the different members of a service are accepted and taken for granted without reflection and are considered to be "the way things are done around here". Finally, coercive practices are used in some cases because they are mandated in the national laws of countries (66).

In addition to changes to law and policy, the creation of services free of coercion (see <u>WHO QualityRights</u> <u>training modules</u>) requires actions on several fronts including:

- i. education of service staff about power differentials, hierarchies and how these can lead to intimidation, fear and loss of trust;
- **ii.** helping staff to understand what is considered a coercive practice and the harmful consequences of its use;
- iii. systematic training for all staff on non-coercive responses to crisis situations including de-escalation strategies and good communication practices;
- iv. individualized planning with people using the service including crisis plans and advance directives (51);
- v. modifying the physical and social environment to create a welcoming atmosphere including the use of 'comfort rooms' (67) and 'response teams' (68) to avoid or address and overcome conflictual or otherwise challenging situations;
- vi. effective means of hearing and responding to complaints and learning from them; systematic debriefing after any use of coercion in an effort to avoid incidents happening in the future; and
- vii. reflection and change concerning the role of all stakeholders including the justice system, the police, general health care workers and the community at large.

Participation

Historically, people with mental health conditions or psychosocial disabilities have been excluded from participating in decision-making regarding not only their own health and life choices, but also from decision-making processes in society as a whole. This marginalizes them from all spheres of society and strips them from the opportunity to participate and engage in society on an equal basis with other people. This is also true in the mental health field, where people have largely been excluded from participating in the design and delivery of mental health services and the development of policy, despite their expertise and experience in this area.

The preamble to the CRPD provides a legal framework that explicitly recognizes "the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities'. It further states that "persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them". The Convention also articulates the right of all people with disabilities to full and effective participation and inclusion in society and in political, public, and cultural life. It also requires governments to "actively promote an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others".

There is increasing recognition that people with lived experience, due to their own knowledge and experience in the area, have an important contribution to make and a central role to play in the design, development, improvement or transformation of mental health services, as well as in supporting and delivering direct services to others such as peer specialist, peer support and peer-run crisis services (69).

Providing services that actively seek to promote the knowledge and insights of those who have experienced psychosocial disabilities and to understand what services are helpful to them, is essential for providing support that people want and find useful. Services need to recognize the vital role that people with lived experience have to play in all aspects of service planning, delivery and governance.

The vital and beneficial role that people with lived experience can have, for example, through providing peer support, is increasingly being acknowledged (70-72). As a consequence, peer support is progressively being adopted within mental health services and systems in countries. Peer-based interventions are integral to services and should be part of a movement towards the provision of more positive responses to people who are seeking care and support (73).

Community inclusion

The institutionalization of people with mental health conditions and psychosocial disabilities that has occurred throughout the centuries has often resulted in their exclusion from society. When people are unable to participate in ordinary family and social life, they become marginalized from communities. In turn, the demeaning and stultifying nature of many psychiatric facilities and social care homes has devastating consequences on people's health and well-being.

The WHO has long advocated for the development of community-based services and supports for people with mental health conditions and psychosocial disabilities. This is now reinforced by the CRPD which articulates governments' commitments to support people with disabilities to live independently where and with whom they choose (74) and to participate in their communities to the extent they wish to do so. If this is to be achieved, psychiatric and social care institutions need to be closed and all mental health services need to respect people's right to remain free and independent, and to receive services in the place of their own choosing.

It also commits governments to deinstitutionalize existing facilities, integrating mental health care and support into general health services and providing people with "a range of in-home, supported living and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community". It also requires governments to provide people with disabilities access to the same community-based services and facilities as everyone else (44).

A critical role for mental health services is therefore to support people to access relevant services, supports, organizations and activities of their choosing, that can help them to live and be included in the community. This includes for example, facilitating access to social welfare services and benefits, housing, employment and educational opportunities (see section 3). In times of crisis it is especially necessary for mental health services to respect and fulfil the right to live independently in the community, by providing support according to the person's will and preferences where they are comfortable, whether in their own home, or with friends or family, a mental health setting, or other mutually agreeable location.

Recovery approach

The recovery approach has emerged in response to dissatisfaction with the prevailing implementation of many mental health services, and the provision of care which focuses predominantly on symptom reduction.

The recovery approach does not solely depend on mental health services. Many individuals can and do create their own pathway to recovery, can find natural and informal supports among friends and family and social, cultural, faith-based and other networks and communities, and can join together for mutual support in recovery. However, introducing the recovery approach within mental health service settings is an important means to ensure that the care and support provided to people who wish to access services considers the person in the context of their entire life and experiences.

Although the recovery approach may have different names in different countries, services adopting this approach follow certain key principles. Such services are not primarily focused on 'curing' people or making people 'normal again'. Instead these services focus on supporting people to identify what recovery means to them. They support people to gain or regain control of their identity and life, have hope for the future, and live a life that has meaning for them – whether that be through work, relationships, community engagement or some or all of these. They acknowledge that mental health and wellbeing does not depend predominantly on being 'symptom free', and that people can experience mental health issues and still enjoy a full life (75).

Recovery-oriented services (see <u>WHO QualityRights training modules</u>) commonly centre around the following five dimensions (*76*, *77*).

- Connectedness. This principle means that people need to be included in their community on an equal basis as with all other people. This may involve developing new meaningful relationships, reconnecting with family and friends, or connecting with peer support groups or other groups in the community.
- Hope and Optimism. Although hope is defined differently by different people, the essence of hope is the affirmation that living a full life in the presence or absence of 'symptoms' is possible. It also implies the belief that one's circumstances can change and/or that one will be able to manage or overcome a situation. As such, dreams and aspirations need to be encouraged and valued.
- Identity. The recovery approach can support people to appreciate who they are, strengthen their sense of self and self-worth, and to overcome stigma, external prejudices as well as self-oppression and self-stigma. It is based on respect for people and their unique identity and capacity for selfdetermination, and acknowledges that people themselves are the experts on their own lives. This is not just about personal identity but is also about ethnic and cultural identity.
- Meaning and Purpose. Recovery supports people in rebuilding their lives and gaining or regaining meaning and purpose according to their own choices and preferences. As such, it involves respect for forms of healing that can go beyond biomedical or psychological interventions.
- Empowerment. Empowerment has been at the heart of the recovery approach since its origins, and posits that control and choice is central to a person's recovery and is intrinsically tied to legal capacity (78).

1.4 Conclusion

The implementation of a human rights and recovery-based approach requires that services address social determinants of mental health, responding both to people's immediate and longer-term needs. This includes supporting people to gain or regain meaning and purpose in life, and helping them to explore all important areas of their life, including relationships, work, family, education, spirituality, artistic and intellectual pursuits, politics, and so on.

In this context, mental health services need to respect people's legal capacity, including their choices and decisions regarding treatment and care. They need to find ways to support people without resorting to coercion, and ensure that people with lived experience participate and provide insights into what a good service should look like. Finally, mental health services should also draw on the expertise and experience of peer workers to support others in their recovery journey in a way that meets their needs, wishes and expectations.

To achieve this is no small undertaking. There are many challenges to realizing this approach within the resource, policy and legal constraints that face many services. However, there are several mental health service examples from different regions across the world that show concretely that it can be done. The good practice examples presented in the following section are working successfully within a wide range of legal frameworks while still protecting human rights, avoiding coercion and promoting legal capacity. They demonstrate how it can be done and offer inspiration to policy makers and service providers everywhere



Good practice services that promote rights and recovery

The first chapter underscored the significant efforts needed by countries to transform their mental health services in line with human rights and recovery principles. To demonstrate the application of these principles, the following examples showcase good practice services which have made important steps in this direction. The purpose of highlighting these services is not to be prescriptive, but rather to reveal what can be learned from their diverse experiences. In particular, valuable lessons can be drawn from the mechanisms and strategies put in place to respect and promote human rights and the recovery approach, and these lessons can be applied to support countries as they shape and develop their own mental health services within their national contexts. It is important to note that while the services presented have made concerted efforts towards promoting human rights and the recovery approach, none is doing so perfectly. They nevertheless offer good examples of what can be achieved, when human rights and recovery form the core of the support; particularly since these services are in most cases operating under restrictive legal and policy frameworks and within mental health systems whose services are at different levels of development.

The good practice services presented were identified through four primary sources: literature reviews, a comprehensive internet search, an e-consultation, and through existing WHO networks and collaborators. Each service went through a selection process based on the five specific human rights and recovery criteria, namely: respect for legal capacity, non-coercive practices, participation, community inclusion, and the recovery approach. The services selected were classified according to seven different categories of service provided: crisis services, hospital-based services, community mental health services, outreach services, supported living services and peer support services. Annex 1 presents the methodology in detail.

In the following pages, each mental health service category is presented, followed by summary profiles of each of the related good practice services. More detailed descriptions of the good practice services are provided in the seven technical packages that accompany this guidance document. No service fits perfectly and uniquely under one category, since they each undertake a multitude of functions that relate to one or more of the other categories – for example, a crisis service may be provided as part of a broader hospital-based service – and this has been reflected in the categorizations at the beginning each service description.

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. The services described in the hospital-based mental health services and crisis response services sections are all located in high-income countries. Some low-income countries may assume that the examples from high-income countries are not appropriate or useful, and equally, high-income countries may not consider examples showcased from low-income countries. New types of services and practices can 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 mental health services described in this guidance are not intended to be interpreted as best practice, but rather to demonstrate the wider potential of community-based mental health services that promote human rights and recovery. They present a menu of good practice options that countries can adapt to fit diverse economic and policy settings. The intention is to learn from those principles and practices that are relevant and transferrable to one's own context in providing community-based mental health services that successfully promote human rights and recovery.

2.1 Mental health crisis services

The goal of crisis response services is to support people experiencing acute mental distress. However, these are the very services where people are at a heightened risk of their human rights being violated, including through forced admissions and treatment, the use of coercive practices such as seclusion and physical, mechanical, and chemical restraints. These practices have been shown to be harmful to people's mental, emotional and physical health, sometimes leading to death (*49, 50, 64*).

The following section showcases a selection of crisis services that provide effective care and support without resorting to the use of force or coercion, and that respect the right to legal capacity and other human rights. Such services can be delivered in various ways. Some assist people to overcome their crisis at home with support from a multi-disciplinary team. Others deliver care and support in respite centres or houses. These provide community-based, temporary accommodation designed to allow for short-term breaks from people's usual daily lives.

All services presented in this section take a holistic, person-centred approach to care and support. They acknowledge that there is no consensus on what constitutes a crisis, and that what a person may experience as a crisis may not be viewed as such by someone else. Therefore, each service showcased in this section approaches crisis as a very personal experience that is unique and subjective, requiring different levels of support for an individual to overcome.

Based on a human rights-based and recovery approach, services showcased in this section pay particular attention to power asymmetries within the service. Many also focus on meaningful peer involvement and the provision of a safe space and comfortable environment in which to overcome the crisis. All insist on the importance of communication and dialogue with the people experiencing the crisis and understand that the people themselves are experts when it comes to their own care and support needs.

People receiving support from crisis response services featured in this section are never removed from community life. Many services actively include families and close friends in the care and support of individuals, with their agreement. Additionally, these crisis response services are well connected to other resources available in the community. They are able to connect individuals with and help them navigate the system outside, so that they are supported beyond the crisis period.

Overall, the success of these services demonstrates that crisis response does not necessitate the use of force or coercion. Instead, communication and dialogue, informed consent, peer involvement, flexibility in the support provided, and respect for the individual's legal capacity are shown to achieve quality care and support that is responsive to people's needs.

2.1.1 Afiya House

Massachusetts United States of America



Afiya House is a peer-run respite centre, which aims to support people in distress to turn what is often described as a 'crisis' into a learning and growth opportunity. It is part of a broader community of people working within a peer services framework, operated by the Wildflower Alliance – formerly Western Mass Learning Community – which has been in existence since 2007 (79). All employees identify as having faced life-interrupting challenges themselves, such as psychiatric diagnoses, trauma, homelessness, problems with substances, and other issues.

Primary classification: Crisis service

Other classifications:

Community mental he	ealth centre	nunity outreach	Veer support
Crisis service	Hospital-based servic	e Supp	ported living service
Availability in different locat	ions:		
Yes	No		
Evidence:			
Published literature	Grey literature	None	
Financing:			
State health sector	State social sector	Health insu	rance
Donor funding	Out-of-pocket paymer	nt	

Description of the service

Afiya House was opened in 2012 (80) in an urban residential neighbourhood of Northampton. It is the only peer respite in western Massachusetts, USA, and one of only about three dozen nationally. The service is available to any people over the age of 18 experiencing significant emotional or mental distress, for a stay of up to seven nights. Although this can include people living without a home, lack of housing cannot be a standalone reason for staying at the respite. Individuals who need hands-on personal care, or who need help with the administration of medications, are generally not eligible, unless they have outside assistance (81). People who stay in Afiya House are automatically connected with all of the other activities of the Wildflower Alliance, and all people who work at Afiya House are considered to be employees of the Alliance.

Afiya does not offer clinical services, however paid peer support team members are available around the clock. Team members support people staying at the house to set up a wellness plan if they wish, maintain existing clinical relationships in the community, or make changes to the clinical services they receive. There is no expectation that people using the service keep to a pre-determined schedule (such as sleeping and waking times, mandatory activities, etc.), but peer supporters regularly check on people during their stay to invite them to connect or to help identify other useful activities and resources. Peer supporters may also accompany people to clinical appointments, if desired and feasible. Peer supporters have diverse interests and experiences and harness these in their work, for example offering yoga or meditation.

People staying at Afiya may freely enter and leave to continue their regular schedule in order to attend school, work, community obligations and appointments, etc. (*81*). The house can accommodate three people at any one time in private rooms, with access to a kitchen and basic food items, common rooms, and resources like books, art supplies, musical instruments, yoga mats, etc. Prior to entering, people interested in Afiya have an initial conversation with a team member, and the final decision as to whether to attend is made by three people: the individual, the first team member contact, and a second team member, to ensure nothing was missed.

Core principles and values underlying the service

Respect for legal capacity

Afiya emphasizes choice and self-determination in providing trauma-informed peer support (81). When entering the respite, people are briefed on human rights issues; they are also made aware of Afiya's human rights officer and third-party contacts, who they can access if they think they are being mistreated in any way (81). Emergency mental health crisis services are never called, unless individuals themselves identify such a service as their preferred option. Emotional distress, thoughts or even a plan of suicide is not considered a medical emergency, and staff are trained to support people in these situations, using Intentional Peer Support (82) and Alternatives to Suicide^b approaches (83). People staying at Afiya may optionally complete a preferred contact and support sheet, however the information is considered to remain the property of the individual, along with any personal plans that may be developed (81). Further, the house does not disclose the names of people staying there.

Non-coercive practices

A period of residence at Afiya House is completely voluntary and must be initiated by the person who wishes to stay. In order to avoid interactions historically rooted in power imbalances and coercion, team members do not assist with the administration of any medical treatments and individuals are instead provided with a locked box in their room where they may store their own medication or valuables. However, support and resources for withdrawal from psychotropic drugs can be provided (*81*).

To minimize power dynamics between employees and individuals staying, Afiya's staff are not clinically trained, and do not administer medicines or hold a person's valuables during their stay. These policies reduce the potential for drift into coercive interactions. Police or ambulance services are only contacted without an individual's consent in the event of a medical emergency (such as a heart attack, being found unconscious, drug overdose, etc.), or if a serious threat of violence exists. If such a situation occurs, team members subsequently undertake an internal review (*81*). In 2015, a violent incident occurred as the result of an attempted theft; but there have been no other violent incidents. Staff are trained using the Validation, Curiosity, Vulnerability, Community (VCVC) support model as an approach to navigating situations in which a person is very angry (*83*).

b The Alternatives to Suicide approach was developed in 2008 by the Western Massachusetts Recovery Community. It grew out of the realization that many approaches to suicide prevention were counter-productive and often led to coercive interventions. In practice, it takes the form of peer-support groups that are modelled on the way Hearing Voices groups operate. Over time, a loose formula has been developed involving: 'Validation, Curiosity, Vulnerability, Community'.

Community inclusion

Afiya House recognizes community inclusion as a key component in offering respite and supports people who are staying at the house to explore various local community resources including spiritual, sports, or educational resources. Peoples' ability to come and go freely from the house also helps to initiate or maintain important ties and responsibilities, such as work, education and other activities. People staying at the respite are encouraged to connect with their chosen family, friends, and/or other providers or supporters, and to assist with this, team members can help facilitate healing dialogues. Afiya House also partners with other Wildflower Alliance services including those related to housing and homelessness. Wildflower Alliance operates four resource centres and offers many community-based workshops and events related to education, advocacy, peer support and alternative healing. They employ a number of "community bridgers" offering support to people in prison and people in hospital who are preparing to transition back into the community.

Participation

Afiya House was created and is run by people who have themselves experienced psychiatric diagnosis, trauma, homelessness, problems with substances and other challenges. The service's structure reflects a commitment to participation and demonstrates this principle by example. Team members complete training in four core areas: intentional peer support, alternatives to suicide, hearing voices facilitation and anti-oppression training. Peer supporters are available to individuals for either one-to-one or group support, and support between those staying at the house is also encouraged. All people who stay at Afiya are asked for their verbal feedback in order to continually improve the service.

Recovery approach

Afiya House does not force individuals to create a recovery plan, but they do ask all people staying at the house to complete a form that briefly outlines what they hope to achieve during their stay. Hopes may include something as simple as re-regulating their sleep schedule but can also be more detailed and include developing a wellness plan or finding new housing. Beyond the support offered by the peer team, the recovery approach makes use of the broader Wildflower peer-to-peer Recovery Learning Community, which allows access to community resource centres and groups during and after their stay.

Service evaluation

There were 174 stays at Afiya House between 1 July 2016 and 30 June 2017. Approximately half of respondents reported having prior experience in a traditional respite programme and 57% reported also using other mental health services. There were a total of 1344 contacts that did not result in a stay at Afiya House; 74% of which were due to a lack of space.

A 2017 report (80) documented the results of an anonymous evaluation survey completed by people prior to their departure which indicated that users of Afiya House preferred the environment at Afiya and experienced better outcomes than at traditional or clinical respite houses. Compared to hospitals and other clinical respites, individuals reported that they felt more welcome at Afiya, and that information was communicated more transparently. Most reported Afiya had a positive impact on their life. In terms of meeting each individual's hopes for their stay, 86% of respondents reported that the stay had met at least one hope. People staying at the house also reported feeling that Afiya House staff members genuinely cared and that they felt connected to staff and other service users, able to accomplish goals, and free to do whatever they needed to do while also receiving support.

Costs and cost comparisons

Afiya House is fully funded to 2027 by the State of Massachusetts Department of Mental Health, via the Massachusetts Recovery Learning Centre, thus the service is free of charge to people who stay, and no insurance is required. Positive outcomes from evaluations have provided the evidence required for the continued funding of the service.

In 2015, Afiya accommodated 250 separate stays. It was projected, based on past history and selfreport, that on 125 of those occasions, the individual would likely have been hospitalized had peer respite not been available. In 2015, the estimated average cost per person per day in Afiya was US\$ 1460 compared with US\$ 2695 per person per day in hospital (81). The total annual running cost for Afiya in 2019 was US\$ 443 928, of which personnel expenditure comprises the largest component.

Space limitations have made it difficult for Afiya House to fulfill one of its primary goals – that of hospital diversion. As noted in 2016–2017, nearly 1000 people were turned away because the house was full; in comparison there are 9 psychiatric units in the region. There have been proposals to open a second house modeled on Afiya. However, despite a clear demand for more peer-based crisis services such as Afiya House, and likely cost savings on hospitalizations, state funding has not been forthcoming.

Additional information and resources

Website: <u>https://wildfloweralliance.org/</u>

Videos: Afiya House - <u>https://www.youtube.com/watch?v=9x8h3LvEB04</u>

Contact: Sera Davidow, Director, Wildflower Alliance, USA, Email: <u>sera@westernmassrlc.org</u> or <u>sera@wildfloweralliance.org</u>

2.1.2 Link House

Bristol, United Kingdom of Great Britain and Northern Ireland



Link House is a residential crisis centre for women who are experiencing a mental health crisis and who are either homeless or unable to live at home due to mental health issues. Its service is based on a social model of care, rather than medical support. Link House was established in 2010, and in 2014 joined the innovative Bristol Mental Health network of 18 public and voluntary sector organizations which unified the delivery of care and are fully funded by the National Health Service (NHS).

Primary classification: Crisis service

Other classifications:

Community mental hea	alth centre	nity outreach Peer support
Crisis service	Hospital-based service	Supported living service
Availability in different locati	ons:	
Yes I	10	
Evidence:		
Published literature	Grey literature	None
Financing:		
State health sector	State social sector	Health insurance
Donor funding	Out-of-pocket payment	

Description of the service

A residential crisis centre for women of 18 years and older, Link House was established with the primary aim of diverting women in crisis away from psychiatric admission. It helps women cope with the crisis and build resilience. The service is operated by Missing Link, the largest provider of women-only mental health and housing services in Bristol, in operation since 1982 (84).

The house, with a shared kitchen and garden, has space for 10 women at a time, who can stay for a maximum of four weeks. The service accepts all women including those who are under legal treatment orders or being discharged from psychiatric care. Women with cognitive and physical disabilities are also welcome if they can take care of their own personal care needs, and the disability suite is regularly used. Entry into the service can be via self-referral, crisis and recovery services, or general practitioners (GPs) (85). People with psychosis, suicidal thoughts, as well as alcohol and substance use issues are accepted into the house if they are making good progress towards recovery. To avoid waiting lists during emergencies, Link House has one emergency bed available (86), and makes referrals to other Missing Link services.

People staying at Link House have their own dedicated support worker, and staff are available day and night. There are no medical staff, and no formal staff qualifications are required. Staff receive core training on de-escalation and support strategies, as well as suicide awareness and mental health first

aid (87). Staff support women in creating a personally-tailored programme and routine (88); and in skills related to self-care, money, cooking, time management, relationships, and employment (85). Group recovery programmes are offered several times a week along with daily activities. Women are free to leave the house on their own for a time, but due to space constraints, visits are limited.

Core principles and values underlying the service

Respect for legal capacity

Listening to the voice of the person using the service and self-determination are essential elements of the Link House philosophy. All activities of the service are guided by the core values of respect and understanding. All actions are taken in line with the preferences of the women who use the service. Overall, service users are able to continue their lives, with Link House in the background as a safety net (88). Activities are tailored to help the women articulate their own goals; for example, staff can help service users to find an advocate to join them during a doctor's appointment. If service users are dissatisfied with Link House, Missing Link has a complaints procedure to allow a service user (or a third party they may wish to involve) to make a report (89).

Non-coercive practices

Access to Link House is always on a voluntary basis; during the initial assessment care is taken to ensure that the woman requesting the service is genuinely interested in staying at the house. Although encouraged to follow a routine during their stay, service users are not forced to do this, and there is no use of restrictive practices. In a 2016 evaluation, service users reported the 'best thing about being in Link House', was that it feels "safe, homely, is women only (including staff)" and that they appreciated the "nonmedical, positive and supportive approach by staff" (90). Women staying in Link House are in charge of their own medication; staff members are not involved with monitoring or administration. If a person decides not to take medication, this has no implications for her stay at Link House, unless her mental health situation deteriorates to the extent that it makes her, or other people, feel unsafe. In that case, she is referred to the crisis team or inpatient services.

Community inclusion

Significantly, Link House encourages women who stay to continue their regular activities in the community (88) and actively links them to different community services based on their wishes, including other services of the Missing Link network. These services include a wide variety of other employment and mental health support programmes for women, as well a range of supported housing, group housing and interim housing accommodations. Within Link House, there is an emphasis on providing an inclusive environment; women using the service are encouraged to interact and cook together and organized group sessions are held two to three times a week.

Participation

At Link House people with lived experience are involved at every level of the organization. At a managerial level, Link House has created the Crisis House User Reference Group (CHURG) which meets every 6 weeks. This group is composed of past service users and aims to further increase participation, also acting as a peer support group for the people who attend. This group has been consulted on house rules, policy, research literature, and activities.

Residents of Link House also have an important say in the day-to-day running of the house and activities provided. Focus groups are conducted with women using the service in order to inform service development and improvement efforts. In a 2016 service evaluation, 98% of service users reported they had sufficient participation in running the house (90).

Recovery approach

Link House uses a social care model of recovery emphasizing a strengths-based approach, values-lived experience and self-determination. It focuses on equality, cultural sensitivity and taking a holistic view, while providing flexible support and helping women to reconnect with their lives. All staff are trained in reflective practice and trauma-informed approaches, and support women to develop coping strategies and strengths that can help them to recover. Individual Wellness Action Recovery Plans (91) are used for all women going through the service (88% of service users found these helpful (90)), and staff tailor activities around each individual's goals. To further support service users, their current care providers are also integrated into recovery plans. Women are also encouraged to develop a Recovery Star (92) chart, to identify areas in their lives they want to improve. When they leave Link House, they can revisit the chart to see the progress they have made.

Service evaluation

When women leave Link House, they are asked to complete an exit feedback survey (90). In 2017–2018, Link House supported 150 women and of the 122 respondents who completed the survey: 99% said they found their stay a helpful experience, 99% said the support was responsive to their needs, 94% said they felt their mental health had improved, 100% found the activities and group sessions helpful, and 100% said they would recommend it to a friend (93). Link House service users reported that they used the hospital less and that the Link House service helped them to reduce their lengths of stay. All the women referred from mental health services were assessed as needing a hospital bed. Thus, it can be inferred that the use of the house by these women directly reduces hospital admissions (93).

Costs and cost comparisons

In 2017–2018, Missing Link helped a total of 864 women find services and housing in their community, and 150 of these women used Link House. The service costs \pounds 467 000 per year to deliver (approximately US\$ 647 000)^c, including building, staff and overhead expenses. The total cost per person per bed per night is \pounds 127 (approximately US\$ 176)^d. Insofar as a hospital bed costs approximately three times more per night (94), Link House represents a major savings to the health system.

c Conversion as of March 2021.

d Conversion as of February 2021.

Additional information and resources

Website:

https://missinglinkhousing.co.uk/services-we-offer/link-house-for-women-in-mental-healthcrisis/

Videos:

Link House - <u>https://missinglinkhousing.co.uk/link-house-film/</u> Sara Gray, staff member, Link House <u>https://www.youtube.com/watch?v=GMSofLVJMcY&feature=youtu.be</u>

Contacts:

Sarah O'Leary, Chief Executive Officer, Missing Link Mental Health Services, Bristol, United Kingdom; Email: <u>Sarah.OLeary@nextlinkhousing.co.uk</u>

Carol Metters, past Chief Executive Officer, Missing Link Mental Health Services, Bristol, United Kingdom, Email: <u>Carol.metters@missinglinkhousing.co.uk</u>

2.1.3

Open Dialogue Crisis Service Lapland, Finland



Open Dialogue is a specific technique for working with individuals and families dealing with a mental health condition. It was developed in Western Lapland, Finland near the Arctic Circle, and uses elements of individual psychodynamic therapy and systemic family therapy with a key focus on the centrality of relationships and the promotion of connectedness through family and network involvement. The Open Dialogue approach informs all elements of the mental health service in Western Lapland. The focus of this mental health service summary is the Open Dialogue crisis service.

Primary classification: Crisis service

Other classifications:

	Community mental hea	alth centre	Community outreach	Peer support
	Crisis service	Hospital-based	service Sup	oported living service
Availa	bility in different location	ons:		
\checkmark	Yes	lo		
Evide	ice:			
\checkmark	Published literature	Grey literature	None	
Finand	cing:			
\checkmark	State health sector	State social see	ctor 🗹 Health ins	surance
	Donor funding	Out-of-pocket p	payment	

Description of the service

The Open Dialogue crisis and home outreach service is based at Keropudas Hospital, in the city of Tornio and is coordinated and administered by the Keropudas Outpatient Clinic. It serves the whole of Western Lapland and coordinates with other outpatient clinics and services in the region. Keropudas Hospital is focused solely on mental health and provides inpatient care for all municipalities in Western Lapland with a 22-bed psychiatric unit. The Open Dialogue crisis service team consists of 16 nurses, a social worker, psychiatrist, psychologist, occupational therapist and secretary. Trainee doctors and peer workers also participate in the work of the clinic, which serves an average of 100 new individuals a month as part of the Finnish public health service.

The crisis service aims to provide a psychotherapy-based intervention for individuals who present with a mental health crisis, including those with psychotic symptoms, and is available 24 hours per day, seven days per week, via phone, text, email or on a walk-in basis. The service provides the single contact point for crisis situations in Western Lapland and aims to respond to each referral immediately, and always within 24 hours, unless the person involved specifically requests a delay.

Once contact is made, the team member who received the initial request organizes a case-specific team including crisis service staff and sometimes other services, such as social workers. This team

works with the person in crisis throughout the time that they are needed. Regular team meetings with service users are held at their homes or in the service's offices according to the person's preferences – daily if needed. Consultation is expanded to include the individual's family and/or support network, with their permission.

Key value-added aspects of the service are its flexibility, mobility and the continuity of care by the support team. The service works to minimize the use of medication, be fully transparent and ensure individuals and their opinions are central to all discussions and decisions about their care. Open Dialogue attempts to promote the client's potential for self-exploration, self-explanation, and self-determination.

Core principles underlying the service

Respect for legal capacity

A central tenet of Open Dialogue is that treatment decisions are determined by the person using the service and the treatment team is fully available to provide them with the support they may want. By creating the conditions for real dialogue, the service aims to promote the dignity of the person and respect for their legal capacity. Team members work to create a situation where all voices are heard equally, and the therapeutic care plans emerge from this dialogue.

The Open Dialogue crisis team also aims to be sensitive to the power differentials involved at times of crisis, which can have the effect of undermining the opportunity for those using the service to articulate their needs and preferences. The service addresses the issue of power, and how to manage and minimize its imbalances, in its training and supervision of team members. Advance directives are not used in the service, nor in the rest of Finland.

Non-coercive practices

The crisis service works to avoid coercive interventions by seeking to de-escalate tense situations. People who refuse to take medication are not threatened with hospital admission and there is negotiation to find a safe and agreeable solution to these situations. The service staff are trained in Management of Actual or Potential Aggression (95) as a de-escalation intervention. However, despite the processes in place to avoid coercive practices, on occasion people are admitted to and treated against their will in the inpatient unit of Keropudas Hospital when it is a question of securing people's safety and no other options emerge.

Community inclusion

The primary goal of the service is to provide support to an individual in crisis in order to avoid hospitalization. As such, most of the work of the crisis service is done in the community. The service works closely with schools, training institutes and workplaces as well as with other organizations that might provide support. Meetings may involve actors from various parts of the individual's support network, and can include family, neighbours, friends, teachers, social workers, and employers, as well as traditional healers, etc. (96). Service users may also consult with individual practitioners, if they wish, and access weekly physical activities, such as swimming, golf, etc.

Participation

Although peer workers lack recognition in the Finnish health system, four peer workers are employed by the Open Dialogue crisis service on a consultancy basis. They are mainly engaged in training and management, but also organize and facilitate support group meetings. They may work with specific individuals and participate in meetings, but they are not considered full members of the case-specific teams. Since 2014, the service has been developing a new form of training involving both professionals and peers. This training is seen as a vehicle for hearing the peer point of view more powerfully.

Recovery approach

The Open Dialogue model uses elements of individual psychodynamic therapy and systemic family therapy in a single intervention with the person using the service, and their families. Its focus on the centrality of relationships, values and understanding differing perspectives, is consistent with the recovery approach. It empowers the person using the service by avoiding the use of technical professional language and instead seeks to normalize and develop meaning from the person's own experiences. It also encourages them to be actively involved in deciding how problems should be discussed and approached.

Service evaluation

A systematic approach is used to obtain feedback directly from people using the service through annual anonymous surveys. In a 2018 register-based cohort study, outcomes of Open Dialogue were evaluated in a comparison with a large Finland-wide control group, covering about 19 years. Duration of hospital care, disability allowances and the need for neuroleptic medication remained significantly lower for the Open Dialogue cohort (97). The Open Dialogue participants also were reported to have better employment outcomes compared with those treated conventionally (98).

Another national cohort study, covering five years, found that the Western Lapland catchment area had the lowest figures in Finland for durations of hospital treatment and disability pensions (99). Qualitative studies have also found that people using the service were positive about it, along with families and professionals involved (*100*).

Costs and cost comparisons

The crisis service is free of charge to those using it, however it has been estimated that one dialogical network meeting of 60–120 minutes costs \in 130–400 (about US\$ 155–475)^e ([Kurtti M], [Western-Lapland Health Care District], personal communication, [2021]). As a state-funded service via the health sector, funding comes through taxation from local municipalities. National health insurance covers the costs of some medication and private psychotherapy, and neuroleptic drugs are provided without charge. The localized way in which health-service funding is organized in Finland enables a significant investment in staff training.

e Conversion as of March 2021.

Additional information and resources

Website:

http://developingopendialogue.com/

Videos:

Open Dialogue, An Alternative, Finnish approach to Healing Psychosis <u>http://wildtruth.net/films-english/opendialogue</u>

Jaakko Seikkula - Challenges in Developing Open Dialogue Practice <u>https://www.youtube.com/watch?v=VQoRGfskKUA</u>

Contact:

Mia Kurtti, Nurse, MSc, Trainer on Family - and Psychotherapy, Western-Lapland Health Care District, Finland. Email: <u>mia.is.kurtti@gmail.com</u>

2.1.4

Tupu Ake South Auckland, New Zealand



Tupu Ake is a peer-led, alternative crisis admission service located in Papatoetoe, a suburb of South Auckland, offering short stays and a day support programme. Peer support specialists are trained to work without resorting to coercion or restrictive techniques, and people are free to enter or leave the services as they wish. Emphasis is placed on a tailored, recovery-focused and strengths-based plan, through approaches such as Wellness Recovery Action Planning. As peer workers, staff share their own lived experience of mental health conditions or psychosocial disabilities.

Primary classification: Crisis service

Other classifications:

Community mental health centre	Community outreach	Peer support
Crisis service Hospit	al-based service Su	oported living service
Availability in different locations:		
Yes No		
Evidence:		
Published literature 🧹 Grey lit	terature	
Financing:		
State health sector	ocial sector Health ins	surance
Donor funding Out-of-	pocket payment	

Description of the service

Tupu Ake was established as a pilot recovery house service in 2008 by the NGO, Pathways Health (*101*), a national provider of community-based mental health services – and one of the first mental health services in New Zealand to provide an alternative to hospital admission. Serving a region of 512 000 people, Tupu Ake offers short stays of up to one week for a maximum of 10 people, and a day support programme for up to five people.

Entry to the service is through the state-run District Health Board (DHB) community crisis teams, who only refer people whose levels of distress and acuity will allow their safe support within the open setting. People can stay in Tupu Ake regardless of their diagnosis: in a 2015–2016 evaluation it was found that 42% had a diagnosis of psychosis and 42% a diagnosis of depression/anxiety (*102*). Most people were between 21 to 50 years old, with slightly more women than men using the service. With regard to ethnicity, 32% were New Zealand Europeans, 29% indigenous Maori and 20% Pacific Islanders. Mãori (who make up 15% of New Zealand's population), face significant mental health challenges related to high levels of economic deprivation and cultural alienation (*103*), as well as differential treatment in the mental health system, including more compulsory treatment (*104*).

People staying at Tupu Ake are referred to as guests to encourage a less hierarchical relationship with staff. Tupu Ake works closely with the person receiving services and their designated crisis team clinician provided by the DHB, to establish a personalized recovery plan that addresses the purpose of their stay in Tupu Ake. The clinical team visits frequently to review the progress of the plan and can alter it accordingly. The staff at Tupu Ake help guests learn coping strategies, reinforce behavioural and motivational techniques, support and assist with medication, and give feedback and progress reports to the clinical team.

The Tupu Ake villa is immersed in landscaped gardens and entirely co-designed by peers, including extensive wall painting and other art created by previous guests. There is a family room to accommodate meetings with family and friends. Activities offered include: wellness classes, psychosocial interventions, cultural and physical wellbeing activities such as: cultural songs (waiata), prayer (karakia), weaving (harakeke), dealing with distress programmes, art therapy, gardening, healthy eating, and mindfulness. Guests can create a Wellness Recovery Action Plan (WRAP), a tool widely used to manage the recovery process (*91*).

Tupu Ake also promotes immersion in nature as a helpful factor in recovery, through walks, bird-watching, and horticulture. Self-soothing techniques based on sensory modulation, use of sensory rooms, and development of sensory plans, also help guests tolerate and recover from acute distress.

The day programme offers transitional support for former guests. Up to five guests can attend the day programme at any given time, for up to seven days. Activities include socialization, gardening, learning musical instruments, therapeutic art and other wellbeing-based activities, including the learning and use of sensory modulation and self-soothing techniques.

The vision for the service is underpinned by a "peer competencies" framework comprising six core values: mutuality, experiential knowledge, self-determination, participation, equity, and recovery and hope. The majority of the staff are peer support specialists who provide individualized support to people through the integration of these core values into their practice.

Core principles and values underlying the service

Respect for legal capacity

In line with the core value of self-determination, people using their service are supported to make informed choices and give informed consent in every aspect of their lives, including: the support they receive from Tupu Ake, their recovery journey, the involvement of others, the pursuit of dreams and attainment of personal goals, their living situation, employment opportunities, social and leisure activities, and relationships.

The peer-led nature of the staff and the peer support principles under which the service operates, help to reduce the power differential between staff and guests. During their stay, staff not only support guests in making wellness plans but they also support them in bringing their plans back to the meetings with DHB clinical staff. This element of advocacy is an important role of the Tupu Ake staff in countering the power differential between people (some of whom are admitted to the hospital involuntarily under New Zealand's Mental Health Act) and their clinical providers. Tupu Ake strives to ensure that options and choices are made available to guests whenever possible. In many situations involving legal capacity, peer staff serve as advocates for the guests; this may involve organizing urgent legal representation.

Non-coercive practices

In line with its core values, Tupu Ake does not practice coercive treatment, seclusion or restraint; peer support specialists are trained to work without resorting to coercion or restrictive techniques. Staff are trained in de-escalation techniques (including non-violent crisis prevention training, trauma awareness and trauma informed practices) and are trained to tolerate a level of discomfort in order to normalize the guests' experience while they process their distress.

While Tupu Ake works with a model that encourages self-determination; it operates within a larger system – the mental health services provided by DHBs – that does not always do so (105). This tension is most apparent when the state-run crisis team attempts to use coercion or dominate the discussion about the guest's recovery plan. On these occasions, skilled negotiation and advocacy with the guest to assert their wishes or to empower them to be self-determining, becomes a focus of the intervention of Tupu Ake staff. Guests are free to enter or leave the services as they wish.

In situations where a person does not want to take prescribed medication, Tupu Ake engage with the person and seek to understand the reasons for their reluctance, then work with the person to determine ways of engaging with the clinical team to resolve the issue. The staff aim to achieve this by accompanying the person as advocates. Some people attend Tupu Ake with the intention of reducing their medications in a supportive environment where they can be safely assisted to do so.

Community Inclusion

Guests are able to attend community activities, go for a walk, or visit local shops accompanied by a peer support worker if they wish. Tupu Ake recognizes the importance of family (whanau) in people's lives (over 40% of their guests live with family). Many guests have significant social or cultural stressors in their home environments and Tupu Ake works with other community health and social service providers to address these. When working with guests to plan their transition back to independent living the service helps connect people with community mental health and addiction support workers, to ensure that they can continue to address family relationships, social networks, housing and vocational or professional needs when they leave.

Participation

All of Tupu Ake's staff self-identify as having lived experiences of mental health conditions or psychosocial disabilities, and peer support specialists make up the majority of the staff. Peer co-production and involvement have been prioritized from the earliest stages of service development, from defining the language and vocabulary (for example, referring to service users as guests), to the design and renovation of the house itself.

People who use the service are routinely asked to complete a user experience questionnaire which asks the degree to which they felt: listened to and heard, respected, involved in decision-making, and safe and supported in recovery, among other aspects. Other assessment tools used include the Your Wellbeing outcome questionnaire based on the *WHO Quality of Life* (WHOQOL) assessment tool and the New South Wales Ministry of Health *Activity and Participation Questionnaire*. This information, together with any verbal feedback from people using the service is analysed by the service's leadership every three months to direct the next three-month planning and improvement cycle for the service.

Recovery approach

Tupu Ake staff support guests to reflect on and clarify their life goals and aspirations, promoting their sense of autonomy and control over their future. A tailored, strengths and recovery-focused plan using approaches such as WRAP (91) is used to increase peoples' resilience and ability to cope after returning to the community. Staff members view the person as a whole and offer holistic support by identifying factors that are causing or contributing to their distress. As peer workers, staff share their own lived experience in a meaningful way using wellness plans, activities and wellness tools, which empowers guests through instilling hope. The relationship with peer support specialists and their belief in a guest's ability to lead their own recovery using their own strengths and skills, can be transformative.

Service evaluation

An independent evaluation was conducted in 2017 (*102*) based on qualitative interviews with service users and other stakeholders including staff from Tupu Ake, Pathways and the DHB. The results showed guests experienced positive outcomes in terms of levels of self-determination and an increased ability to cope with their experiences. Guests reported higher levels of satisfaction with care and shorter average lengths of stay at Tupu Ake than comparable hospital inpatient units. The evaluation highlighted the positive role Tupu Ake played in repairing their relationships with family and social networks, and the supportive physical environment provided by the villa and grounds.

The number of users over time reflects steady growth. During the period January 2015–December 2016, 564 guests accessed the overnight service for one episode of care and 26 utilized the day programme. In comparison, during the period 2018–2019, a total of 642 guests stayed overnight, and 75 accessed the day programme. Feedback from participants reflected higher levels of satisfaction with Tupu Ake compared to conventional services, and suggested it was helpful in reducing readmissions to acute services. Of the 303 guests in 2019, 29 (9.5%) ultimately required hospitalization and nine people left by choice. The remaining 88% left when their goals for the stay had been met. The average length of stay for 2019 was 7.7 days. In comparison, the average length of stay in the mental health inpatient unit of Counties Manukau hospital was 19.8 days; however, the profiles of the people using the two services can differ ([Phillips R], [Pathways], unpublished data, [2020]).

Costs and cost comparisons

Tupu Ake is free of charge to individuals using the service as it is fully funded by New Zealand's public health system. The service is funded at a rate of NZ\$ 297 (US\$ 213)^f per bed per night, which covers all required staffing, facilities costs, programme consumables, food, information technology and other associated costs of service provision. In contrast, an inpatient hospital bed costs an average of NZ\$ 1000 (US\$ 720)^g per night ([Phillips R], [Pathways]. personal communication, [2020]).

f Conversion as of February 2021.

g Conversion as of March 2021.

Additional information and resources

Website:

https://www.pathways.co.nz/services/peer-services

Videos:

Prime Minister visits Tupu Ake 31 May 2019 https://www.youtube.com/watch?v=SwQfaQ3BJVk

Contact:

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2.2 Hospital-Based Mental Health Services

General hospital-based mental health services provide treatment and care through mental health inpatient units, outpatient services and community outreach services. Historically, hospital-based services for mental health in many countries have comprised psychiatric hospitals or social care institutions that are isolated from the rest of the community. People often reside in these settings for weeks, months and even years. These settings are often associated with extensive coercive practices and human rights violations including violence, abuse and neglect, as well as involuntary admission and treatment, seclusion and physical, mechanical and chemical restraints, as well as inhuman and degrading living conditions (*8, 106, 107*).

The services presented in this section depart from this model and instead provide hospital-based care in general hospital settings that are integrated within the general health system and the rest of the community. Indeed, these services are organized so that people spend a minimum amount of time in inpatient care and remain connected to their support networks throughout their stay. The services strive to connect people to other community-based services and supports beyond those provided in the hospital setting, to facilitate peoples' return to their lives and community.

Moreover, all of the services showcased have processes in place to end the use of coercive practices. These services also strive to respect people's right to informed consent and to make decisions for themselves about treatment and other matters. For example, they may be encouraged to draft advance directives or crisis plans, or participate in other initiatives to promote decision-making and autonomy.

Phasing out stand-alone psychiatric hospitals and social care institutions in favour of community-based alternatives is critical. Ensuring people receive care and support that is responsive to their needs and respects their human rights is paramount. Mental health services provided in general hospital settings can be helpful in achieving these goals, when provided as part of a range of community-based services and support. Such services, delivered in a non-coercive way, can respect a person's will, preferences and autonomy and support them through their recovery journey. The examples provided in this section show that it is possible to have quality mental health care and support in general hospital settings and is an option for people who believe they would benefit from hospital-based services.

2.2.1

BET Unit, Blakstad Hospital, Vestre Viken Hospital Trust

Viken, Norway



Norway's BET Unit at Blakstad Hospital (BET seksjon, Blakstad Sykehus) provides services to people with complex mental health conditions, who have not benefited from other forms of mental health support. Rather than concentrating simply on symptom reduction, the psychosocial treatment model called Basal Exposure Therapy (BET) focuses on the acceptance of frightening thoughts, feelings and inner experiences as a way to self-regulate and cope with these existential challenges.

Primary classification: Hospital-based service

Other classifications:

Community mental he	alth centre 📃 Commu	nity 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		

Description of the service

The BET Unit is an independent model mental health unit that is part of, although physically separated from, Blakstad Hospital, a large urban psychiatric hospital in Asker, Norway. The BET Unit serves the wider community of the Vestre Viken Hospital Trust which supports other hospitals and medical centres covering a population of 500 000 in the region southwest of Oslo.

Previously part of the locked psychosis unit at Blakstad Hospital, in 2018 the BET Unit became an independent open-door service available 24 hours a day, seven days a week. The unit is equipped with six beds and provides treatment and support to an average of 6-10 people per month. The service has a total of 19.5 employees, including a psychiatrist and two psychologists (*108*). Treatment is organized as a work week, with a full day of group and individual sessions, physical activity, treatment planning and process meetings. Most individuals go home every weekend unless they live far away.

Typically, people referred to the BET Unit – by GPs, outpatient clinics and inpatient wards from other hospitals – have previously experienced numerous or lengthy intensive inpatient admissions, without improvement (*109*). Many have received multiple diagnoses, from psychosis to personality disorders, have experienced harmful substance use, repeated self-harm or suicide attempts, used multiple psychotropic drugs for prolonged periods of time, and been subject to coercive interventions in mental health services (*109, 110*).

The BET concept invites individuals to acknowledge and accept frightening thoughts and feelings, and manage them with new, more functional coping strategies, rather than relying on avoidance strategies such as self-harm, inactivity and hyperactivity, starvation and overeating, dissociation, and excessive use of legal and illegal drugs (*111*). Validating communication treats feelings as true and real, which allows people to acknowledge their emotions, and better regulate their own thoughts, feelings and actions. Therapists also help users develop basic skills that increase autonomy, such as reaching out for help before a crisis evolves (*108*).

Complementary External Regulation (CER) is one of the underlying principles of the BET concept, which aims to facilitate and consolidate functional choices and actions and to eliminate coercive measures from the care process. It relies primarily on the strategy of under-regulation, in which therapists interact with service users in a non-hierarchical manner, treating them as equals who are fully responsible for their own choices and actions (*111*). For example, individuals are free to leave the ward any time, but they are accountable for appearing at meetings and appointments. Staff do not remind people to eat or take medication – instead, there is constant acknowledgement and recognition that they are capable of making their own decisions. Conversely, over-regulation strategies may be used to prevent suicide and severe physical injury if a person does not respond to under-regulation strategies and repeatedly puts life and health in danger. Over-regulation is a coordinated approach in which care and attention provided by staff is intensified, but exposure to stimuli in the environment is reduced. It is carried out in a compassionate, cautious and respectful manner and in collaboration with the person concerned. This intervention mobilizes the person's resources and motivates them to resume therapeutic work to replace experiential avoidance with acceptance (*111*, *112*).

One unique feature of the BET Unit is the approach to reducing medications among hospitalized patients who are often heavy, long-term users of multiple benzodiazepines, opioids, antipsychotics, antidepressants and mood stabilizers. Apart from the beneficial health consequences of reducing medications, the BET Unit considers medications to be secondary to the psychotherapeutic approach particularly since certain medications may suppress emotions. Staff therefore help patients reduce or taper off, if they wish, in order to improve health outcomes and allow people to better access their feelings and fears as part of therapy (*110*). Tapering of medications is not mandatory, yet most patients being treated with multiple medications agree to reduce. The BET team often initiates this dialogue with the service user during the weeks or months prior to admission.

Core principles and values underlying the service

Respect for legal capacity

Because the BET service requires people to take responsibility for their own choices, all therapeutic steps are discussed with the service user in formal structured meetings to reach informed consent and decision-making. Service users are involved in drafting their own psychotropic drug withdrawal plan, for example (*113, 114*). The CER approach is solution-focused, and encourages people to make functional choices in order to regulate themselves. Service users are held fully accountable for their actions; they can for example choose whether to eat or not, and how they want to spend their leisure time (*115*). If acute medical attention is required, staff work with the person's declared will and preferences. In more severe cases of self-harm, and based on previous discussions, service users are treated on the assumption that they would have wanted medical attention.

Non-coercive practices

Therapy with a focus on accepting frightening thoughts and feelings is never forced upon the individual – it always is based on the person's choice (*111*). In the past two years, no coercive measures have been used in the BET Unit. Usually, the under-regulation approach effectively addresses the crisis, and re-establishes cooperation between the service user and staff. Team members at the BET Unit are also trained in the Management of Aggression Problems (MAP) framework which helps identify early signs of aggression and practice techniques of de-escalation and reducing risk of physical harm. A UN Special Rapporteur on the Rights of Persons with Disabilities in 2019 commended the service for demonstrating that it is possible to provide intensive care and support without the use of force and coercion (*116*).

Participation

People using the service participate actively in planning their own care and the BET Unit routinely collects feedback from them to improve service quality. Weekly psychoeducation groups are led by a person with lived experience as a member of the BET programme. A group of people with lived experience also is represented in the high-level decision-making in the Vestre Viken Hospital Trust. They participate in discussions and decisions on budgets, services and implementation, and organizational structure. Currently the BET Unit is working towards employing people with lived experience as full-time staff members.

Community inclusion

BET staff often help people find housing, return to work or school, or connect with peer networks or similar services in the community. The BET programme actively encourages the involvement of family and/or social networks, enabling people to remain connected with their community. Importantly, people are also encouraged to go home on weekends, in order to maintain community ties during the period that they receive treatment in the BET Unit.

Recovery approach

In its overall design and practice, the BET service promotes a holistic approach to health and treatment. In a study that described how the CER approach can contribute to reducing coercion in treatment, the authors concluded that, "an important component is … the introduction of a holistic treatment philosophy that emphasizes voluntarism, cooperation and autonomy" (112). Personal empowerment is central to the BET Unit's therapeutic process. Care is centred on the individual service user's goals and values which are identified and assimilated into a plan for treatment (115). Some service users may aim to be symptom-free, some to use less medication, while others simply want to reach a stage where they no longer require inpatient admission when in crisis.

Service evaluation

A growing body of evidence demonstrates that the use of coercion in treatment can be reduced by as much as 97% and that service users' quality of life and psychological and psychosocial functioning can be significantly improved. A retrospective study from 2017 found individuals who used the service had fewer admissions to psychiatric and general hospitals in the 12 month period after discharge from BET, compared with the 12 month period before admission (*115*).

One qualitative study of service users at the BET Unit found that participants displayed less symptoms, a significantly improved level of functioning and re-established connections with their families. Some even started their own families, and were engaged in education or work. Some stopped using medication altogether (*113*). Several users of the BET service have participated in qualitative studies and reported experiencing a normal life (*111*). As one service user recounts, "I had been told 'You have a serious mental disorder that can't be cured. You have to rely on medicine for the rest of your life.' And so, I went to the BET Unit, and got discharged without any diagnosis, with no medication, without anything" (*117, 118*).

Costs and cost comparisons

The BET service has been publicly funded for 20 years as part of the public health care system. The cost per person per day in the BET Unit is about 8 800 Norwegian kroner (approximately US\$ 1040)^h, which is about 30.40% less than costs of other mental health units at the Vestre Viken Hospital Trust. Lack of coercion, in fact, requires fewer staff to carry out intensive interventions such as one-to-one observation and other regulating measures. The BET Unit also has lower medication costs compared with other inpatient units. Importantly, the BET Unit benefits from a low sick leave ratio, with staff consistently reporting high levels of job satisfaction.

Additional information and resources

Website:

https://vestreviken.no/avdelinger/klinikk-for-psykisk-helse-og-rus/psykiatrisk-avdelingblakstad/bet-seksjon-blakstad

Videos:

Didrik Heggdal: What is Basal Exposure Therapy? Presentation in Norwegian, with English subtitles and chapter descriptions <u>https://www.youtube.com/watch?v=PXrdwOMznvs&t=10s</u>

Didrik Heggdal: Basal Exposure Therapy (BET): Alternative to coercion and control in suicide prevention. Presentation in English, National conference on the prevention of suicide https://youtu.be/fsfdrFoEhfQ

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h Conversion as of February 2021.
2.2.2

Kliniken Landkreis Heidenheim gGmbH Heidenheim, Germany



Kliniken Landkreis Heidenheim is the only general hospital located in Heidenheim, a small rural town in Baden-Württemberg, south-west Germany. In 2017 Heidenheim became a model region for mental health according to Section 64b of Germany's social code (SGB V), allowing for full flexibility of mental health services within an agreed yearly budget (119). This innovation allowed the hospital to introduce a flexible, user-oriented and community-based mental health service that has been described as a lighthouse model, particularly for its focus on the prevention of coercion.

Primary classification: Hospital-based service

Other classifications:

Community m	ental health centre	Community outreach	Veer support
Crisis service	Hospital-based	service Sup	ported living service
Availability in differe	nt locations:		
Yes	No No		
Evidence:			
Published liter	rature 🧹 Grey literature	None	
Financing:			
State health se	ector State social sec	tor 🗹 Health insu	urance
Donor funding	Out-of-pocket p	ayment	

Description of the service

The Kliniken Landkreis Heidenheim mental health service, officially known as the Department of Psychiatry, Psychotherapy, and Psychosomatic Medicine, was established in 1994 and serves the district's population of 130 000 as well as people from neighbouring districts. The service operates 24 hours a day, 365 days a year supporting people with more severe mental health conditions and is an essential part of the network of community mental health services (*Gemeindepsychiatrischer Verbund*) coordinated by the district council (*120*). All services are available without delay or waiting lists, including outpatient services, inpatient services, day clinics, and home treatment and support. People can flexibly change from inpatient to home-based treatment, or to day-based hospital care at any time. The will and preferences of service users form the basis of such changes and are discussed with the clinical team, service users, their families and support networks. Since the different services are closely aligned, and in fact, run by the same teams, a consistent recovery plan is followed even if a person moves between services.

There are three inpatient units for adults, with no diagnostic exclusions, and one day clinic. The service is managed by four teams; three dedicated to the inpatient units and one team dedicated to the day clinic. The service does not operate a separate home-based treatment team, as all four teams provide their own home-based treatment options. With 79 beds, the average length of stay is 21 days. Two of

the three units provide services for people who have received diagnoses such as depression, psychosis, dementia, personality disorders and trauma-related disorders. Service users are free to pick from the therapeutic activities offered, which include group and individual psychotherapy, peer support, social assistance, and art, dance/movement and occupational therapy. These services may also be provided through home visits on request.

The third inpatient unit provides for people with addiction problems and many of the above-mentioned diagnoses, on an inpatient or day clinic basis. A structured programme is provided for alcohol and drug dependency including individual and group therapy sessions, meetings with self-help groups and occupational therapy. For those at this third unit without addiction problems, there is a separate programme with individual and group therapy, as well as art, dance/movement and occupational therapy. Weekly peer support sessions are held on the wards, with individual service users or a small group of service users, family members and support networks.

Day treatment and support can be arranged in all three units. If a person prefers to be treated at home rather than being admitted to inpatient care, home treatment and support can start at any time and involves daily home visits by a nurse and weekly home visits by a doctor. Service users in the home treatment programme can access any other treatment or support the hospital offers, including occupational therapy and art therapy, at home or in hospital. The average length of home treatment and support is 28 days.

People who opt for outpatient services can access the whole range of therapy and support, in a group or individually. Four therapy dogs, owned by staff, also help people to feel comfortable in new environments. One therapy dog also joins a nurse who works in home treatment. People using the service often take the dog for a walk.

Core principles and values underlying the service

Respect for legal capacity

Although Kliniken Landkreis Heidenheim is obliged to provide for compulsory admission under mental health laws, the service tries to avoid compulsory admissions and treatment through partnerships with the community, service users and their families. Average rates of compulsory admissions in the service are less than one-fifth of those in Germany nationally – standing at 1.7% in comparison to 10.7% (*121*). Compulsory admissions are avoided by using supported decision-making based on will and preference, particularly when there is a risk of harm (*122-124*). The option of receiving home treatment has also contributed to the low rates of compulsory admissions. Significantly, acceptance of medication is not a condition for inpatient or home treatment.

With regard to medication, service users receive support from a social worker, medical professional or other person of their choosing, for informed decision-making concerning treatment without medication, with intermittent medication or with continuous long-term medication, exploring the pros and cons in the context of their individual situation.

The service also supports people who have previously experienced detention and or coercion (*125-128*). With help from the hospital team, peer support workers or lawyers (*126, 127*), service users formulate joint crisis plans and advance directives, anchored in the German Civil Code (*125*). These are incorporated into hospital records, to be readily available in a future crisis.

Non-coercive practices

Rates of coercive interventions are extremely low compared to the state average: in 2019, 2.1% of people using the service experienced coercive measures, compared to an average reported rate of 6.7% in Baden-Württemberg in 2016 (129). Everyone, including those detained in hospital, has the right to refuse medication, and forced medication is rare, requiring a separate application to the court and an independent expert opinion. During the period 2011–2016 no one was forced to take medication, and in the years since the rate has amounted to one person per year (121). Rapid tranquilization is never used without consent. The service does not seclude people at all, and during daytime hours the wards remain open. Inpatient units are locked from 20:00 to 08:00 to meet State law requirements.

Various strategies are used to prevent the use of coercive practices. For example, those legally detained can receive one-to-one support from a nurse, therapist, doctor or social worker, who may remain with the person almost continuously for several hours, a night or even several days (130). The service also helps users create joint crisis plans to prevent coercion (126). All hospital staff are trained in de-escalation techniques and the prevention of aggressive incidents and coercive measures, using the Prevention, Assessment, Intervention and Reflection (PAIR) manual (131, 132). For particularly intense crises, a response team consisting of two nurses and a doctor trained in the PAIR method (131, 132) can assist.

Community inclusion

Home treatment and support help keep people who are experiencing psychosocial distress connected with their community. To support community inclusion, the service has direct links with religious communities, self-help groups, support groups for homeless people, unemployment agencies, and charities supporting the elderly, the isolated and those with addictions. It also supports a charity, *Schritt für Schritt*, facilitating leisure activities for people with psychosocial disabilities. The service meets on a regular basis with the local courts, police, the local public health agency and public order authorities to work on non-discriminating practices and collaboration. Further, it has developed the *Irre* Gut school prevention project – an initiative which sends a small team comprising a service user, a person with lived experience who is a family member, and someone working in mental health services such as a nurse or social worker, to visit secondary schools to talk about stigma, prevention, self-help and access to mental health services (133).

Participation

Peer-to-peer counselling and support (134) is provided via individual and group sessions held weekly on the hospital wards. Service users can share their experiences and seek confidential advice on medication, their diagnosis, as well as discrimination they may face, with peers as well as hospital team members. Peer support workers also provide advice on how to access services and file complaints. Some even assist service users who want to prepare their own food while in inpatient care. Peer support workers and designated family members of people with mental health conditions also meet with the service management team at the hospital to review and discuss improvements to the service. While the service does not systematically collect feedback from service users, several distinct complaints procedures are in place, within the hospital, the community mental health network, through the public health insurance system and the regional medical regulation body (*135-138*).

Recovery approach

Home treatment teams use the Open Dialogue model (as discussed in section 2.1.3), which has also been introduced for the inpatient service where it is currently being integrated. Within this approach, service users work with their support network and families, to set the agenda and recovery plans based on the wishes and preferences of the service user. Support network meetings can be held too; these are summarized in case notes and in the personal notes of the service user. An open recovery meeting, (139) takes place away from the hospital in a setting such as a community centre, once a month. Here service users, family members and hospital staff meet to discuss individual paths and obstacles to recovery. Meetings are open to the public. Informal meetings may also be held at venues such as pubs.

Service evaluation

The service has gradually transformed from a traditional hospital department of psychiatry to a community mental health service (140). The eva64 evaluation project conducted by Dresden University (141), found that with the introduction of home treatment and flexible day-clinic treatment, average bed occupancy decreased from 95% in 2016 to 60% in 2019 and to 52% in 2020 (142). Fewer people are admitted to the inpatient service; more are seen in the outpatient clinic or are supported through the home outreach service.

The service continuously monitors the use of coercive measures and involuntary treatment and provides its data into the region-wide register of coercion in psychiatric institutions (143). Collecting data on coercive measures in psychiatric hospitals and supplying this data to a central register has been mandatory in Baden-Wüerttemberg since 2015 (121). Importantly, when involuntary medication in psychiatric hospitals in Germany was outlawed for a brief period of time between 2011 and 2013, the Heidenheim hospital service did not record an increase in other forms of coercion or an increase in the use of medication overall, while other services found it more challenging to cope with this temporary ban (129, 143, 144). In terms of other criteria such as the frequency of detention, frequency of restraint/seclusion, and frequency of compulsory medication, rates are below average as well (121). In 2018, Baden-Württemberg's Ministry of Social affairs stated: "... the Heidenheim Hospital department of mental health is a lighthouse project in relation to coercive measures according to the mental health act" (145).

Costs and cost comparisons

As a model region, the service has entered into a contract with all public and private health insurance companies which made it eligible for a yearly budget amounting to $\notin 9.2$ million in 2019 (142), (approximately US\$ 10.9 million)ⁱ or about $\notin 69.50$ (US\$ 82.50)ⁱ per district resident per year. This budget created incentives for providing treatment and support in the community rather than the hospital. The budget increases annually in line with increments in wages agreed between unions and public health care providers. The contract is fixed-term for the years 2017–2023 with an option to renew for a further eight years. Public and private health insurance covers all treatment options. The services are provided free of charge to people using the service.

i Conversion as of March 2021.

j Conversion as of February 2021.

The hospital's fixed annual budget and its status within a government-designated model region, means that it can rely upon a sustainable funding flow. The hospital is owned by the district council and has been strongly supported by the population, even when public finances have been strained (146). Since 2017, moreover, the hospital's financial costs have been successfully contained (141).

Additional information and resources

Website:

https://kliniken-heidenheim.de/klinikum/patienten/kliniken/psychiatrie-psychotherapie-und-psychosomatik/

Videos:

Mildere Mittel. A film about the experience in Heidenheim, made by a service users' collective from Berlin. (German language) <u>https://vimeo.com/521292563</u>

Contact:

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2.2.3 **Soteria** Berne, Switzerland



Soteria Berne, operating since 1984, offers a hospital-based, residential crisis service in the city of Berne as an alternative option for those experiencing so-called extreme states, or have a diagnosis of psychosis or schizophrenia. In Greek mythology, Soteria was the goddess of safety and protection. Similarly, Soteria Berne aims to offer a low-key, relaxing, low-stimulus, home-like and 'normal' environment to produce as little stress as possible. As the network of Soteria Houses expanded in other countries, a set of common practices and principles was developed and maintained for those bearing the Soteria name.

Primary classification: Hospital-based service

Other classifications:

	Community mental healt	h centre	nity outreach	Peer support
\checkmark	Crisis service	Hospital-based service	Supported livi	ng service
Availa	bility in different location	IS:		
\checkmark	Yes No			
Evide	nce:			
\checkmark	Published literature	Grey literature	None	
Finan	cing:			
\checkmark	State health sector	State social sector	Health insurance	
	Donor funding	Out-of-pocket payment		

Description of the service

Soteria Berne has the legal status of a specialized public psychiatric hospital and is integrated with two other psychiatric services in Berne (147), however its approach differs significantly from the city's other psychiatric inpatient and outpatient services. Soteria Berne offers an integrated care approach to people living through a psychotic episode, modelled on the first Soteria house, which was founded in 1971 in San Francisco, USA. Then and now, Soteria was based on the philosophy that, "being with" or being accompanied during a crisis, coupled with a small and supportive, non-hospital, family-like environment (147-149) with low or no medication, can produce similar or even better therapeutic outcomes than hospital methods. In contrast, hospital environments can be counter-therapeutic for people experiencing an episode of psychosis due to their high levels of stimuli, changes in staff, rigid rules, absence of privacy and lack of transparency, especially in treatment decisions.

The Berne Soteria House is based in a residential area with 10 bedrooms for individuals and two team members (*150*). Residents, referred from services in Berne and the neighbouring canton, usually stay from seven to nine weeks, and up to three months. On average 60 people stay at Soteria House annually (*151*). Team members include two psychiatrists and a psychologist, mental health nurses, educational workers and an artist. People with lived experience are particularly encouraged to work at Soteria, and are referred to in Switzerland as people with "experienced involvement". Team members work in

shifts over 48-hour periods without interruption to ensure continuity and immersion in the daily life at Soteria House (152).

Over 90% of people experiencing psychosis can be treated at Soteria (152), however, people considered to be at very high risk of suicide or extreme harm to self or others are not accepted, unless the risk level diminishes (153). Today people can be admitted either by planned entry or emergency admission at any time of day or night (154). A referral from a doctor or hospital is not always required; individuals, family members or therapists may contact Soteria directly to seek admission (155). Family and relevant others are involved in the treatment process from beginning to end and have monthly meetings with team members (156, 157).

Support in Soteria house is divided into three phases. The first phase of support is about anxiety resolution and emotional relaxation during the acute psychotic state, in the so-called soft room – a low-stimulus, calm and comfortable environment. The second phase of "activation and realism adjustment" supports gradual integration into normal everyday household activities once the crisis has lessened. Finally, in the third stage people gradually reinsert themselves into the external world, with preparation for social and professional integration and planning for relapse prevention.

Daily life in the house is organized by the service users together with the team members to create a reality that doesn't only focus on mental health issues. Psychotherapy, cognitive therapy and sometimes a more psychodynamic approach are all used as therapeutic tools. In 2018, the Open Dialogue approach was introduced (as discussed in section 2.1.3) – during a weekly "treatment conference" a person reflects on the past week with team members, and focuses on next steps or aims in treatment. Once they depart, service users can opt for an outpatient after-care service (*150*) provided by Soteria House, including an onsite day care centre and full outpatient home support (*158*). Soteria House also offers a supervised apartment in the city centre to support two to three people transitioning to independent living, for up to two years (*159*).

Core principles and values underlying the service

Respect for legal capacity

Preservation of personal power is a key element of the Soteria approach, reflecting an alignment with the protection and promotion of individuals' legal capacity. Informed consent is always obtained when people enter the service. The international Soterity Fidelity Scale, the code of common principles adopted by the international Association of Soteria Houses worldwide, refers to "co-determination during treatment" (*160, 161*), which means that decisions about therapeutic goals are actively developed by the person themselves, in conjunction with the treating team. No treatment is given without explicit agreement. By completing a questionnaire on vulnerability to psychotic symptoms, service users can develop their own explanatory model of why they have developed psychosis and how their life experiences might have fed into this. Service users also complete a questionnaire on relapse prevention, which is essentially an advance directive in which people identify their early warning symptoms ahead of crisis and list people they can trust, strategies that are helpful and hospitals they might prefer.

Supported decision-making is facilitated by Soteria's "being with" philosophy, which means an emphasis on spending time with the person until they can make a decision independently. This philosophy pertains to all activities, such as choices about meals, coping with the effects of medication, when and how to leave the house, and how to access financial support and housing.

Non-coercive practices

Soteria Berne is a voluntary service, which means only those willing to enter the service attend. A core principle of the Soteria house is that "all psychotropic medications [are] being taken by choice and without coercion" (*162*). Although staff are not specifically trained in non-coercive techniques, restraint and force are never used. There are no isolation rooms in Soteria, but a "soft room" is used when a person is experiencing acute psychosis, so the team members focus on de-escalating the crisis by providing the person with a secure environment where they can feel safe and rest. When no working alliance can be established, or when treatment cannot continue for any reason, a person can make alternative arrangements for themselves, or they can be referred by the Soteria team to one of the local psychiatric hospitals. This is rare and happens on average two to three times a year (*163*).

Community inclusion

Performing everyday activities in a therapeutic setting and recovering in a "normal" environment is seen as a key empowering therapeutic tool for those experiencing psychosis, so all tasks relevant for independent living in a community, such as cleaning and cooking, are performed by residents. The second and third phases of treatment, and later outpatient support, are designed specifically to allow patients to create links with the community. Soteria House is just 20 minutes' walk from the city centre. Family and friends have constant access to the house, and residents are free to come and go, so there is no barrier or feeling of isolation from the community. Team members also discuss with each resident their future projects such as employment or living independently. Staff facilitate connection with community services, support and organizations, help residents build positive relationships in the community or even help set-up working arrangements so that residents can keep a job that is fundamental to recovery" (*158*).

Participation

Soteria House connects current residents with former residents through peer support meetings. A team member with lived experience establishes links between service users and peer networks in the community and moderates a cannabis and psychosis group and a recovery group. A group of former residents and a peer support group meet every month. There are also plans to allow people with lived experience to participate in high-level decision-making in Soteria Berne.

Recovery approach

The recovery approach is explicitly stated as one of Soteria Berne's core eight principles and is an integral part of practices and underlying philosophy. Soteria's recovery approach is centred in developing a person's hopes and goals rather than focusing purely on symptoms. Taking the view that there is meaning to be found in a crisis helps normalize feelings, actions and thoughts in the acute phases of psychosis. With help, residents create individual recovery plans regarding health, housing, work, finances, leisure that systematically capture their hopes, worries, goals, and strategies for dealing with difficult situations and staying well. Finally, Soteria Berne's guiding principles are aligned with the recovery model in that non-medical staff support each resident's personal power, involvement of their social networks and their communal responsibilities.

Service evaluation

Soteria House systematically collects feedback from service users to improve service delivery. Each service user completes a questionnaire before discharge, organized by the National Association for Quality Development in Hospitals and Clinics (ANQ) (164). Questions address subjects including the quality of Soteria's professionals and the information provided to residents regarding areas such as medication, preparation of discharge and whether service users have ample opportunity to ask questions and are satisfied with the answers provided. Recent ANQ data on key quality indicators for inpatient care, rates service user satisfaction at Soteria House "above average" compared to other participating hospitals (165, 166). Previous internal evaluations also showed user satisfaction regarding treatment success, staff interactions, support received and inclusion of external support networks (167). Annual professional surveys of mental health services consistently rate Soteria above the Swiss national average.

Several research studies have found that Soteria is at least as effective as traditional hospital-based treatment, but crucially, with much lower levels of medication such as antipsychotics (*168-170*).

Costs and cost comparisons

Soteria Berne has the legal status of a public psychiatric hospital financed by the Swiss health system and health insurance that all Swiss residents are required to have (170). Soteria is allocated 673 Swiss francs per day (US\$ 740)^k for each person using the service; 55% from the Canton of Berne and 45% from insurance providers. In 2020, the cost of a stay at Soteria Berne was reported to be 6-8% lower than that of comparable psychiatric hospitals in the city for people going through psychotic episodes. Such cost savings are aligned with findings at the US Soteria House as well (169, 171).

Additional information and resources

Website:

Soteria, Berne, Switzerland <u>www.soteria.ch</u> The international Soteria network, <u>https://soteria-netzwerk.de/</u>

Videos:

Einhornfilm, Part 1 - Soteria Berne - Acute (English Subtitles 1/3) https://www.youtube.com/watch?v=_fMoJvwMZrk

Einhornfilm, 2 Teil - Soteria Bern - Integration (English Subtitles 2/3) <u>https://www.youtube.com/watch?v=8ilj7BcS7XU</u>

Einhornfilm, Part 3 - Soteria Berne - Conversation (English Subtitles 3/3) <u>https://www.youtube.com/watch?v=Ggvb_ObrVS8</u>

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k Conversion as of February 2021.

2.3 Community mental health centres

Community mental health centres provide care and support options for people with mental health conditions and psychosocial disabilities in the community. These centres are intended to provide support outside of an institutional setting and in proximity to people's homes.

The range of support options provided in these centres varies depending on size, context and links to the overall health system in a country. However, all of the good practices showcased in this document provide consultation services, including individual or group sessions in which a person can be supported to begin, continue and/or stop different forms of care such as counselling, therapy, or medication.

To support the people they serve, these services also emphasize the importance of social inclusion and participation in community life, and take actions to achieve these goals. In this context, peer support, and support in accessing employment and training opportunities, education, and social and leisure activities are important features. Many mental health centres actively take on a coordinating role in referring people to different services and supports in the community. The examples provided in the following section reflect the diversity of some of these different roles and activities.

It is important to note that all mental health centres showcased in this section take a holistic, personcentred approach to care and support, attempt to reduce power asymmetries between staff and the people using the service, and consider support beyond medical treatment.

In some countries, these community mental health centres are a fundamental pillar in the mental health system. Not only do they provide essential, community-based care and support, they also serve as a cornerstone for coordination and continuity of care. Ensuring that they provide care and support that is community-based, rights-oriented and focused on the recovery approach is therefore paramount.

2.3.1 **Aung Clinic** Yangon, Myanmar



The Aung clinic is a community-based mental health service located in Yangon, the largest city in Myanmar. With support from the Open Society Foundations, the clinic provides an extensive range of support activities for people with mental health conditions and psychosocial disabilities – from emergency drop-in services to long-term therapy, peer support, advocacy and vocational activities. The service is based on a holistic, person-centred philosophy of care. It supports over 200 individuals and their families per year and is the only service of its kind in the country.

Primary classification: Community mental health centre

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

Description of the service

As one of the poorest low-income countries in Southeast Asia (172), state mental health services in Myanmar are limited. Some 75% of the mental health budget goes to hospital care (173, 174). At the same time, decades of internal ethnic and political conflict have taken a high toll on the population's mental health (175) and people with disabilities face high levels of stigma and discrimination (176).

Aung Clinic receives clients regardless of diagnosis – including people suffering from PTSD, psychosis, bipolar disorder, depression and substance use. The clinic is open daily for clinical treatment and provides outreach services to individuals and families, with follow-up by telephone and online support if needed. Emergencies are responded to outside of regular hours and on weekends.

People are welcome to attend during the day, including those who are homeless, but there are no overnight stays. By spending daytime hours at the clinic, people in crisis are often able to avoid hospitalization. Anyone can attend the clinic, but people intoxicated with drugs or alcohol are excluded while intoxicated.

The clinic team is composed of a psychiatrist and medical doctor who is also an art therapist, as well as five paid peer support workers. People who attend the clinic are first assessed by the psychiatrist and a treatment plan is developed with the person, in line with their preferences. External support networks are involved in the therapeutic process where possible (including family and close friends), with the consent of the person using the service.

As well as assessments, the clinic provides individual counselling, group therapy, medication, vocational skills training and peer support groups for service users and their families. Talk therapy, family therapy and mindfulness are all used. The clinic also focuses on helping service users and their families understand their rights under state law, and advocates for the rights of people with mental health conditions and psychosocial disabilities, working closely with schools, employers, and local organizations to make sure service users can participate in all aspects of life. Art therapy is also used in the clinic (177), and art exhibitions allow service users to sell their work (178). There is also a weekly cooking club, and support for training in literacy, mathematics, basic money management, and carpentry.

The clinic collaborates with local government services and NGOs in Yangon, including the Myanmar Autism Association (*179*) and Future Stars (*180*), which supports individuals with intellectual disabilities and their families. It also trains health workers associated with the large non-governmental primary health care network called the Back Pack Health Worker Team (*181*), which employs 456 mobile health workers and serves vulnerable and displaced ethnic minority communities around the country.

Core principles and values underlying the service

Respect for legal capacity

Through its therapeutic activities, Aung Clinic seeks to empower people who would otherwise be at risk of institutionalization. Service users are encouraged to make their own choices and decisions about which treatments will be provided as part of their care plan. Medication is only administered with prior consent, and non-medical interventions always remain fully available. People are helped to reduce the amount of medication they are taking if they are experiencing disabling side-effects, and sometimes are able to cease taking medication altogether.

Aung Clinic recognizes that the power differential that can exist between staff members and service users has the potential to influence decisions. Staff members are trained to recognize such dynamics and reduce them. People are encouraged to express their will and preference during peer support groups, which is documented to ensure that treatment and support provided is consistent with their wishes.

Non-coercive practices

All clinic services are offered on a voluntary basis. No coercion is used, and people are not forced to take medication or undergo any intervention without their consent. Staff are trained to use de-escalation measures to avoid the use of coercion and forced hospital admissions. In the event that a patient is at risk of hospitalization, the staff work very hard to find non-hospital outcomes. If admission is inevitable, they strongly advocate against coercion and strive to have the person discharged as quickly as possible.

Community inclusion

A large part of the Aung Clinic's work focuses on advocacy and community capacity-building to ensure that people with mental health conditions and psychosocial disabilities are not discriminated against in education or employment. The clinic helps service users find work by engaging with families and communities and advocating for people to be employed or re-employed. In post-conflict areas, the service helps to build positive relationships in the community by participating in local development and political dialogues, creating the conditions for improved employment, educational and other opportunities for people with mental health conditions.

Participation

Informal feedback is actively sought from people who use the service and is then used to inform practices. An active peer support group of about 30 members helps participants learn to articulate their wishes and preferences, promoting a culture of empowerment. A family peer support group also meets monthly. Peer support workers are trained in basic counselling skills and are now part of Aung Clinic's decision-making processes. Female members of the peer support group also lead advocacy activities on women's rights. Through the work of these groups, people attending the clinic and their families learn their rights under the CRPD and are supported to advocate for better treatment.

Recovery approach

Recovery plans involve development of short- and long-term goals, crisis planning, family input, medical input, and defining the specific therapeutic approaches to be used. Through this process the service seeks to identify and work with an individual's strengths to help the person regain a sense of control over their life. To promote a sense of personal responsibility and help develop a positive sense of identity, the clinic supports people to find a role for themselves in society. Through learning to communicate more easily and with more confidence, people attending the clinic find a sense of empowerment, meaning and hope.

Service evaluation

An unpublished 2020 qualitative evaluation of 20 participants reported positive gains from attendance at the clinic, and particular value was placed on the art therapy and group therapy sessions. Service users spoke of finding acceptance at the clinic and feeling more able to manage mental health conditions since attending (*182*).

Costs and cost comparisons

The Aung Clinic is a non-profit service and its services are provided free to users. It opened in 2010 without external funding and expanded in recent years with funding from the Open Society Foundations. Between 2015 and 2016, the Aung Clinic received US\$ 25 000 from the Open Society Foundations (*183*) and in October 2018, it received US\$ 176 000 for the period ending September 2020. Recognizing that some individuals may be able to afford its services, Aung Clinic is now considering a sliding scale payment structure; however, sustainable funding of the clinic remains an ongoing challenge.

Additional information and resources

Website:

https://www.aungclinicmh.org/

Videos:

Myint Myat Thu. Healing Images: Exhibition Showcases Works by Art Therapy Patients. 2019. (In Burmese): <u>https://burmese.voanews.com/a/myanmar-mental-health-arts/5487323.html</u>

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2.3.2

Centros de Atenção Psicossocial (CAPS) III

Brasilândia, São Paulo, Brazil



Situated in the Brasilândia region of São Paulo, an area with a high concentration of favelas and population of 430 000, CAPS III Brasilândia provides individualized and comprehensive support to people with severe or persistent mental health conditions and psychosocial disabilities, including during crises. In an area marked by high levels of urban violence and social vulnerability, the centre uses a rights-based and people-centred approach to psychosocial care. Key principles guiding the service include: promotion of autonomy, addressing power imbalances and increased social participation. The service is provided under Brazil's unified public health system – Sistema Único de Saúde (SUS).

Primary classification: Community mental health centre

Other classifications:

	Community mental hea	Ith centre	Commur	nity outreach		Peer support
\checkmark	Crisis service	Hospital-bas	sed service		Supported liv	ving service
Availa	bility in different locatio	ons:				
\checkmark	Yes N	0				
Evide	ice:					
\checkmark	Published literature	Grey literatu	ire	None		
Finand	cing:					
\checkmark	State health sector	State social	sector	Health	insurance	
	Donor funding	Out-of-pock	et payment			

Description of the service

Community-based mental health centres, known as *Centro de Atenção Psicosocial* (CAPS), are the cornerstone of the community-based mental health network in Brazil (184). CAPS are specialized services of medium complexity, which are well integrated at the primary care level. There are various types of CAPS with some serving primarily adults and others focused on children and adolescents. CAPS III services cater for adults as well as children and adolescents and provide 24-hour service in areas with a population greater than 150 000. Additional detail on the different types of CAPS is provided in section 4.1.1. These services, which exist throughout Brazil, act as a direct substitute to the role traditionally provided by psychiatric hospitals.

CAPS III Brasilândia began operations as a CAPS II in 2002 and became a CAPS III service operating 24 hours a day, seven days a week, in early 2020. The service is managed by the Family Health Association (*Associação Saúde da Família*), a social organization. Like all CAPS III facilities, the centre provides continuous, tailored community-based mental health care and support, including crisis services. It develops values-driven actions based on the principles of freedom first and deinstitutionalization.

The service links with community-based primary health centres (*Unidade Básica de Saúde*) and their Family Health Teams (185), along with Family Health Support Centres (*Núcleo de Atenção à Saúde da*

Família (NASF)) (186) – multidisciplinary teams with specialist expertise including in the area of mental health. This integration between primary health and mental health care networks within the context of Brazil's universal health care system adds special value to the service for users, family members and professionals (186). A strong community focus is also integral to the CAPS III Brasilândia approach – involving everything from liaison with community businesses and sports, to advocacy and outreach.

CAPS III Brasilândia is designed to create a structure and environment similar to that of a house. Structurally, the centre has indoor and outdoor common areas for socializing and interacting with others, a dining area, individual counselling rooms, a group activities room, pharmacy, and female and male dorms, each with four beds, where people who are in crisis or need respite can stay for up to 14 days. The centre also holds activities and events in the community using public spaces such as parks, community leisure centres and museums.

The centre has 58 staff members including psychiatrists, psychologists, occupational therapists, nurses, social assistants, pharmacy staff and administrative staff. Approximately 400 individuals attend the centre on a regular basis each month, and on average, 60 new individuals attend first consultations per month. There is no restriction on who can use the service, and no one is refused access based on capacity – if full, the centre links with other CAPS III services for accommodation. The centre does not refer people to psychiatric hospitals.

Once registered as a CAPS user, a person using the service develops an individual care plan (*Projeto Terapêutico Singular* (PTS)) with their reference practitioner (184, 187). The PTS maps a person's history, needs, social and support network, diagnostic hypothesis, personal challenges, strengths and life goals. The PTS is regularly reviewed by the reference practitioner and the team members who work most consistently with the service user. Team members support service users in many other ways, from mediating conflicts to accompanying them to certain meetings or activities.

Five rights-oriented working groups support the centre's work, four of which involve service users. They are based on the centre's guiding principles and include an art and culture working group; a housing group linked to supported independent living facilities (*Serviços Residenciais Terapêuticos* (SRT)); a work and income generation group; a crisis working group; and a territory-community group which identifies and provides links to welcoming community services and promotes community inclusion cultural initiatives.

Core principles and values underlying the service

Respect for legal capacity

The centre supports service users to exercise their legal capacity in everyday life, promoting individual autonomy and independent decision-making. Recognition of citizenship and affirmation of individuals' rights are central issues for CAPS. Attendance is fully voluntary and based on the principle of freedom first; individuals cannot be referred to the centre or receive treatment without their consent.

Non-coercive practices

The avoidance of coercive practices is a key principle of the CAPS model. Seclusion has never been used at CAPS III Brasilândia. Efforts to avoid coercive practices are supported by an everyday focus on power imbalances and its consequences. When they occur, the centre identifies solutions. For example, while confidentiality is protected, there is no place in the centre that service users cannot enter or use, including the staff room and its facilities.

All support and care strategies, including medication, are discussed and mutually agreed with the individual involved. If an individual does not wish to take medication, other care strategies, such as daily home visits, can still be offered. An individual in crisis is never referred to another service where coercive practices could be used and the crisis working group is available to provide additional support if required. However, during the period February 2019–February 2020, restraints were used three times, for less than one hour in each instance, and a team member remained with the individual during that time. After each occurrence, the service met to identify where and why the service had failed.

Community inclusion

At an individual level, service users are supported to actively identify their community inclusion goals in their PTS. The territory-community working group identifies positive community locations, such as welcoming cafes or groups, that support an individual's inclusion in their community. At a wider community level, CAPS team members engage with people in the community to understand the social dynamics, mapping the frequent problems that most impact people's lives and mental health. Community resources (community leaders, parks etc.) are identified and partnerships with people and services developed to carry out mental health care initiatives. CAPS working groups also raise awareness of the centre and hold events aimed at reducing stigma. To improve social engagement, the centre proactively builds relationships with local businesses, institutions and services.

Participation

The service has a daily morning meeting that allows service users to discuss the day ahead and decide if the planned activities need adjustment or if other activities would be more interesting. A weekly assembly is attended by approximately 60 people including service users, family members and professionals, which allows people to express their point of view about service practices and guidelines, identify problems and find common solutions. It is also an opportunity to deal with power imbalances and to discuss common social problems, such as stigma and violence. Service users take an active role in leading groups, including the Hearing Voices group and peer support group meeting. These activities are organized by service users with the support of team members. As with all other CAPS centres, service users can participate in the Management Council, a consultation group for high-level public policy decisions developed in all health services under the SUS.

Recovery approach

Through developing their personal PTS, individuals take an active role in developing their own personcentred recovery plan. They are supported in identifying their needs and wants, life projects are discussed and care and support strategies with shared responsibilities are agreed. The process is rights-oriented and based on deinstitutionalization values to empower people to take charge of their own recovery process and to enhance social participation (188). The active community nature of CAPS also ensures that an individual's recovery journey is concretely supported beyond the centre itself. By creating positive social opportunities and by supporting a person in daily life, the centre supports and equips that person to actively and autonomously lead their lives in the community.

Service evaluation

Since 2002, a total of 12 333 people have used the CAPS III Brasilândia service. A 2009 study conducted by Campos et al found that service users and their families have high levels of confidence in CAPS III services, both in the support of crises as well as in psychosocial rehabilitation (189). A 2020

evaluation of CAPS III Brasilândia found that the services offered are consistent with a human rights and recovery-oriented approach (190). The centre was assessed using the World Health Organization's QualityRights assessment tool kit (191) and was found to have a comfortable and clean, home-like atmosphere, including a large outdoor space. Individuals who used the service were supported in both their mental and physical health through person-centred recovery plans, provided by a multidisciplinary staff and complemented by service and community initiatives. Admission and treatment were based on an individual's informed consent. The evaluation found no reports of violent or disrespectful incidents in the previous year; seclusion and restraint were not accepted practices in the service and processes were in place to avoid their use. Regular meetings were held to prevent any instances of abuse. In firsthand observations of the service, the evaluation found that the crisis working group and the availability of beds during the night provided effective support to people in severe distress. The service also was found to promote community participation, including supporting individuals to access housing, work, income generation activities, and/or income support.

Costs and cost comparisons

CAPS services are delivered and funded under the SUS with no cost to users. Operational costs are covered by the federal government (50–70% of total cost of service) with the remaining amount provided by the municipality. In 2020, CAPS III Brasilândia cost around R\$ 500 000 (approximately US\$ 88 200) ¹per month, or R\$ 1100 (approximately US\$ 200)^m per user, per month. In comparison, the per day cost of hospitalization in a psychiatric hospital in Brazil is approximately R\$ 1200–R\$ 2400 (US\$ 210–420) m (192). However, given the wider CAPS initiatives in mental health promotion and prevention, including activities to combat stigma and prejudice and support community inclusion, those benefiting from CAPS outnumber those who access the service directly. This benefit cannot be quantified.

Additional information and resources

Website:

https://www.prefeitura.sp.gov.br/cidade/secretarias/saude/atencao_basica/index.php?p=20424

Videos:

Projeto coletivo de geração de trabalho, renda e valor - Ô da Brasa (Work, income and values generation collective project - Ô da Brasa) <u>https://www.youtube.com/watch?v=5v0jki3GaBw&feature=youtu.be</u>

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m Conversion as of February 2021.

2.3.3

Phoenix Clubhouse

Hong Kong Special Administrative Region (SAR), China



Phoenix Clubhouse is part of a large international network of Clubhouses around the world linked to Clubhouse International. Clubhouses provide community-based vocational and educational support to people who have used mental health services, and incorporate a significant element of peer support. They are independent social enterprises linked by core principles including the right to have a place to gather, meaningful work, meaningful relationships and the right to a place to return (193).

Primary classification: Community mental health centre

Other classifications:

Community mental he	ealth centre Comm	unity outreach	Peer support
Crisis service	Hospital-based service	e Supp	orted living service
Availability in different locat	ions:		
Ves	No		
Evidence:			
Published literature	Grey literature	None	
Financing:			
State health sector	State social sector	Health insu	rance
Donor funding	Out-of-pocket paymen	t	

Description of the service

Operating since 1998, Phoenix Clubhouse is a long time member of Clubhouse International, which includes a network of 326 Clubhouses in 36 countries (194, 195). Clubhouses aim to provide opportunities for people with mental illness to live, work, and learn together while contributing their talents through a community of mutual support. They help people stay out of hospitals while achieving their social, financial, and vocational goals (196). All Clubhouses undertake a formal accreditation programme and adhere to the International Standards for Clubhouse Programs^M (197). These best practice standards include all aspects of the operation of a clubhouse, including membership, the physical structure, location, daily functioning, access to employment and education, funding, and governance. Clubhouse International offers a comprehensive training programme which delivers a consistent approach to the functioning of Clubhouses, delivered through 12 authorized training centres globally. In 2016, Phoenix Clubhouse became a Clubhouse International Training Base (198) and has so far trained 21 organizations, of which one quarter have so far received full accreditation (199).

Of great importance to the Clubhouse Model is the fact that the people using the service are considered members, rather than service-users. Membership of the Clubhouse can be lifelong, which encourages a sense of ownership and long-term commitment on the part of those who use the Clubhouse. Longer term members of Clubhouse are able to support newer members on their journey. Phoenix Clubhouse members are people with a mental health condition or psychosocial disability between the ages of 18

and 64, who have been referred by psychiatrists at Queen Mary Hospital or private psychiatrists. There are no exclusion criteria, unless the person is considered a significant and current threat. The service currently has nearly 600 members, 150 of whom are active members, in that they use the service at least once a month. The average attendance level is 54 members per day (*200*).

Phoenix Clubhouse has a total of nine staff members: three are professional staff deployed from the Occupational Therapy Department of Queen Mary Hospital, and six are general staff with care or administration-related experience. A group of volunteers also supports the work of the Clubhouse, assisting with in-house training and social programmes.

The Phoenix Clubhouse programme is based around a "work-ordered day" allowing members to work alongside staff on tasks essential to the day-to-day operation of the clubhouse, acquiring important vocational and educational skills (*201*). Its members participate in consensus-based decisions regarding all important aspects of the running of the service. Opportunities for paid employment in the local labour market are created through a structured vocational rehabilitation programme which includes a Transitional Employment Programme, which is part-time, entry level work closely accompanied by staff; a Supported Employment Programme offering part- or full-time employment with onsite and offsite support; and Independent Employment. The service also provides supported education opportunities, it organizes evening, weekend and holiday social and recreational programmes, and provides a wellness and healthy lifestyle education programme. Finally, the Clubhouse provides assistance as needed in securing safe, decent and affordable housing.

Psycho-social treatment services are not provided at the Clubhouse per se, but staff help members create a personal recovery plan and on request help to arrange meetings with psychiatrists, nurses and medical social workers and any other relevant medical facilities, such as primary care (*202*). The service facilitates access to immediate mental health intervention and other health services if needed.

Core principles and values underlying the service

Respect for legal capacity

Membership of Phoenix Clubhouse is voluntary and without time limit. The service promotes a culture of members being in control, and their choices are fully respected. Although members are encouraged to work, there are no mandatory activities, rules or contracts, and members are never forced to work. Members often choose to be assisted with decisions about their lives by other members and staff, based on relationships of trust that develop naturally. They are also supported in their interactions with clinical teams in the public mental health system outside of the Clubhouse. All recovery plans, advance plans and staff observations are captured electronically and can be shared. Members are free to disagree with observations and document disagreements.

Non-coercive practices

The culture of the Clubhouse emphasizes positive relationships between members and staff, with the idea that they are akin to friends, teammates, siblings or mentors. Force is never used; there is no use of seclusion or restraint. Mediation and de-escalation methods are used when needed, and staff are trained in crisis management. Members can freely decide whether to use prescribed medication or receive treatment such as counselling and psychotherapy. Staff explore the pros and cons of interventions with members and discuss management of the condition and relapse prevention. Any decision to involuntarily admit a person to hospital is made by the Accident and Emergency Department, and does not involve Clubhouse staff or members.

Community inclusion

The Clubhouse model strongly promotes community engagement. Members live in the community and Phoenix Clubhouse supports them to access community resources including health and social services, recreational activities, wellness and Chinese medicine clinics, university education and adult education programmes, as well as employment opportunities with local businesses and employers. Information is provided to members concerning the rights of employees with disabilities, statutory minimum wages and disability discrimination. Members are also offered advice on financial issues and social assistance available to them. Staff also offer support to find housing; however, decisions on where to live, and with whom, are always left to members.

Participation

All Clubhouse meetings are open to both members and staff. Responsibility for the operation of the Clubhouse also lies with both the members and staff (197). Members are involved in all decisions about Clubhouse policies, programmes and services, and in planning future development directions. They participate in the hiring of new staff and evaluation of their work. Members also sit on the Advisory Committee and on all working committees.

Recovery approach

Clubhouses are built on the belief that every member has the potential to recover and lead a personally satisfying life as an integral member of society, empowered by their own will and decisions (203). The Clubhouse model has a strong focus on meaningful activities, such as work, education and training. It promotes a sense of community, in which members help themselves and others to achieve their goals (204). At Phoenix Clubhouse, there is a strong emphasis on choice, and each member is actively helped to identify and pursue recovery opportunities in the areas of friendships, shared work, health care, education, employment, wellness, and engagement in the wider community. Phoenix Clubhouse puts a deliberate focus on people's strengths, rather than on their symptoms (205, 206).

Service evaluation

Extensive international research literature exists on the Clubhouse model. One comprehensive review of existing literature found benefits in employment, hospitalization rates quality of life/satisfaction, social relationships, education, and health promotion activities (*194*). Phoenix Clubhouse evaluates its own effectiveness through internal surveys on an annual basis. The internal satisfaction survey conducted in 2019 found that 84% of members felt very satisfied or satisfied with the Clubhouse. The proportion of active members engaged in outside work rose significantly over the last 18 years. In 2001, 72% of active members were engaged in outside work ([Leung F], [Phoenix Clubhouse], unpublished data, [2001]), while in 2019, this figure rose to 92% ([Leung F], [Phoenix Clubhouse], unpublished data, [2019]).

In an internal, organization-wide survey of Queen Mary Hospital in 2014, the Clubhouse was praised as exhibiting extraordinary achievement in the areas of inclusion of people using the service, ongoing care, and the involvement of people using the service, carers and community, in planning, delivery and evaluation of services ([Leung F], [Phoenix Clubhouse], personal communication, [2020]). The ongoing positive feedback has reinforced hospital management's support for continued funding

Costs and cost comparisons

People using the service are charged a flat fee of HK\$ 60 per day (approximately US\$ 8) and can access any or all of the range of mental health services provided through the mental health system of Hong Kong SAR, including Phoenix Clubhouse and all its programmes. However, Phoenix Clubhouse members are not charged this fee if they are using the Clubhouse alone, and none of the other mental health system services. Members who cannot afford the fee can apply for Comprehensive Social Security Assistance and other day hospital fee waivers. Approximately 85% of those who attend Phoenix Clubhouse make use of these benefits. Phoenix Clubhouse is supported by Queen Mary Hospital and the University of Hong Kong. Queen Mary Hospital, as the governing body, finances the entire operating budget including staff costs. Staff costs amount to roughly HK\$ 2 900 000 per year (approximately US\$ 373 000)n and total operations cost is around HK\$ 140 000 (approximately US\$ 18 000)ⁿ per year.

Additional information and resources

Website:

Hong Kong Phoenix Clubhouse, <u>http://www.phoenixclubhouse.org/</u> Clubhouse International, <u>https://clubhouse-intl.org/</u>

Videos:

Clubhouse International, member's stories: <u>https://clubhouse-intl.org/news-stories/videos/</u>

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n Conversion as of March 2021.

2.4 Peer support mental health services

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

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

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

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

2.4.1

Hearing Voices support groups



Hearing Voices Groups (HVGs) bring together people who hear voices, in peer-supported group meetings that seek to help those with similar experiences explore the nature of voices, meanings and ultimately, acceptance. HVGs have grown in popularity as suppressing voices using medication and other interventions is not always effective (207-210). Medication side-effects also are severe, with rates of non-adherence as high as 50% (211-213).

Primary classification: Peer support

Other classifications:

Community r	nental health centre	Community out	treach	Peer support
Crisis service	Hospital-b	based service	Supported liv	ing service
Availability in differ	ent locations:			
Ves	No			
Evidence:				
Published lite	erature 🧹 Grey litera	ature N	lone	
Financing:				
State health s	sector State soc	ial sector	Health insurance	
Donor fundin	g Out-of-po	cket payment	Other°	

Description of the service

The Hearing Voices Movement (HVM), whose principles underpin HVGs, began in the Netherlands in the late 1980s. It emerged from a collaboration between a Dutch psychiatrist, a researcher and a voice hearer, and other individuals with lived experience of voice hearing (214). The movement now has national networks in 30 countries (215, 216). Some groups are co-founded by professionals and closely aligned with mental health services while others are initiated independently by voice hearers (217). Groups are organized into local and national networks that offer support, advice and guidance for new groups, without a hierarchical structure. The English Hearing Voices Network (HVN) has produced a charter for groups that are affiliated to it (218), and HVN-USA has revised and expanded this charter to include the newest developments in HVGs (219). Intervoice also connects people, shares ideas, highlights innovative initiatives, and encourages high quality research into voice hearing (215).

A large number of hearing voices groups exist around the world from the US, to Australia to Hong Kong (220), and more recently in countries like Uganda. While many operate independently, there are examples of NGO-supported groups, such as Voice Collective, run by Mind, a UK mental health charity (221); a London-wide project to support young people (aged 12-18 years) who hear voices.

o Funding for hearing voices groups can come from different sources depending on the group, including donor funding, some small amounts of out-of-pocket funding, funding from health services.

In Hong Kong, New Life (222) has six HVG groups operating within its centres and houses. Different social and cultural world views shape the way that voices are experienced and interpreted and this cross-cultural variation in voice hearing experience resonates with the central tenets of the HVM, which celebrates diversity (223, 224).

An important HVM tenet is that health is a fundamentally social, cultural, and political process (*216*, *225*), and that hearing voices is a normal part of human experience (*226-228*). The diversity of ideas as to the origins of voice-hearing, whether biological, psychological, spiritual or even paranormal, and their significance, is respected (*229, 230*). Members must have an intentionally non-judgmental attitude, so people can deal with emotionally painful experiences and memories (*229, 231*).

Another key HVM tenet is that voice hearing can be best explained by reference to life events and interpersonal narratives. Indeed, voice hearing as a response to traumatic life events, especially from childhood, is well documented in the literature (232-234). Sometimes voices are confusing, distressing and debilitating; yet voice hearers usually want to understand where their voices come from (235, 236). While voices may attack the identity of the person, they also may be viewed as a way of preserving identity by articulating and embodying emotional pain (216, 237).

Unlike other peer support approaches, HVG group meetings do not follow a standard format. Local groups are encouraged to develop independently. Some welcome only voice hearers while others are open to people who have visions, experiences that would be typically regarded as psychotic, or other forms of mental distress (*217*, *238*). Professionals or family members can join some HVGs, other groups admit women only, young people (*239*) or those from communities including orthodox Jewish, black and minority ethnic or South Asian.

Group meetings are held in a range of community facilities, from libraries and arts centres, to mental health settings, prisons and inpatient psychiatric units (240). Most HVGs meet on a weekly or fortnightly basis as open groups; attendance is informal and not time-limited (241, 242). Some groups organize informal discussions only, while others invite guest speakers or arrange group outings or activities (217). Along with informal discussions, sessions may include exercises or worksheets, such as the Maastricht Interview schedule (243) Voices might also be explored through artwork, drama or role plays, and different explanatory frameworks and coping strategies may be discussed.

Some voice-hearers and professionals are provided with training to set up, run and facilitate groups (244). Generally, groups are facilitated by two people or more, and at least one must have lived experience of voices. Facilitators organize meetings and keep the discussion focused, but they do not lead or act as therapists. The groups encourage voice hearers to develop their own understanding, so that they can claim ownership and rebuild relationships with their voices in a safe space. In that context, peer support and collaboration are empowering, especially for those who have come to see voice hearing as taboo.

Curiosity about voice-hearing is encouraged in HVGs. Through voice profiling, a full picture of a person's voices may be created by the members asking each other questions; exploring, for example, what the voices say, the tone they use, the number of different voices, whether they are male or female, how the person feels when hearing the voices, and what purpose the person thinks they serve (*234*).

Core principles and values underlying the service

Respect for legal capacity

HVGs operate on a purely voluntary basis. They are never imposed on a person and never work to undermine a person's legal capacity. The ultimate aim of HVGs is to empower the voice hearer's ability to articulate their own understanding of their voices, and to make more informed decisions about whether or not to use medication, psychotherapy or other mental health services they come across.

Non-coercive practices

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

Community inclusion

While individuals may receive advice and suggestions within group meetings, HVGs are not involved directly in finding work, education or housing for attendees.

Participation

The whole ethos of the groups and the wider movement is one of peer participation and support. Many attendees find the experience of other people asking questions about their voices enabling. Importantly, a person may be able to identify the circumstances most likely to trigger the voices, giving them more control over the experience. One person reported that attending an HVG had helped her to develop a vocabulary to describe her own experiences. This transformation and the processes involved is explained by a three-phase model developed by Hornstein, Putnam and Branitsky (2020) (*229*).

Recovery approach

The core principles of HVGs are closely allied with the recovery approach, including the connectedness, hope, identity, meaning in life and empowerment (CHIME) processes, as identified in the literature (76, 231). HVGs work to help individuals develop their own framework of understanding, set their own goals and objectives in relation to their voices, and generate hope through peer support. There is an avoidance of medicalized terminology such as 'auditory hallucinations', 'delusions' and 'symptoms'. That said, some members reject the very notion of recovery and argue that their voices are a core part of their personality, not a symptom of any illness from which they need to recover.

Service evaluation

Evaluating HVGs is difficult because the benefits cannot be captured using standard clinical rating scales (245, 246). Indeed, most HVGs see themselves as social groups rather than traditional therapy groups (218).

Nevertheless, one study found that the duration of hospital admissions, as well as voice frequency and power, decreased significantly after attendance at HVG meetings (247). Other studies also showed that attendees find support that is often unavailable elsewhere, which can reduce isolation and improve self-esteem, social functioning, ability to cope and hopefulness, while strengthening bonds with friends and family (248). In other studies, people reported a better understanding of their voice experiences and an

increased ability to articulate the relationship with their voices to others (249, 250). For example, one respondent reported, "I have an understanding of what my voices are and where they come from and I've been able to cope with them better, and as I've got better in myself and they've reduced, then that's made life a lot better, because I don't have these voices all the time" (231).

Benefits may accrue incrementally. The largest study of HVGs found that people initially go through a process of discovery regarding other voice hearers and different ways of understanding voices, then they begin to explore ways of reframing their own experience to make sense of it. Eventually, the group serves as a laboratory for change in relationships outside the group (251). In one study a respondent reported, "It was the veil being lifted because I'd heard somebody actually voice these feelings and I sort of thought ... I know it's abnormal but equally there sort of seems to be a normality about it" (251).

While many people who attend HVGs continue to use psychiatric medication, others reduced or tapered off entirely (229, 241). Importantly, use of hospital and crisis services was reduced (229).

Group meetings can be distressing, especially if there is a so-called 'kick back from the voices' (252). Yet this did not diminish the benefits of attending, perhaps because people were able to talk about distressing material, without being judged or pathologized.

Costs and cost comparisons

Funding for hearing voices groups comes from different sources depending on the group, including donor funding, some small amounts of out-of-pocket funding, and funding from health services. Minimal costs are involved beyond rent of a weekly meeting space and a possible fee for the facilitator. Groups can be supported by mental health services and NGOs. HVGs are free to the people who attend; apart from in Japan where there is a small membership fee (253).

Additional information and resources

Website: <u>http://www.hearing-voices.org/</u>

Videos:

Beyond Possible, How the Hearing Voices Approach Transforms Lives <u>http://beyondpossiblefilm.info/</u> Eleanor Longden, The voices in my head, TED2013. <u>https://www.ted.com/talks/eleanor_longden_the_voices_in_my_head?language=en</u>

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2.4.2

Nairobi Mind Empowerment Peer Support Group

USP Kenya



Users and Survivors of Psychiatry in Kenya (USP-K) is a national membership-based organization that deploys peer support groups (254) to bring together people with psychosocial disabilities and mental health conditions, within an explicit human rights and social advocacy framework. Its aim is to support, promote and advocate for the rights of individuals to live and work as integral members of their communities (255, 256).

Primary classification: Peer support

Other classifications:

Community mental he	alth centre 🛛 🗹 Co	mmunity outreach	Peer support
Crisis service	Hospital-based se	rvice Supp	orted living service
Availability in different locat	ions:		
Yes	No		
Evidence:			
Published literature	Grey literature	None	
Financing:			
State health sector	State social sector	r 📃 Health insu	rance
Donor funding	Out-of-pocket pay	ment	

Description of the service

USP-K is an umbrella organization that provides peer support groups in Kenya as one of their core activities which also include training on human rights, self-advocacy, crisis response and livelihoods; as well as providing information to members on social benefits and funding opportunities and grants.

Since its inception in 2012, USP-K peer support groups have expanded to 13 groups in six counties across Kenya. The USP-K -affiliated peer support groups bring together individuals who self-identify as users of mental health services, survivors of psychiatry, people with mental health conditions and psychosocial disabilities. Support groups are formally registered with the Ministry of Labour and Social Protection and with the National Council for Persons with Disabilities. Caregivers may also join the groups, but at least 70% of members of any peer support group must have lived experience.

Although USP-K runs many groups, the Nairobi Mind Empowerment Peer Support Group was selected as a model to illustrate the functioning of USP-K groups, particularly as it has supporting evaluation data available.

The Nairobi peer support group provides a space for people with lived experience to come together. They work within a human rights and social framework promoting non-discrimination; full and effective participation and inclusion; respect for inherent dignity; individual autonomy including the freedom to make one's own choices and mistakes; and gender equality. Each meeting is divided into several sessions. Firstly, an informal session offers peer psychosocial support, a structured session deals with group advocacy objectives, then break-out sessions address more sensitive issues. Guest attendees, including professionals, may be invited by group members. An average of 25 members attend each monthly meeting, which can run for about four hours.

Typically, one staff member of USP-K and one volunteer will attend each peer support group meeting to welcome new members and provide updates, advice on disability and mental health issues. They can also steer discussions if necessary, bringing the conversation back to a human rights approach and the social model of disability for example.

Core principles and values underlying the service

Respect for legal capacity

The Nairobi Mind Empowerment Peer Support Group model stands out for its explicit focus on human rights and a social model of disability. For example, members receive training on the CRPD and the SDGs, as well as on how to apply key human rights principles to daily life. This approach supports individuals to exercise their right to make their own decisions and to have those decisions respected by others. Members are encouraged to attend peer support group meetings regularly, to foster close relationships, but can join and leave the group without notice. An individual may bring a dilemma to the group, such as a choice of medical treatment, and other members are encouraged to share their experiences, learning and knowledge on the topic. People learn to have their choices respected, even when they are at odds with other members' advice. The group sometimes helps members create informal advance directives – even though these are not recognized by Kenyan law.

Non-coercive practices

The USP-K Nairobi Mind Empowerment Peer Support Group actively promotes non-coercive practices. Groups identify and promote the use of peer facilitators, social workers and community-based workers able to de-escalate any crisis taking place in the community to avoid use of coercive methods. The group may also access the USP-K database of professionals who have received USP-K training in how to use a human rights-based approach to mental health. If a person experiences a crisis within a meeting, the peer facilitator leads the support response and respects the preferences of the person in crisis. In emergencies such as an attempted suicide, the immediate risks to the individual are addressed first, and at the earliest possible opportunity the person's wishes are respected.

Community inclusion

Members of the Nairobi peer support group are supported in a wide range of issues including social protection, accessing tax exemptions and economic empowerment programs. The group helps members to apply for disability benefits and other entitlements, including education grants, trade tool grants and waivers on local market operations fees for people in informal employment (257). With a member's consent, the support group engages with families in recognition of their role as the natural support structure for most people. If an individual does not consent, but the family is the source of a problem, the group may consult with local community structures, such as village elders.
Participation

The Nairobi Mind Empowerment Peer Support Group is member-led and managed. Group facilitators are appointed directly from and by the members and, with training, are expected to encourage individuals to develop and see a new narrative of themselves beyond their diagnosis. Facilitators help build members' connections with caregivers, mental health professionals, community health volunteers and social workers. The group sets its own advocacy objectives on issues of relevance and may execute outreach and communications campaigns, with support by the broader USP-K organization. Each year through secret ballot, the group elects a chairperson, treasurer and secretary, along with three committee members. A member-elected dispute resolution committee helps address conflict and complaints within the group, or between a member and their family, especially in issues of abuse or neglect.

Recovery approach

Members of the Nairobi Mind Empowerment Peer Support Group share their experiences and information, and provide support to each other in coping with any challenges or decisions they may be facing. The group encourages learning, questioning and self-reflection. Members also share and encourage each other to try different strategies for coping and decision-making (258). Discussions are held within a safe and constructive space allow members to make sense of their experiences, particularly as individuals may have become accustomed to being passive recipients of treatment or support. Seeing others with a similar diagnosis or living situation, in control of their lives, is encouraging to many members, as is the support volunteers provide beyond meetings. This may include hospital visits, availability during a crisis, and help with daily living tasks. For instance, if someone needs support just getting out of bed, a volunteer may call a member at a certain time every morning. Finally, members report the value of being able to make mistakes, just like anyone else. One Peer Support Group member reported, "I am growing. I am changing. The story I tell about myself is changing" (258).

Service evaluation

Independent qualitative research on the USP-K Nairobi Mind Empowerment Peer Support Group involved observations of peer support group meetings, focus group discussions and interviews with carers and USP-K staff. The study found that the peer support groups and members specifically promoted members' agency and autonomy and that through the group and peer discussions, members began to "reclaim their voice and become more assertive" (258).

Members also reported being inspired to return to education or start a business after meeting a peer who had taken similar steps. Members were encouraged to challenge relationships with unsatisfactory power imbalances, such as with medical professionals who make treatment decisions without consultation. The study found that people are supported to plan for a potential mental health crisis situation in such a way that their will and preferences will be recognized by others. Members spoke of more frequent "situations in which they were able to speak up for themselves where before they would just have been silent" (258).

Costs and cost comparisons

The USP-K umbrella organization provides initial seed funding for new groups for the first two to three years. It also provides technical support through training on topics such as human rights, self-advocacy, crisis response and livelihoods. It supports groups to access information and government funding for the group's own operations as well as for individual members, such as grants for activities addressing stigma and discrimination, economic empowerment, or for women- or youth-specific funds (*257*). The Open Society Initiative for East Africa (OSIEA) provides USP-K with US\$ 30 000 per year and the National Council for Persons with Disabilities (NCPWD), US\$ 26 000 per annum. In 2016, the social sector of the Kenyan government also contributed funding.

Financially, each individual USP-K group operates independently. The annual cost of the Nairobi Mind Empowerment Peer Support Group is approximately US\$ 4000 including venue, facilitators and advocacy costs. USP-K staff receive a salary and volunteers, a monthly stipend. Additional funding and loans are provided by NGOs, including the Red Cross and Basic Needs, as well as religious organizations and banking institutions.

Additional information and resources

Website:

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

Other:

The Role of Peer Support in Exercising Legal Capacity, USP Kenya, (2016): <u>https://www.uspkenya.org/wp-content/uploads/2018/01/Role-of-Peer-Support-in-Exercising-Legal-Capacity.pdf</u>

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2.4.3

Peer Support South East Ontario

Ontario, Canada



Peer Support South East Ontario (PSSEO) provides one-to-one peer support based on the Transitional Discharge Model (TDM) to support people transitioning back into their communities following treatment in an inpatient mental health hospital service. In this model, peer support workers play an important role in providing support and links to community-based services based on people's expressed needs for support (259). With this support people do not have to wait for weeks or months after discharge for community supports to become available. It also helps prevent re-admission to hospital which is most likely to occur within the first year after a person has been discharged (260, 261).

Primary classification: Veer support
Other classifications:
Community mental health centre Community outreach Peer support
Crisis service Hospital-based service Supported living service
Availability in different locations:
Yes No
Evidence:
Vublished literature Grey literature None
Financing:
State health sector State social sector Health insurance
Donor funding Out-of-pocket payment

Description of the service

PSSEO offers peer support at five different hospital sites in South East Ontario including Providence Care Hospital in Kingston^p where the service is offered in four mental health inpatient units (including the forensic unit), each accommodating up to 30 people. The peer support service provided consists of weekly peer support groups and one-to-one peer support for people after leaving the hospital. Peer workers act as a bridge of support from the point of a person's discharge to their first contact with mental health services in the community or their first outpatient appointment. They provide further assistance, friendship and support for up to one year after discharge.

PSSEO peer support is firmly embedded into the daily routine at Providence Care Hospital. The same peer worker visits the mental health units on one day every week to lead a peer support group and to meet and engage with people who have recently started to receive treatment and care at the hospital. The peer worker informs newly admitted people about the peer support services offered by PSSEO, providing information material, contact details and an invitation to participate in the TDM programme and the weekly peer support group. During the group meetings, which are designed to be an open and

p Providence Care Hospital is a publicly-funded hospital that integrates long-term mental health and psychiatry programs with physical rehabilitation, palliative care and complex medical management.

welcoming space for everyone interested, the peer worker introduces the one-to-one peer support as part of the TDM and interested participants are invited to schedule a meeting to initiate a matching process with a one-to-one peer support worker before discharge.

When a person expresses interest, the PSSEO peer worker at Providence Care sets up a meeting with that person to initiate the matching process with a peer, based on their background and interests. Diagnosis or other clinical characteristics do not have to be shared and do not form the basis for matching. Once a peer worker has been matched with a person, a first meeting is arranged in the week before discharge from hospital, or one to two weeks after discharge at the latest. If, after the first meeting, the match doesn't feel right to the person using the service, they can request to be re-matched with a different PSSEO peer worker.

Where a successful match has been made, the peers arrange weekly one-hour meetings for a period of up to a year. The weekly meetings can be used for whatever the person wants or needs support with. The peer worker from the hospital unit who organized the original match regularly checks in with the discharged person to see if everything is going well, if they are still happy with the match and to help resolve potential issues along the way.

PSSEO ensures that everyone who is interested in receiving peer support is matched with a peer worker. At times of exceptionally high demand, there can be a waiting list of three to four weeks until a person can be matched. In these cases, PSSEO offers the alternative of participating in group meetings at a Peer Support Centre until the individual is matched. If an individual is discharged to a different catchment area, PSSEO provides resources for potential peer support services in that area.

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

Core principles and values underlying the service

Respect for legal capacity

PSSEO operates on a purely voluntary basis and being matched with a peer support worker is never imposed on a person. PSSEO peer workers actively promote legal capacity by supporting people to make informed decisions and choices about treatment, care and support options by exploring the alternatives together with the person. They also support people in developing advance plans for potential crises in the future.

Non-coercive practices

No coercive practices are used by PSSEO staff or the community services and supports to which PSSEO facilitates access. All PSSEO peer workers are thoroughly trained in de-escalation techniques and are therefore able to respond to tense situations in a calm and reassuring manner. Under exceptional circumstances, for example if a person acts violently towards others and/or is harming themselves,

PSSEO contacts the responsible crisis service which could then refer the person to a hospital where coercive practices may be used. In these cases, the PSSEO peer worker tries to accompany the individual to the hospital and stay with the person during the admission process to provide support, continuing to try to de-escalate the situation. Further, at Providence Care Hospital, PSSEO engages in different working groups and councils that advise hospital management decisions in order to stimulate discussion around avoiding coercive measures.

Community inclusion

Peer support provided by PSSEO as part of the TDM is specifically dedicated to facilitating the transition of an individual back into the community after discharge from hospital. Once a peer worker is matched with an individual and informed about their support needs and wishes, the peer worker introduces the person to the community-based services available that could be a good fit. PSSEO does not have a pre-designated referral policy and individuals are at all times free to decide which services they are interested in. Although PSSEO's focus lies in facilitating access to community-based mental health and/or addiction services, the peer workers also support people to gain access to housing, education or social protection benefits if this is the person's wish.

Participation

All of PSSEO's peer workers have lived experience and people with lived experience are represented in the management group which ensures that the perspective of lived experience is reflected throughout the service, including in decisions about funding and budget allocation, service development and implementation. Satisfaction surveys are conducted within a minimum of a two-year timeframe for all programmes run by PSSEO including the TDM at Providence Care. The results of these surveys are used to improve and adapt the services provided by PSSEO as appropriate.

Recovery approach

The core principles of PSSEO peer support are closely aligned with the recovery approach. PSSEO peer workers work with individuals to develop their own framework, goals and wishes for their personal recovery journey and to identify which services and supports might be helpful for them as an individual. PSSEO emphasizes the importance of seeing an individual as a whole person and avoiding medicalizing terminology and a focus on diagnoses. The focus rather lies on strengthening autonomy and empowerment of the individual by establishing with the peer what recovery means to them and working alongside to support, advocate and provide hope.

Service evaluation

Analyses of quality improvement surveys on the peer support delivered by PSSEO as part of TDM at Providence Care Hospital – including questionnaires, interviews and testimonials – showed high levels of satisfaction with the services among both people using the services and staff members (262).

In a 2019 study, 92% of individuals using the PSSEO peer support services at Providence Care reported a positive experience and high levels of satisfaction with the services provided. People reported feeling empowered, understood, listened to and supported by the peer worker and considered the peer support as a key positive factor in their recovery journey. Staff members at Providence Care reported equally positive experiences with the peer support provided by PSSEO and considered the peer support as an "invaluable service" and "an essential part of the care and recovery of patients" (*262*).

Furthermore, studies evaluating the overall TDM, including peer support at different hospital sites, have shown that service users' quality of life improved and that average length of stay and costs of care were reduced (259, 263-265).

Costs and cost comparisons

Since its founding in 2001, PSSEO has received continuous funding for 19 years by the Ontario Ministry of Health and Long-term Care. During fiscal year 2017–2018 the total cost of peer support services delivered though the TDM at Providence Care was Can\$ 53 280 (US\$ 42 140)^q. In 2018–2019, the cost was slightly higher at Can\$ 59 200 (US\$ 46 830)^q. The total cost includes peer supporter salaries, one-to-one service delivery, snacks and beverages for groups, as well as mileage accrued by peer support staff when traveling to visits. The cost of service delivery per individual for fiscal year 2017–2018 (119 individuals) averaged Can\$ 447 (US\$ 354)^q per person, and for 2018–2019 (127 individuals), Can\$ 466 (US\$ 369)^q per person.

Additional Information and Resources

Website:

https://psseo.ca/

Videos:

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

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q Conversion as of February 2021.

2.5 Community outreach mental health services

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 section, 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 section cater specifically to homeless or rural populations, for example.

The examples of good practice provided in this section 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.

2.5.1

Atmiyata

Gujarat, India



Atmiyata^r (266) is a community volunteer service that identifies and supports people experiencing distress in rural communities of Gujarat state in Western India. The intervention is built on empathy and volunteerism, providing a viable path to delivering support in low-resource settings (267). Shared compassion serves as the core tenet of this intervention and is based, in part, on the ancient Indian theory of communication, Sadharanikaran (267).

Primary classification: Community outreach

Other classifications:

	Community mental hea	alth centre	unity outreach	Peer support
	Crisis service	Hospital-based service	e Supporte	ed living service
Availa	bility in different location	ons:		
	Yes 📝 N	lo		
Evider	ice:			
\checkmark	Published literature	Grey literature	None	
Financ	ing:			
	State health sector	State social sector	Health insuranc	e
\checkmark	Donor funding	Out-of-pocket paymen	t	

Description of the service

Atmiyata Gujarat was established in 2017 in the Mehsana district of Gujarat state, home to 1.52 million people and 645 villages (268). With 53% employed in the agricultural sector, nearly half (45.4%) are in low-income brackets (269). The service is the second of its kind to be rolled out in India, following a successful pilot project in 41 villages of Maharashtra State from 2013 to 2015 (266).

The service employs a stepped care and support approach, using community-based volunteers. The village-based volunteers conduct four activities: (i) identify individuals experiencing distress and provide four to six sessions of evidence-based counselling; (ii) raise community awareness by showing four films to community members on social determinants of mental health on an Atmiyata smartphone; (iii) refer people who may be experiencing a severe mental health condition to public mental health services when required, and (iv) enable access to social care benefits to increase financial stability.

The service is delivered by two tiers of village-based community volunteers. The first, called Atmiyata Mitras, are people from different religions and sects and castes, trained to identify people experiencing distress. The second tier, called Atmiyata Champions, are community leaders or teachers who are approachable and well-known in their village. Champions are identified by Atmiyata's Community

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

Facilitators – trained social workers who visit the village, map community groups, and identify suitable candidates. Champions are trained to provide structured counselling using evidence-based counselling techniques, including behaviour activation, activity scheduling or problem-solving (PS) depending on the needs and goals set by the person (*270-273*). Atmiyata also maintains a close link with the state-run District Mental Health Program (DMHP), assisting people who wish to access the DMHP or psychiatric services at the District Hospital.

Core principles and values underlying the service

Respect for legal capacity

Atmiyata's activities are based on a 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 delivery of care by the Champions, who are trained to work with the will and preferences of the person receiving services. All activities are based on informed consent, and individuals have the right to withdraw from the support provided. As a means of providing ongoing support and mentoring to Champions, Community Facilitators discuss with them the challenges and difficulties faced, however, personal identifiers are not disclosed. Champions use de-identified data in their documentation of work, to protect identity of the person in distress, who is known only to the Champion and the Mitra who made the original referral. The Champion only suggests seeking specialized services in the event it is urgently needed. The Champions' training also reinforces the principles and practice of informed consent.

Non-coercive practices

Interventions provided by Champions address both social and mental health care needs, based on the principles of non-coercive practices. The evidence-based counselling techniques include: active listening, problem solving and activity scheduling (*274*). Champions also facilitate access to social benefits such as disability or unemployment benefits, widow's pensions, rural employment support, social security, and scholarships.

Community inclusion

The service itself is based at village level directly within the community, and 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 and does not attempt to establish new ones. Champions conduct awareness-raising activities for members of their villages, showing and discussing four 10-minute films dubbed in Gujarati in community meeting places (such as a temple or a farm) on a smart phone. These films tackle commonly experienced social issues in the community that impact mental health, such as unemployment, family conflict, domestic violence and alcoholism. Providing support for individuals to obtain social benefits also facilitates greater inclusion of the person in the community.

Participation

While lived experience is not a mandatory requirement to be a Champion or a Mitra, most Champions are motivated to become volunteers as a result of their own personal experience of distress. Champions are encouraged to share their personal experience of mental health distress during the counselling sessions to build a relationship of trust, and to inspire hope and reassurance.

Recovery approach

Atmiyata promotes recovery-oriented care to those in distress, focusing on empathy, hope and support. Champions use counselling sessions to build a relationship of trust, and to inspire hope and reassurance. Counselling sessions build the person's capacity to respond to their distress, thereby gaining control over their lives. The support delivered by Atmiyata builds on a strengths perspective that encourages the person to lead an independent life of personal meaning.

Service evaluation

Atmiyata Gujarat was evaluated in 2017 over a period of eight months using a stepped wedge cluster randomized, controlled trial (275). The trial spanned 645 villages in Mehsana District, with a rural adult population of 1.52 million. The primary outcome was an improvement in general health as measured through the 12-item General Health Questionnaire (276) at a three-month follow-up. Secondary outcomes were measured using a variety of scales, and included quality of life, symptom improvement, social functioning, and depression symptoms (277-282).

Results showed that recovery rates for people experiencing distress were clinically and statistically higher in people receiving the Atmiyata service compared with the control condition. In addition, improvements in depression, anxiety, and overall symptoms of mental distress were seen at the end of three and eight months. 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 significant improvements in quality of life and disability levels as well as in symptoms related to mental health conditions (*275*).

Costs and cost comparisons

Atmiyata Gujarat was initially funded by Grand Challenges Canada but now receives support from Mariwala Health Initiative (283) in partnership with Altruist, a local NGO funded by the Government of Gujarat and TRIMBOS Institute (284). Funding is approved until March 2022. Atmiyata services are delivered locally and free of charge. In 2019, the total annual cost of delivering the Atmiyata programme to 500 villages with a rural adult population of 1 million, was US\$ 120 000. The service reached 12 758 people experiencing distress or common mental health conditions during the fiscal year 2019–2020 ([Kalha J], [Indian Law Society], unpublished data, [2021]). Budget costs include Community Facilitators, project managers, training, travel, smartphones for Champions, and administration.

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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2.5.2

Friendship Bench Zimbabwe



At Friendship Bench, which began in Zimbabwe in 2006, lay counsellors support people experiencing significant emotional distress. This community outreach service offers empathy, local community and cultural knowledge, skills, and formal problem-solving techniques (285), and has now been implemented nation-wide as part of Zimbabwe's public primary health services.

Primary classification: Community outreach

Other classifications:

\checkmark	Community mental hea	alth centre	Community outread	h Peer sup	oport
	Crisis service	Hospital-based	d service	Supported living servic	e
Availa	bility in different locati	ons:			
\checkmark	Yes	10			
Evider	ice:				
\checkmark	Published literature	Grey literature	None		
Financ	ing:				
\checkmark	State health sector	State social se	ector Healt	h insurance	
\checkmark	Donor funding	Out-of-pocket	payment		

Description of the service

The name Friendship Bench derives from the Shona term, *chigaro chekupanamazano*, which translates literally as, "bench to sit on to exchange ideas" (286). It provides a short-term form of problem-solving therapy to people with common mental health conditions, known in Shona as *kufungisisa*, which translates literally as "thinking too much". The free service is linked to the local primary health care centre and is usually delivered outside the centre on a wooden bench. People can self-refer or be referred by schools, police stations or the primary care clinic.

Friendship Bench services are currently offered in three cities in Zimbabwe and 25 clinics in two rural areas, through a total of 70 primary health care clinics (*287*). Since 2016, the service has offered support to 50,000 people and in 2019, Friendship Bench became fully part of the Ministry of Health's National Mental Health Strategy (*288*).

Given the scarcity of mental health services in Zimbabwe, the Friendship Bench fills an important gap and need for community mental health service provision. The service is delivered by lay health workers – local women employed by the local health authority to support other health services, such as vaccine awareness. That most lay health workers are older women, is an extremely important part of the service. In Zimbabwe, older persons are seen as important guardians of the community and are therefore respected. With an average age of 58, these lay counsellors are referred to as grandmother health providers (*ambuya utano*) (*272*). The women are steeped in Shona language and culture and have

extensive knowledge of the local economy and social networks. Not only do they live and work in the same communities as those using the service, they have lived through difficulties in their own lives and bring a great deal of empathy into their work (285). Lay counsellors receive eight days of training in symptom recognition, the use of screening instruments, psycho-education, problem-solving therapy and counselling basics (289).

The Friendship Bench's problem-solving therapy is delivered over six or more sessions, based on a standard approach to problem identification and solving, and using the Shona Symptom Questionnaire (290), to both screen people and support treatment. Importantly, the lay counsellors provide services in Shona, the indigenous language of the country's main ethnic group and use proverbs and cultural terms as reference points; this is thought to have contributed to the therapy's acceptability in Shona-speaking areas and use in primary care facilities (289). Depending on the size of the primary care clinic, up to 25 people can be seen per day.

The problem-solving therapy involves three elements: through opening up the mind (*Kuvhura pfungwa*) the counsellor and client explore the client's situation, list the problems and difficulties faced and select a problem to address; through uplifting (*Kuzimudzira*) the client and counsellor develop a solution-focused action plan; and through strengthening (*Kusimbisisa*) the client receives support and is invited to return for a follow-up visit.

Although Friendship Bench was set up initially to offer just six sessions of counselling, the service has evolved. Many informal sessions continue because lay counsellors tend to meet their clients in the community and continue to support them (285). Meetings may be held at the client's home, the lay counsellor's home, or informal settings such as the market or by the public borehole. As prayer in gatherings related to health is a common practice in Zimbabwe (272), many counsellors join clients and their families in prayer. Clients are further supported by text messages and phone calls to reinforce the problem-solving therapy approach (291).

Friendship Bench clients are also invited to join a peer support group, called Holding Hands Together (*Circle Kubatana Tose*) where people can share experiences in a safe space at weekly meetings (*292*). These groups are led by women who have already used Friendship Bench services, and who have received group management training. Sometimes while sharing personal experiences the group also undertakes an income generation activity.

Core principles and Values underlying the Service

Respect for legal capacity

Using the Friendship Bench service is strictly voluntary. The aim is to empower the person attending by supporting them to find ways of overcoming their problems, to make decisions, and take actions on issues that are troubling them.

Non-coercive practices

Friendship Bench staff do not use coercive practices. Services are provided on an entirely voluntary and consenting basis. Staff members do not organize involuntary admissions. However, if a person is identified as being at high risk, the counsellor can request that they be seen by a professional worker at the primary health care clinic, who may decide to refer the person to an inpatient unit.

Participation

The Friendship Bench peer support groups bring people with lived experience together with a sense of solidarity – participants support one another and create opportunities for joint problem-solving. The peer groups operate both in the primary health care centres and in the community. The income-generating dimension also gives them a practical focus, as many attendees face serious financial challenges.

Community inclusion

Along with being a public health service linked to primary health care provision, the service is embedded deeply in the community thanks to its lay counsellors who deliver the service. The current counsellors have lived locally for at least 15 years and are selected at community gatherings of key stakeholders, including church leaders, police, head teachers and other community leaders. Thus the appointed counsellors have a unique social and cultural standing and understanding of issues facing their clients (286).

The problem-solving therapy is often enhanced by an activity-scheduling component in which people are encouraged to schedule and carry out activities that are meaningful to them and make their lives more rewarding. Additionally, some people with mental health conditions in financial need are referred to local community resources, such as local income-generating projects (*272*).

Recovery approach

The aim of the Friendship Bench service is to help people set goals for themselves and to find ways of achieving these goals. It does not involve medication or other forms of medical treatment unless someone is referred to the clinic staff for a higher level of care. Psychiatric diagnoses are not made by the counsellors. The Shona Symptom Questionnaire (SSQ) is used as a screening tool and as a way of offering reassurance to clients, in that their experiences are recognized and have been experienced by others. Through its work, the service focuses on empowering people to become strong problem-solvers, who can go on to make a difference in their communities.

Service evaluation

An early study was conducted based on surveys of 320 people who completed 3-6 sessions of therapy, over 50% of whom were HIV positive (272). The study showed that the basic Friendship Bench approach was successful and that clients experienced a reduction in symptoms. A subsequent cluster randomized-controlled trial of 573 people found that those who received Friendship Bench services, including through joining a peer support group, had fewer symptoms overall, than those who received enhanced usual care (including psychoeducation about symptoms, supportive SMS messages or voice calls, medication if indicated, and/or referral to a psychiatric facility) (291). In another qualitative study, the importance of empathy and local cultural knowledge were identified as particularly important (286).

Costs and cost comparisons

The Friendship Bench service is part of Zimbabwe's primary health care provision and is free of charge for those registered with a health care centre. The lay counsellors are employed by the local health authorities and receive a monthly salary. A first session on the Friendship Bench was estimated to cost US\$ 5 (based on 2019 data), including: group sensitization to the program, individual screening, health care centre staff time, lay health worker time, and materials – all of which are covered by health authority.

Additional information and resources

Website:

www.friendshipbenchzimbabwe.org

Videos:

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

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

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2.5.3

Home Focus West Cork, Ireland



Ireland's Home Focus service, established in 2006, provides practical and emotional support to people with mental health conditions living in a predominantly rural area, where community services are geographically dispersed. The service has won national recognition for helping people enhance their mental health and wellbeing, develop independent living skills, and access education and employment opportunities (293).

Primary classification: Community outreach

Other classifications:

	Community mental he	alth ce	entre Commu	nity outreach	\checkmark	Peer support
	Crisis service		Hospital-based service	Sup	ported livi	ng service
Availa	bility in different locat	ons:				
	Yes	No				
Evider	ice:					
	Published literature	\checkmark	Grey literature	None		
Financ	ing:					
\checkmark	State health sector		State social sector	Health ins	urance	
	Donor funding		Out-of-pocket payment			

Description of the service

While Ireland is a high-income country, there are significant levels of poverty and disadvantage in some depopulated, and increasingly marginalized rural areas (294). West Cork lies in the extreme south-west of the country, its population of 55 000 spread thinly over a rugged area. The Home Focus community outreach service emerged to respond to the needs of residents in West Cork - a region characterized by poor transport links and little access to not only mental health services, but also jobs and training opportunities (293). Home Focus complements existing mental health services and builds on existing local creative arts initiatives and Hearing Voices Groups (see section 2.4.1) (295, 296). Although funded by Ireland's national health system, the Health Service Executive (HSE), the initiative is managed by the National Learning Network, an NGO that is part of RehabGroup (297).

Home Focus is based on personalized care-planning, flexibility and recovery principles, and has a central focus on community inclusion. It incorporates peer support and people with lived experience as full members of the team. The service team comprises: a community mental health nurse, rehabilitative training instructors to help with employment and training, a recovery support worker trained in recovery-oriented, person-centred approaches, including Open Dialogue (see section 2.1.3) and Hearing Voices (see section 2.4.1), and a recovery and development advocate with lived experience. Staff are trained in Wellness Recovery Action Planning (91) and Peer Leadership, through a recognized Support Network (298).

Referrals are made by the West Cork Mental Health Service community health teams. People referred to the service include those with a history of two or more unplanned admissions to psychiatric in-patient services in the past year or who have experienced a recent acute mental health episode, and those experiencing social isolation and significant functional impairment. People with problems related to substance use are in general not accepted.

The service operates daily from 09:00–17h00 working with people in their own homes, and also helping them to access community-based services. It has supported individuals for periods ranging from three to 18 months, providing services for up to 34 people at a time (299). The extensive time spent with service users is regarded as a crucial factor in the initiative's success (299).

Community outreach services are provided to individuals and families, for problems related to stress management, conflict resolution, coping strategies, goal setting, literacy and social skills. The service also provides support for medication management, job searches and community-based group activities such as walking and gardening, and helps people access peer support groups including Alcoholics Anonymous (*300*), GROW (*301*), Shine (*302*) and local Hearing Voices groups.

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 all who use the service, including a commitment that people using the service will be involved in all decision-making about their futures and will be helped to make informed choices in regard to treatments and interventions. Service users are helped to develop an individual action plan, reviewed every six months, which includes their personal goals and priorities and articulates what they want to happen during crises. WRAP crisis plans (91) are also created. While advance directives are not legally binding in Ireland, the individual action plans and WRAP crisis plans are respected and enforced by the service in West Cork.

Non-coercive practices

Those using the service do so on a voluntary basis and without sanction if they fail to attend. There are no stipulations on mental health interventions they should receive or adherence to medication. However, those who wish, are supported to taper and reduce medication. The Home Focus team works to manage any potential conflict situations and is trained to use various de-escalation techniques and approaches such as SafeTalk (*303*) and Assist (*304*). If risk levels do rise, people using the service may be 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, their general practitioner and a hospital psychiatrist.

Community inclusion

Community inclusion is at the heart of the programme – from training to work, as well as cultural pursuits and exercise such as walking and swimming. There are active efforts to connect people with their families and also broaden their social network. The service regularly liaises with Cork County Council as well as community-based organizations such as Community Resource Centres, Cork Mental Health Foundation, GROW (*301*), the Clonakilty Wellness Group (*305*), Novas (*306*) and Social Farming (*307*). The Home Focus team withdraws gradually as the person gains confidence, independence, and increased community integration.

Participation

The Home Focus team's recovery and development advocate has lived experience with mental health issues. This team member has undergone training in peer facilitation and is now one of the organizers of peer support groups in West Cork. 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. A partner organization, Irish Advocacy Network, which was set up, managed and delivered by people with lived experience, is represented at all levels of WCMHS, thus ensuring peer input to the management of the Home Focus service.

Recovery approach

The service works with an explicit recovery orientation. By focusing on the strengths of the individual, the Home Focus team helps people develop recovery plans based on their own hopes for the future. The team prioritizes the establishment of respectful, supportive relationships and works in a flexible way. All activities are designed to promote connectedness, hope, identity, meaningful roles and empowerment: the so-called CHIME approach (76).

Service evaluation

A qualitative evaluation of the service was carried out by the University College Cork (UCC) in 2008 (299). Importantly, 89% of those interviewed reported improvements in their personal and social functioning, including improvements in: decision-making, sleep, interactions with family and social networks, and social skills. Some 71% of people reported improved independent living skills. Better mental health was reported by a total of 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.

Home Focus was also reviewed by the HSE Inspectorate of Mental Health Services in 2011, which stated: "One of the unique features 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 to 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 balkanised agency working" (293).

Costs and cost comparisons

The service was initially funded on a trial basis, but now receives recurring national funding. It has achieved national recognition as an example of good practice. Because of local community and political support, Home Focus has survived a period of national austerity following the financial crisis, when many other services were cut. Even so, HSE continues to fund Home Focus through the budget of the National Learning Network non-profit, and not directly through the local mental health service budget. Even so, it remains the only service of its kind in Ireland. The service is fully state funded through the HSE and costs approximately €260 000 per annum – approximately €7 600 per person per year using the service. There are no costs to the individuals using the service and thus no insurance payments or co-payments.

2 | GOOD PRACTICE SERVICES THAT PROMOTE RIGHTS AND RECOVERY

Additional information and resources

Health Service Executive, 2008, Having Choices - An Evaluation of the Home Focus Project in West Cork <u>https://www.hse.ie/eng/services/publications/mentalhealth/havingchoices.html</u>

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2.5.4

Naya Daur West Bengal, India



Naya Daur provides community-based support, treatment and care for homeless people who have a mental health condition or psychosocial disability, and is anchored by a network of community caregivers and initiatives for community inclusion. Naya Daur (New Age) is the flagship project of the Kolkata-based NGO, Iswar Sankalpa (308).

Primary classification: Community outreach

Other classifications:

Community mental he	alth centre 📃 Comm	unity outreach	Peer support
Crisis service	Hospital-based servic	e Support	ed living service
Availability in different locat	ons:		
Yes I	No		
Evidence:			
Published literature	Grey literature	None	
Financing:			
State health sector	State social sector	Health insurance	се
Donor funding	Out-of-pocket paymer	ıt	

Description of the service

Naya Daur was established in 2007 and provides community-based outreach to homeless people with mental health conditions or psychosocial disabilities in 60 municipal wards of Kolkata. It fills an important role in this city of 14 million people (*309*) of which an estimated 700 000 are homeless, many of whom experience chronic mental health issues. In the absence of state-run outreach services, Naya Daur fills an important gap between state hospitals, individuals and families (*309*, *310*). Its 16-member multidisciplinary team includes a coordinator, social workers, psychiatrists, counsellors, support staff and a large network of community volunteers who engage with homeless adults from 16-80 years of age.

Engagement, with the homeless person's consent, focuses on long-term relationship-building. The team provides regular check-ups, physical and mental health care, clothes, food, and supports access to social entitlements. Clients are identified by outreach field workers in consultation with mental health professionals (*311*), and are offered an assessment by the organization's psychiatrist, which takes place in the area where the person lives. At this stage, rehabilitation and recovery activities also commence including recovery goal-setting. Medication options are discussed, if the person is willing (*311*). Clients may be referred to Iswar Sankalpa-run shelters – particularly female clients vulnerable to violence. The team also facilitates access to Iswar Sankalpa's day centres, encourages supported employment, and explores reunion with the client's family, with their consent. Naya Daur accepts all people who are homeless and who have a mental health condition or psychosocial disability, with the exception of highly mobile people who do not have a fixed neighbourhood or people behaving in an aggressive way.

Core principles and values underlying the service

Respect for legal capacity

The central premise of Naya Daur is the client's autonomy. People who use the service do not need to leave their home on the street. If they are vulnerable and require urgent care, they are asked if they would like to go to a shelter, or, if necessary, to the hospital. However, they are not forced, and negotiation continues in acute cases. The client's choice is central to all decisions and interventions, including accepting food or taking medicines, the degree and manner of interactions, information sharing, etc.

Staff members support clients to exercise their legal capacity, and client comments are extensively documented. Individual care plans (ICPs) are drafted with the client, who makes decisions through a process of informed consent. The multidisciplinary team's case conferences and periodic reviews ensure that client preferences are incorporated and respected, including in crisis situations. This approach has been successful because of the rapport and trust building that is incrementally built over a period of several months, often starting with attention to basic needs such as food, clothing, basic physical care and medicines.

Non-coercive practices

A guiding principle of Naya Daur is to provide care and support within the community so that no one is forced to move from their neighbourhood. The psychiatrist, for example, may visit clients on the streets as needed and begin a slow process of building a trust-based relationship. As services are provided openly in the community, clients can disengage or withdraw consent at any time by walking away. The client communicates verbally or nonverbally – the latter being necessary in the case of language or dialect issues as well as the severity of physical or mental health conditions.

Community caregivers also directly intervene to prevent community acts of violence and institutional coercion, such as involuntary admission to hospitals by police. There is currently no formal policy for crisis situations; however, Naya Daur strives to avoid involuntary admissions through open discussion and by giving people space. In situations of aggression or violent behaviour, hospitalization may be negotiated with the client, often with the support of community members who know the person, and who have undergone training to provide more effective support. The team also models non-coercive practices to community caregivers, and trains them on their importance.

Community inclusion

A signature aspect of Naya Daur's approach is the role played by community caregivers, who live in the same neighbourhood and provide support alongside the team. Community caregivers are typically people engaged in small businesses such as vending carts, street eateries or shops, and know the homeless person. With Naya Daur's involvement they feel more confident about offering practical and personal support. These community volunteers are trained and supervised in supporting their clients' overall psychoeducation, basic needs, access to public health services, shelter and employment. The training takes place mostly on site and community volunteers are also invited to Naya Daur's meetings and an annual caregivers' forum (*311*). In this way, responsibility for providing support is jointly shared between the multidisciplinary team, the client and the community volunteers.

Field outreach workers and counsellors regularly visit the clients and volunteers to provide oversight, advocate for clients' health and social welfare entitlements, and resolve any tensions in the client-volunteer relationship. Family reunions may also be facilitated with mutual consent. The final stages of intervention at Naya Daur involves handing over the role of daily support to the community volunteers.

Naya Daur also forms direct links with the community through awareness programmes. These are held at municipal health units, schools, colleges and local youth clubs, and serve to sensitize community members to the conditions of homeless people, psychosocial disability and mental health in general. The team also interacts with police and municipal authorities as needed. In this way, a strong community network is built, including community members and services, as well as local officials and law enforcement.

Participation

In many cases Naya Daur's former clients take on peer support roles or responsibilities as carers for new clients. One homeless former client became a community caregiver. While the service does not yet have formal mechanisms for the inclusion of clients as employees, clients' feedback are informally incorporated in service design and implementation.

Recovery approach

The recovery approach followed by Naya Daur is a holistic one which puts the person at the centre of the care process – it focuses on their social as well as clinical recovery. Naya Daur staff go through rigorous orientation and training in client-centred practices (311), including detailed practical training on diverse psychosocial interventions and steps, from building empathy and mindfulness to more practical interventions. Individual Care Plans are based on the clients' personal goals, and an intervention is collaboratively developed with the Naya Daur team. The plan is revisited every quarter with the client to assess the progress made and to change the goals or planned actions if required.

The team adopts a strengths perspective – all interactions are aimed at helping clients identify their strengths and resources that they can continue to build upon. Counsellors and/or community caregivers visit almost daily and provide motivational and supportive counselling, as well as considered self-disclosure, sharing their personal experiences to kindle hope, increase self-acceptance and help clients move toward life goals. Communication is goal-oriented, focusing on objectives such as obtaining entitlements, re-establishing family and social connections, and securing a livelihood.

Service evaluation

On average 90–100 street clients are supported by community member carers every year. To date, Naya Daur has built a care circle comprising 250 community caregivers and strives to expand it ([Das Roy S], [Iswar Sankalpa], unpublished data, [2021]). A review of operations from 2007 to July 2020 found that Naya Daur provided services to over 3000 homeless people with a psychosocial disability (*312, 313*). A separate review of Naya Dour's operations from 2007–2011 was conducted by Iswar Sankalpar, which found that the service provided food to 1015 clients, clothing and hygiene services to 765, and medical care to 615. A further 69 people were supported into housing (*312*). From 2011 to August 2020, the service was in contact with 2003 homeless persons of which 65% were diagnosed with a mental health condition; the majority with psychosis. During this period medicines and counselling services were provided to 1122 clients and 197 people were supported into housing (*312*). With the support provided

by Naya Dour, over 60 clients gained access to government entitlements between 2015-2018. No formal client feedback survey or evaluation has been conducted; however the review contains case studies of people who have benefited from the service.

Costs and cost comparisons

Naya Daur is free of charge to the people using the service. It costs 107 rupees ($\overline{\mathbf{e}}$) per person per day (US\$ 1.50)^s or US\$ 45 per month, which is approximately 75% of the cost per person per day of the West Bengal government-sanctioned open shelters run by Iswar Sankalpa (314). It represents one third of the per person cost for institutional support in privately-run centres (US\$ 150), including food, medicines, treatment, hygiene materials, clothes, manpower and overheads ([Das Roy S], [Iswar Sankalpa], personal communication, [2020]) (315).

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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2.5.5

Personal Ombudsman Sweden



In a country with a highly developed mental health system (316), Sweden's Personal Ombudsman (317) provides a community outreach service to people with mental health conditions and psychosocial disabilities, providing assistance with family matters, health care, housing, finances, employment support and community integration, helping clients to live their lives actively and autonomously. Importantly, the service works to ensure that other mental health and social services cooperate and collaborate (318). The services are provided with full input and consent of the client; which has been described as a "professional friendship" (319).

Primary classification: Community outreach

	Other of	classifica	tions:
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	Community mental heal	Ith centre Commu	nity outreach	Peer support
	Crisis service	Hospital-based service	Supported	living service
Availa	bility in different locatio	ns:		
\checkmark	Yes No	C		
Evide	ice:			
\checkmark	Published literature	Grey literature	None	
Finan	ing:			
\checkmark	State health sector	State social sector	Health insurance	
	Donor funding	Out-of-pocket payment		

Description of the service

The Personal Ombudsman (PO) system was launched in in the year 2000 following a national reform of Sweden's mental health services. As part of the reform, 15% of the mental health budget was transferred to the municipalities to support community level alternatives, improve service provision and prevent hospitalization (*320-323*). The PO service aims to improve the quality of life of people with severe or long-term psychosocial disabilities, and over the past 20 years, has become an established part of community social services in most Swedish municipalities (*323*). By 2018, a total of 336 PO services were operational and reached 9517 people in 87% of the country's municipalities (*318*).

Sweden has six large PO provider organizations (two of which are user-led) that can be contracted by municipalities to provide services. The service is managed locally and is institutionally independent of other health and social services (*319*, *321*, *322*).

The service and is available to adults over 18 years of age with severe psychosocial disabilities and a significant need for long-term care, support and access to services including accommodation, rehabilitation and/or employment (*324*, *325*). It is advertised through leaflets and by word-of-mouth (*323*). Clients may request a PO directly, or through intermediaries, or POs may reach out to potential

clients. Prioritization is given to young adults, people with children at home who have health problems, people who are at risk of suicide and homeless people or those at risk of eviction, as well as people who lack supports and a social network.

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 (323) and may have lived experience themselves. New POs undergo training in topics as diverse as suicide prevention, migration and gambling. Recently, a newly recognized social profession has been established for POs, with its own professional body (*Yrkesföreningen för personligt ombud Sverige*). Typically, POs have between 13–20 clients at a time (323) and work either alone or in groups under an overarching PO management body. This oversight group is made up of representatives from the municipality, county council, primary care and psychiatric health services, employment and social insurance services, local advocacy groups and/or organizations of people with lived experience.

To work successfully with a client, the PO must establish a relationship of trust at the outset. By listening to and working with a client, the PO can help them identify their issues, hopes and goals for support. This may include challenging a guardianship order, help seeking housing or support in building community connections and a peer network. Together, they can set out a roadmap to achieve these goals. These meetings are informal and may take place in a café, the PO services office or at the person's home. The initial introductory phase may take time if a client has had negative past experiences, as service users include many people who have been disempowered by the mental health system and are thus wary of any engagement (*321, 322*). Some PO services use a written agreement describing how the client and PO will work together but others do not, in cases where it could be off-putting for the client. In all situations, the client's needs and wishes guide the order and urgency of issues to be addressed.

Core principles and values underlying the service

Respect for legal capacity

The basic premise of PO services is one of respect for the legal capacity of the client. An individual cannot be involuntarily assigned a PO by their family, public authorities or the courts. Only the individual can request support from a PO and they are free to end the relationship at any time. The PO may only act with the consent of the client. The PO never acts as an authority figure in relation to the client, only as a support, recognizing and addressing potential power imbalances.

Non-coercive practices

The use of force or coercion is against the principles of the PO service. A PO cannot force a client to accept any services, including medical treatment. If the client experiences a crisis or a psychotic episode, the PO makes every effort to guide the person to the right social or health services, while respecting client preferences, which may have been discussed in advance. If a client is involuntarily admitted to hospital the PO remains in contact and continues to support the client. If the PO believes a client's behaviour is a serious risk to self or others, they notify the relevant authority.

Community inclusion

A key aim of the service is to support clients to be active participants in and leaders of their own lives. Inclusion and participation in the community can be sought and supported if the client wishes. The PO facilitates links with community services, organizations and activities, and helps the client to identify barriers or conflicts that may be preventing them from feeling included in their community, along with potential solutions. A PO can also support a client if they experience difficulties as part of living in the community, such as difficulties handling conflict, finding mediation services, or moving to a different community.

Participation

The PO service encourages the engagement of clients as well as user and family organizations in the PO management body and more broadly. These stakeholders have a key advisory role in identifying and ultimately addressing barriers that prevent individuals from accessing care, support and services available in the community. User organizations may share service evaluation reports and client satisfaction surveys directly with the National Board of Health and Welfare to inform PO practices and the development of overall PO programmes. The PO management body and the representation of key stakeholders plays an important role in bridging the gap between the PO and local authorities, and in driving system-wide change.

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 the confidence and skills necessary to take control over their everyday life. As the client gains greater influence and power over their situation, the possibility of recovery increases. POs receive training in the recovery approach to support them in their role (*321*, *324*). The PO service takes a whole person-centred approach to working with clients and providing the care, support and services they need. Recovery is not viewed in terms of recovery from a mental ill-health condition, per se, but in terms of the creation of new goals and finding new meaning in life. Recovery too, is not a linear process, but one in which different solutions or paths are tried, which may take different lengths of time and support depending on clients' needs (*324*).

Service Evaluation

The PO system is evaluated on an ongoing basis. Both quantitative and qualitative evaluation data is available on the effectiveness and efficiency of the service and has showed improved quality-of-life and socio-economic benefits for people using the service (*321, 326*). A rigorous quantitative study of 92 clients over several years found, "fewer psychiatric symptoms, a better subjective quality of life, [and] an increased social network" (*327*). Other evaluations have described more dramatic results, including: "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" (*321*).

The Swedish National Board of Health and Welfare also carries out regular evaluations (*321, 326*). A 2014 study showed that the support of POs improved the client's financial situation by empowering them to address issues like debt settlement and employment. Interestingly, clients' health care costs increased in the first three years but returned to pre-PO levels thereafter. The national report found, as

others had before, that there is a gradual shift away from supportive costs to rehabilitative costs, such as housing support and home care. Other evaluations noted benefits such as: more access to meaningful employment and the "provision of care and support consistent with what people wanted" (*321*, *326*).

Costs and cost comparisons

Sweden's PO services are provided free of charge to service users. In 2013, a new regulation entered into force that established permanent funding for the PO system (*321, 323*). Sweden's National Board of Health and Welfare recently increased the overall funding available for PO services from 99.9 million krona (kr) in 2019 (approximately US\$ 12 million)t to kr 130 million in 2020 (approximately US\$ 15.5 million)^t ([Bengtsson A], [Socialstyrelsen], personal communication, [2020]). This 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, the municipalities cover part of the PO salary and additional costs such as transport, expenses, etc. County councils may also be involved in funding PO activities; however, this varies significantly between counties.

The PO service in Sweden has reported socioeconomic benefits with PO services reducing government costs by approximately kr 700 000 per client (approximately US\$ 83 760) over a five-year period, representing savings equivalent to 17 times the costs (321, 326).

Additional information and resources

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

Videos: Paving the way to recovery – the Personal Ombudsman System: <u>https://www.mhe-sme.org/paving-the-way-to-recovery-the-personal-ombudsman-system/</u>

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2.6 Supported living services for mental health

Supported living services promote independent living by offering accommodation or support to obtain and maintain accommodation. Sometimes support is offered for basic needs, such as food and clothing, and for varying lengths of time. Supported living services are intended for people who have no housing or are homeless, and who may also have complex, long-term mental health needs. People may require extra support to live independently or need time away from their own home environment. For more detailed discussion on housing support please refer to section 3 – *Towards holistic service provision: Housing, education, employment and social protection.*

Supported living services should reflect and be responsive to the diverse needs people may have. The examples featured adhere to the fundamental principle that supported living services must respect a person's right to choose where and with whom they want to live. Therefore, services can take many different forms. Some supported living services are temporary; people may want to move out once they feel ready to live somewhere else. In other contexts, supported living services can help people to find longer-term housing and negotiate tenancy agreements. Both types are showcased in the section.

Some of the examples show that supported living services can be provided in a community group home or apartment, in which several people live together like a family. Others showcase housing support in which people who need supported living services live together with those who do not. Further examples show individuals who either live in their own home or on their own in accommodation supplied by the service, while accessing help from the supported living service.

The type and intensity of support provided also varies widely depending on the people's individual needs. For instance, some services may offer day and night assistance for daily living and self-care. Sometimes, staff and assistants live within the housing facility, alongside those using the service. In other supported living services, minimal care and support is provided, as people are able to manage living independently on their own. In some services, the intensity of support provided evolves over time, as the needs of people using the service change.

In many countries, supported living services have historically been hospital-based, isolating people and preventing them from participating and engaging with their communities. The following section showcases alternative services that depart from this model; they are community-based, recovery-oriented, consistent with human rights and respectful of the service users' right to legal capacity at all times.

2.6.1

Hand in Hand supported living

Georgia



Hand in Hand is a Georgian NGO providing supported independent community living facilities for people with long-term psychosocial disabilities, including people who have previously been institutionalized. Its mission is to create better living conditions for people with disabilities and to support their inclusion and integration into society (328). The NGO also provides personal assistance and training for families and/or individuals supporting those people with psychosocial disabilities.

Primary classification: Supported living service

Other classifications:

Community mental hea	Ith centre Commu	unity outreach Peer support
Crisis service	Hospital-based service	Supported living service
Availability in different location	ons:	
Yes N	0	
Evidence:		
Published literature	Grey literature	None
Financing:		
State health sector	State social sector	Health insurance
Donor funding	Out-of-pocket payment	:

Description of the service

Georgia is a fast-growing upper middle-income country. While in 2015 a five-year National Action Plan for deinstitutionalization and the development of community-based mental health services was published, Georgia's mental health system remains predominately institution-based (*329, 330*). In contrast, Hand in Hand offers a home-like, people-centred approach; each home admits no more than 5 adults who sleep in individual or double bedrooms. In the last decade, Hand in Hand has expanded from one to six houses and now accommodates a total of 30 adults at its houses in Gurjaani and Tbilisi.

People wishing to join a residence must complete a written application outlining the kind of support they require. This assessment includes details of the individual's personality, communication abilities, support needs and general compatibility with the other residents. The State Fund for Protection and Assistance of (statutory) Victims of Human Trafficking ultimately decides who can become a resident, although it takes into account Hand in Hand's own assessments. Those prioritized for acceptance include people with psychosocial disabilities who are part of the biological family of another resident (e.g. a child); those who were raised in foster families but moved out at the age of 18; and those who are living at home but don't receive family support.
Since reforms in Georgian law have ended guardianship and substituted decision-making for people with psychosocial disabilities, people must give their full consent to join the residences and are also free to leave if they wish.

Each house has 3.5 staff, called assistants, who work flexibly in 24-hour shifts so there is at least one always available at any time of day and night. Assistants use the principles of active support (331) to help residents make appointments with psychologists or social workers; help them participate in work, sport or leisure activities; and to accompany people to outdoor activities. Assistants also support service users to defend their rights and manage their personal affairs (332). Under the new laws which replaced the old guardianship system, assistants can also assume the role of a "designated supporter" of a resident, in cases where a mutual bond develops and both parties agree.

Other staff also attend to the needs of residents including psychologists. The Hand in Hand coordinator is based at the NGO's office in Tbilisi (332). The coordinator consults on individual cases, facilitates external medical care and also advocates for residents' rights before authorities. All staff receive training on a range of topics including: long-term care provision, recovery-oriented care, sex and disability; and management of challenging behaviour.

Residents are encouraged to participate in the daily activities of their choice in order to develop or maintain autonomy and support networks. Inclusion in the community is also encouraged and supported. Residents prepare food, take care of the house and garden, buy household products, contact and interact with neighbours, participate in hobbies, and attend various cultural events (333). Each resident receives a designated space to lock and store their belongings (334). They create and review their own support plans along with Hand-in-Hand assistants, using the MAPS (335) or PATHS (336) method, which are all based on the person's needs and wishes.

Core principles and values underlying the service

Respect for legal capacity

The Hand in Hand model fosters staff cooperation with residents to provide the assistance they need to live full lives. Support for residents' legal capacity is provided in accordance with the principles of active support (337). Live-in staff are trained to make sure individuals are empowered to make decisions in all areas of their lives. For instance, while residents usually decide as a group on meal plans and times, individuals can also make their own choices. People have full access to all of their medical and legal documentation and all personal information is kept confidential.

Each resident indicates a person they trust to be included in the development of their individual service plan; that may be a friend, a relative, a priest, a neighbour, or another assistant, and the service ensures their participation. Families and friends also have access to training sessions on how best to support individuals and promote a dignified, independent life.

Non-coercive practices

Hand in Hand avoids the use of coercion including forced medication or treatment (334). Staff undergo systematic training on non-coercive measures and de-escalation techniques, and training refreshers are given every two to three years. In the rare situations where a person has refused to take medication and their well-being has been negatively impacted as a result, staff go to great lengths to negotiate with

that person together with a trusted member of the circle of support. In most cases this has been a successful approach, however a few people have been hospitalized. Staff report any incidents involving coercion, along with the decisions taken and follow-up measures.

Community inclusion

Hand in Hand is geared towards promoting inclusion in the community. Residents often invite neighbours to visit, and attend birthday parties, other celebrations and social events. Half the residents of Hand in Hand homes have jobs in the community, and they receive support to both find and maintain employment (*338*). Residents are also employed in social enterprises managed by Hand in Hand. Some work for community-based businesses, or run their own individual enterprises, in domains such as farming, honey-making, confectionary production, crafts, and the manufacture of toys and household items from wood and other natural products. Some residents also work in the arts professions. One resident, for instance, is a member of the theatre troupe "Azadaki Garden" and participates in its productions (*334*). Residents are also encouraged to attend sporting events, the cinema, religious services, and eat out occasionally. Every year, they go on a holiday of 10-14 days to a resort in Georgia, accompanied by assistants.

Participation

Beneficiaries of the service are aware and informed about feedback and complaints procedures through which they can freely express their wishes, complaints or concerns to assistants and members of the administration (including the coordinator, director, managers, etc.). Feedback is reviewed by staff at weekly meetings and measures put in place as a result. Although people with lived experience and former Hand in Hand residents have not been hired as staff, volunteers or interns in the NGO, they are regularly involved in monthly discussions about the decisions regarding the service organization and development. One of the Hand in Hand residents works at a Georgian NGO that provides legal advocacy services. He is also to serve on the Board of a new Georgia-wide Hand in Hand initiative whose members identify as being survivors of human rights abuses in services.

Recovery approach

Hand in Hand supported living works in accordance with the recovery approach. Each resident in the house is empowered to become an active participant in their own recovery by making their own daily choices about their life, and by learning to live collectively in a safe environment. They are encouraged to keep their individual plans up to date so that they can regularly reassess their hopes and goals, as well as strategies for coping with fears. Individuals are also supported to develop skills that make life more meaningful and help them find a role in society, to help develop a sense of personal responsibility, identity and meaning. The housing service also promotes positive risk-taking by focusing concretely on peoples' strengths (328).

Service evaluation

An informal internal survey of five residents ([Dateshidze A], [NGO · Hand in Hand], personal communication, [2020]) found that people liked their living situation. They appreciated the fact that they are the main decision-makers, deciding what clothes they wear, when to clean their room and apartment, when to sleep, use the phone, who could visit them, and when they can visit friends and family, etc. A 2018 government report which evaluated a Hand in Hand house in Tbilisi found that the

accommodation provided an adequate standard of living in a hygienic and comfortable environment (334). It also found that individuals had access to a variety of services in the community and participated in entertaining and stimulating activities. Crucially, they were able to develop skills key to independent living including personal organization, cleaning, cooking, hygiene, using household objects, going to shops, pharmacies and using money.

Costs and cost comparisons

All Hand in Hand homes have a yearly budget of about 300 000 Georgian lari (@) (approximately US\$ 90 300) of which staff salaries represent around 60%. The average daily cost per resident in 2019 was @33 (US\$ 10)u. In comparison, more traditional institutional residences cost @29 per resident per day (US\$ 8.70), meaning that Hand in Hand homes are cost-effective while also providing residents with a higher quality of life. Residents of the houses are expected to co-pay a symbolic rent monthly of @15 in Gurjaani (about US\$ 4.50)^u, and @40 in Tbilisi (about US\$ 12)u, however, there are no strict rules or obligation for co-payment.

Since its creation in 2010, the service has demonstrated the feasibility of providing community-based mental health and supported living services. This recognition has resulted in the inclusion of Hand in Hand's homes as one of the Ministry of Labor, Health and Social Affairs' financed social programmes in 2014. This led to a near doubling of state funding per resident in 2018. Overall, the state now covers 80% of the total NGO's expenses. The remaining 20% of funds come from charities including the Open Society Foundations, as well as social enterprises operated by Hand in Hand or its residents. In kind donations and fundraising campaigns have also contributed to supporting the organization.

Additional information and resources

Website: www.handinhand.ge

Video Community For All, Georgia - Mental Health Initiative <u>https://vimeopro.com/gralfilm/include/video/336759271</u>

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2.6.2

Home Again Chennai, India



Home Again is a housing service for women with long-term mental health conditions, who are living in poverty and/or are homeless based in three states of India: Tamil Nadu, Kerala, and Maharashtra, including in the city of Chennai. Founded in 2015 by The Banyan, a non-profit organization providing institution- and community-based mental health services (339), Home Again supports those moving from institutionalized care to independent living in the community with other people in a home-like environment.

Primary classification: Supported living service

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

Description of the service

Home Again is driven by the belief that living in the community in a family or home-like environment should be available unconditionally – without the normative definitions of "fit for discharge" or "community readiness" assessments. Home Again is an integral component of The Banyan's Inclusive Living Service. It operates in two neighbourhoods of Chennai, and in other areas of Tamil Nadu, as well as in three districts in Kerala and two in Maharashtra. The Banyan also operates a group home in Kovalam, a seaside city near Chennai. In addition to its housing programmes, the NGO provides emergency care and recovery services to those in need of crisis support or acute care, and promotes psychosocial health through community mental health programmes, all of which serve the homeless, indigenous communities and those living below the poverty line.

The Home Again service rents homes in urban, suburban and rural neighbourhoods, near essential services such as shops, cultural hotspots and health care. Accommodation varies between houses and apartments, including even gated communities; each home welcomes four to five people. Choice is an essential factor in determining the place service users will stay; residents can choose between an urban or rural environment, with whom they wish to live, and their preference of shared spaces.

In addition to housing, the service provides a range of supports to residents to enhance their psychological health, community integration, quality of life and social mobility. People using the service are encouraged to engage with all aspects of living including work, leisure, recreation and a variety of social opportunities (340). Home Again also offers help accessing social entitlements; making members aware of their rights; medical and psychosocial support assessments and reviews; access to general health care; and for those with high needs, on-site personal assistance (341).

Entry is offered to people who have been living for a year or more in any of The Banyan's other facilities or in certain state-run psychiatric hospitals, and the service is restricted to people who are unable to live with family members. The state of Kerala excludes people with a history of extreme violence from the service. There are no other exclusion criteria (*342*). In 2019, 245 people received support in 50 houses, including those supported by a partner organization, Ashadeep, which operates six homes in Assam State.

The Banyan does not set rigid house rules; rather, people are encouraged to create their own routines and ways of living together responsibly, including boundaries and limits. Respect for privacy (340), discussion and non-intrusive oversight are trademarks of this approach and the members develop a sense of kinship with each other and their supporters. When conflicts arise, the case manager or the personal assistant mediates and helps to negotiate the best way forward.

For every 60 people, there are four staff members (a programme manager, two case managers, and a nurse), and 15–24 personal assistants, depending on support needs. The personal assistant's role is to understand and help people identify experiences and goals that they want for their lives, to collaboratively assess support needs, and to facilitate opportunities and access to resources (*343*). Personal assistants support individuals to care for themselves, manage their homes, as well as transact socially and economically by seeking employment and accessing banking, recreational and health services. Some homes have no staff, while others have sleep-in staff or full-time residential staff (*343*).

Personal assistants are recruited from local communities, often from rural backgrounds, and typically have no previous mental-health experience. Others may be former residents of a service of The Banyan (341). They undergo a week-long induction programme drawing from a curriculum (co-developed with the University of Pennsylvania) that outlines structure, process and protocols. Case managers, who have Masters level training in social work or psychology, visit the homes weekly, both to oversee the work of the personal assistants as well as to spend time with the residents. Case managers work with about 30 individuals and nurses also visit the homes weekly (341).

Core principles and values underlying the service

Respect for legal capacity

Access to Home Again is completely voluntary; people are free to do as they wish in terms of leisure, community interaction, or work. Most people using Home Again are supported to write an Advance Directive, which is revisited annually. Protocols at The Banyan (across all its services) govern access to case records and the use and dissemination of information from the service. Any use of information for purposes other than service delivery requires written consent from the client. When people enroll into the service, they fill out a consent form and indicate how they wish their information to be used. Any breaches of confidentiality by staff members are taken very seriously. If a person using the service feels that their trust has been broken, they can opt for a different person to work with them.

Non-coercive practices

Seclusion and restraint are not used within the service, and residents may leave if they wish. Regular social visits and Open Dialogue sessions (see section 2.1.3) are organized to ensure that any unintentional explicit or implicit coercion is addressed. Occasionally, a person in crisis is given the option to attend one of the Banyan Emergency Care and Recovery Centre (ECRC) facilities, which are also coercion free. Advance directives are used to follow the wishes and preferences of the person in a crisis situation. Residents can choose whether or not to take prescribed medication. Open Dialogue strategies are used to explore alternative perspectives and reasons for a person's choices.

Home Again has also had an impact on coercive caste and gender-based practices. While choice of housing is based on affinity groups, mixed caste groups have been seen to come together, as have mixed class groups. Home Again also represents the rarer model of women-led households and women living independently without the support of men.

Community inclusion

The Home Again programme specifically aims to promote the inclusion of people with psychosocial disability into the socio-economic fabric of the community. A range of support is provided for residents to participate in activities including village community meetings, creation of a self-help group or support network, initiation of a social enterprise as well learning basic skills (*344*). Relationships are fostered within the home, as well as beyond. Service users are encouraged to participate in social events and are supported to trace families, according to their wishes (*344*, *345*). The service also links people with local peer networks in the community.

Participation

People with lived experience are present across the staff and board from the founders to the senior management team; the aim is to achieve at least 50% representation over the next few years. Many personal assistants have also personally experienced distress which is considered to be a valuable source of lived experience that can improve their support for service users (341). Further, service users are encouraged to attend meetings of the Mental Health Commission set up by The Banyan and led by people with lived experience. The Mental Health Commission audits the feedback received from service users based on quarterly visits, interviews and feedback recorded by case managers in weekly visits. Anyone can attend these meetings, as well as monthly meetings of a Human Rights committee, made up of people who use mental health conditions. Service users also hold a monthly focus group called the Pulse meeting, which consolidates and reviews this feedback and plans how to incrementally improve services (*341*).

Recovery approach

Personal recovery or personal growth-based customized plans are developed through on-going dialogue. Both clinical and non-clinical tools that help build resilience, prepare for uncertainty, celebrate small and large joys, remain hopeful and look forward to the future, are all used in combination to provide a unique individual care plan. Monthly dialogue-based sessions help assess actions and progress towards goals. Service users articulate challenges and collaboratively identify meaningful life strategies using Open Dialogue. Case management involves the use of detailed assessments to determine the person's medical and psychosocial support needs and personalized care plans (*341*).

Service evaluation

An internal study of people using Banyan's services for more than 12 months in one urban and three rural Chennai communities, evaluated the experiences of 53 people who had chosen Home Again housing compared with 60 people who chose to remain in the Banyan's institutional facilities (regarded as care as usual). Measures were collected every six months using different questionnaires and scales, over a period of 18 months (*341*). Significant improvements were found for community integration in the Home Again group, compared with the care as usual group, after six months and 18 months (*341*). These results were based on a Community Integration Questionnaire that measures home, social and work integration.

Costs and cost comparisons

Overall funding support is provided by The Hans Foundation, Rural India Supporting Trust, Azim Premji Philanthropic Initiative, the Paul Hamlyn Foundation, Sundram Fasteners Limited, Bajaj Finserv and the HCL Foundation. The services are free of charge to the user. In 2019, Home Again cost ₹9060 (US\$ 123)^v per person per month, inclusive of all welfare, staffing, capacity-building and administration costs. This represents less than a third of the costs of government-run psychiatric facilities which cost ₹29 245 (US\$ 426)^w per person per month.

Additional information and resources

Website: <u>https://thebanyan.org/</u>

Videos:

The Banyan Home again Film Dec2018, <u>https://www.youtube.com/watch?v=4iX7tSwa2Dc</u> Home Again 16th Jan 2017 1: <u>https://www.youtube.com/watch?v=FOyLSMHJjVg</u>

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v Conversion as of February 2021.

w Conversion as of March 2021.

2.6.3

KeyRing Living Support Networks



Since 1990, KeyRing has provided supported living services for people with mental health conditions, psychosocial disabilities and drug and alcohol addiction (346). Its mission is to inspire people to build independent lives through flexible support, skill-building and networks of connection (347). KeyRing consists of over 100 networks of support across England and Wales (348), each with around 10 homes located within walking distance from each other so that KeyRing members can also connect with each other and become more involved with their community (349-351). The service's mission is to connect people and inspire them to build the life they want.

Primary classification: Supported living service

Community mental he	alth centre 🛛 🗹 Comm	unity outreach Peer support
Crisis service	Hospital-based service	e Supported living service
Availability in different locat	ions:	
Ves	No	
Evidence:		
Published literature	Grey literature	None
Financing:		
State health sector	State social sector	Health insurance
Donor funding	Out-of-pocket paymen	t

Description of the service

As a high-income country, the United Kingdom has a well-developed mental health system and was one of the first industrialized counties to begin a process of deinstitutionalizing mental health services in the 1970s and 1980s (*352*). However, a 40% rise in involuntary detentions under the Mental Health Act between 2005 and 2016 (*353-356*) and the inappropriate placement of people with psychosocial disabilities in nursing homes or their detention in prisons and forensic facilities (*357, 358*) reflected a move towards a 'risk' adverse approach within the mental health sector and a failure to provide sufficient support. KeyRing was established to fill this gap, providing support for independent, connected living arrangements for time-limited periods.

Housing is rented from local authorities or housing associations, or even owned by members. Networks are developed around existing, available accommodations so residents do not always have to move to join KeyRing, and thus abandon significant social and community ties (*348*). Community living volunteers live in KeyRing accommodations and provide informal support to members with day-to-day activities, including accompanying members to appointments for education, employment and volunteer activities (*348*, *359*). A community hub, central to the network, is allows KeyRing members to socialize with other service users and meet up with community living volunteers and staff (*360*). Other KeyRing staff

include community connections volunteers, support managers and community enablers who support residents in different aspects of their community engagements and personal lives (346, 360).

When a new arrival is approved as a KeyRing member, staff initiate a holistic review to determine the person's most immediate support requirements (*361*) and support them to develop a personal recovery plan. Staff training, through the Care Academy (*362*), covers health and safety, lone working, safeguarding, and supporting equality and diversity. Staff are also coached on developing KeyRing values, such as asset-based community development, empowerment, community organizing, and also on how to use the Outcome Star (*363*) to help members become more independent. Further specialized training and certification opportunities also are offered.

Core principles and values underlying the service

Respect for legal capacity

Legal capacity is a core principle underlying KeyRing's mission to promote independent living and facilitate autonomy. Staff focus on accompanying members based on their skills and experience (347), using a strengths-based approach to create an atmosphere of encouragement and positivity. Informed choices are always sought and members have flexible access to support including a 24-hour helpline and access to an advocate (364). Easy-to-read versions of documents are available so that fully informed independent decisions can be made (365). Residents choose where and with whom they live; they are not required to move house to join a network, since new networks can be created around existing accommodations (348). This creates a sense of responsibility and agency.

Non-coercive practices

Coercive practices including seclusion and restraint are never used within KeyRing services. Training is available to employees through the Open Futures Learning platform on de-escalation techniques and working with challenging people or those who self-harm. Staff and volunteers are considered as equal members of the community which prevents power asymmetries from developing. People are never forced to take medication and taking it is not a condition for continued provision of the service and support. If a service user is unwilling to take their medication, KeyRing staff discuss the risks with the individual as well as professionals, family members, care givers and even a peer volunteer, with the agreement of the service user. The 24-hour hotline is available should individuals need to contact a crisis counsellor urgently (*348*, *364*). If staff are not able to manage a crisis situation, they contact the local area's mental health and social work teams for support; but if a person is causing harm to other network members or staff, a safeguarding alert is raised with the Local Authority or police. In case a service user is taken to a hospital, KeyRing staff visit, liaise with mental health teams and deal with housing and financial matters.

Community inclusion

Linking KeyRing residents with community resources is an important part of KeyRing's approach (366). Having a range of support options within the area where they live encourages network members to think further than their support worker; they may call a friend if they are worried about something or visit their local café if they feel lonely – and thus participate directly in community life. Staff map out resources within the community and invite guest speakers to talk to members. Service users are encouraged to take part in clubs, groups and sports locally and other local community activities such

as neighbourhood improvement projects, campaigning for local change, and raising money for charity (364). People are also supported to find employment opportunities.

Participation

KeyRing members are involved at all levels of the organization; members can also take on volunteer or staff positions. Two members of KeyRing's Board of Trustees are people with lived experience in KeyRing services (*346*, *365*). Members also deliver presentations to local authorities, participate in staff and volunteer selection processes and share in the running of national KeyRing conferences. Members have an equal say with managers on appointments and editorial control of the organization's quarterly newspaper. A "Working for Justice" group, which campaigns for people with learning disabilities who have had brushes with the criminal justice system, has provided prison officer training in every prison in England. Members who are KeyCheckers monitor KeyRing services and a member satisfaction survey ensures service user feedback is heard (*365*).

Recovery approach

The recovery approach is central to the KeyRing philosophy (364) and is reinforced by the use of an asset-based community-development approach, whose core principles are to foster citizen-led, relationship-oriented, asset-based, place-based and inclusion-based development (367). Based on the holistic review of new members' most immediate support requirements, staff support members to prepare a recovery plan specifying short term and longer term recovery goals using the Outcome Stars Support Planning Tool, which considers ten stages of a person's journey towards self-reliance (363, 368). Positive risk-taking is also valued, and a Positive Risk Management Plan is developed with members to identify strategies to deal with difficult situations and increase wellbeing. Labelling is seen as limiting peoples' potential and is completely avoided (346, 347).

Service evaluation

During the fiscal year 2017–2018, 2001 people received support in 50 Local Authority areas, in networks that employed some 209 KeyRing staff (369). Over the following year, 2019–2020, KeyRing provided support to a total of 2213 people, with a staff and volunteer team of 220 (370).

Since the first evaluation in 1998, KeyRing has received consistently positive reviews of the quality of its service and its cost-effectiveness (*356*). In 2002, an independent evaluation of KeyRing concluded that it was "considerably beyond most organisations in terms of focus and outcomes" (*356*). In 2006, a UK Department of Health study looked at outcomes for members in three different networks, concluding that they enable people who had high levels of support needs from paid care workers or from family, to gradually live independently. The study found that KeyRing "helps adults with support needs to achieve more than traditional forms of support" (*356*). In 2015, a three-year evaluation of the KeyRing Recovery Network, which supports people recovering from substance misuse and addiction, stated: "Notable improvements were evidenced across various areas of participants' lives, including: wellbeing, retention of tenancy, attendance of mutual aid, engagement in meaningful activity, volunteering and ongoing abstinence"(*371*).

A 2018 evaluation by the Housing Learning and Improvement Network concluded that each year the presence of the KeyRing networks led to: 30% of members avoiding a psychiatric inpatient admission (lasting on average three weeks); 30% fewer cases of homelessness; 25% no longer requiring weekly

visits from community psychiatric nurses or social workers/care coordinators; 20% of members no longer requiring weekly drug/substance misuse worker visits; and 10% of members no longer requiring weekly learning disability nurse visits (351).

Other case study reports also state that adults achieve more at KeyRing in terms of their development goals, than through traditional forms of support, based on measures of well-being, retention of tenancy, ongoing abstinence and engagement in meaningful activity (356, 371). In total, 99.9% of KeyRing members successfully sustain their own tenancy (350). Finally, positive feedback on KeyRing also includes multiple testimonies from community stakeholders including law enforcement (346, 359).

Costs and cost comparisons

The service is funded by the social care budget of Local Authorities, which is allocated by the central government. Substantial cuts to central government funding since 2010, forced Local Authorities to raise income from alternative sources to support KeyRing, including business taxes and parking. The cost of the service varies according to needs, location and the recipients, who undergo a means test, in order to determine what co-payment they should contribute. A 2018 evaluation by the Housing Learning and Improvement Network (*372*) estimated the cost of support at £3665 (approximately US\$ 5100) per person per year (excluding housing or food); or £70 (US\$ 97)^x per week. The cost of KeyRing services is less than the cost of traditional living services, because members require fewer support services over time. The cost-effectiveness of the model has encouraged local and national authorities to invest in developing more networks.

Additional information and resources

Website: www.keyring.org

Videos: KeyRing Network Model: <u>https://vimeo.com/379267912</u>

Contact:

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x Conversion as of February 2021.

2.6.4

Shared Lives

South East Wales, United Kingdom of Great Britain and Northern Ireland



Shared Lives provides community-based support and accommodation for adults in need, including people with mental health conditions and psychosocial disabilities (373). Shared Lives is an alternative to care homes, home care and day centres and also provides transitional care after having been in hospital or the foster care system for young persons. Almost 1000 people are supported by Shared Lives in Wales (374), and over 12,000 people UK-wide (375).

Primary classification: Supported living service

Other classifications:

	Community mental hea	alth cer	ntre 🗹	Commu	nity outreach		Peer suppor	rt
\checkmark (Crisis service	ŀ	Hospital-based	l service		Supported	l living service	
Availabi	lity in different locati	ons:						
V	/es N	١o						
Evidenc	e:							
F	Published literature	\checkmark (Grey literature		None			
Financin	ng:							
<u> </u>	State health sector	<u> </u>	State social se	ctor	Health	i insurance		
	Donor funding		Out-of-pocket p	payment				

Description of the service

Shared Lives is a state-supported form of social care operating throughout the United Kingdom (376) providing support for not only people with mental health conditions and psychosocial disabilities, but also for those with learning disabilities, physical disabilities, or older people with a frailty or dementia (377). It provides people with support in a community environment in a place that feels like home (378), and includes accommodation, daytime support and short term support after discharge from hospital or to prevent admission.

The Shared Lives scheme in South East Wales currently provides supported living arrangements for over 500 people. There are more than 200 Shared Lives Carer households providing arrangements for the service, each of which can support up to three individuals at a time. The 13 Shared Lives team workers and four adult placement coordinators approve and train Shared Lives Carers (379), receive referrals, match the needs of individuals with Shared Lives Carers, and monitor the arrangements (377).

In 2019, a new service was launched by Aneurin Bevan University Health Board in partnership with South East Wales Shared Lives, to facilitate arrangements for people in crisis as an alternative to hospital admission, or to facilitate early discharge from inpatient settings. Under the new Shared Lives for Mental Health Crisis service, individuals can move in to or regularly visit the home of an approved and carefully matched Shared Lives Carer as an alternative to inpatient treatment (*380*). Emergency

placements with the Shared Lives for Mental Health Crisis service are offered on short-term basis (for up to six weeks) with trained families. Upon referral from this team or in-patient ward staff, a Carer is matched within 24 to 48 hours, and meets with the individual in their hospital ward or in the Carer's own home. If both parties agree, the arrangement can begin immediately.

Once this arrangement has started, the individual, a Shared Lives worker, and crisis team staff scheme co-produce a personal plan. The personal plan sets out the actions required to meet the individual's well-being, care and support needs, and how the individual's wishes will be supported to achieve their personal goals and outcomes (381). The plan is reviewed regularly with the individual.

Like their counterparts in the wider Shared Lives service, carers with the Mental Health Crisis scheme have a dedicated Shared Lives worker to support them with home visits and contact by phone and email as needed. They can access out-of-hours support through both Shared Lives and the Mental Health Crisis service. There are also regular carers meetings and an annual review process (*382*). For further support, carers also can join Shared Lives Plus, the national charity supporting Shared Lives schemes, for advice on aspects such as legal issues and human rights (*383*, *384*).

Core principles and values underlying the service

Respect for legal capacity

Choice, empowerment and autonomy, and therefore legal capacity, are at the core of the Southeast Wales Shared Lives scheme. Individuals are given information about Shared Lives and consent is required before a referral is made. Service users choose who they are going to live or stay with (382) and their personal plan is co-produced with Shared Lives workers, and regularly reviewed. Service users are encouraged to include wellbeing goals, specific personal wishes, and plans for the future. Individuals who would like support to make decisions are encouraged to include family members or other important people from their wider network, including professionals. Service users can also select an advocate if they wish.

Non-coercive practices

The use of coercion, force or restraint is prohibited by Shared Lives. Its staff and carers are trained in positive behavior support theory and techniques, as well as de-escalation and preventive measures, including awareness and avoidance of triggers. Collaborative risk assessments and management plans are in place for each individual. Individuals may need support to understand their own behavior, and techniques to positively adjust their lives, in order to address any safety related issues. As each arrangement is highly personalized, many of the triggers that are often present in an institutional, in-patient environment, which can lead to agitation and subsequent restraint, are absent in a Shared Lives setting.

Community inclusion

Community inclusion is at the core of Shared Lives values. All carers work from their own homes, regularly taking individuals out into the local community and introducing them to their wider social network, providing opportunities for people to engage in activities that support their recovery in a less stigmatized setting. Carers can support individuals to pursue activities, hobbies or interests, and to access education, learning and development opportunities. Carers also support an individual's

connections with their cultural or religious community, family and friends. Staff from the Southeast Wales mental health charity, Platfform, also support people using the Shared Lives Mental Health Crisis scheme to access community and peer networks, including projects and therapy groups led by the charity, MIND (*221*).

Participation

Individuals using the service and their representatives are consulted on a yearly basis via the service's annual quality assurance questionnaires which feed into quality of care review reports. Those within the mental health crisis project have a Recovery Quality of Life assessment at the beginning and end of their stay as well as a patient experience questionnaire. Changes to the service are devised using these results.

Individuals with lived experience participate within the Aneurin Bevan University Health Board's Mental Health Crisis Community of Practice and help to shape services including Shared Lives. They also informed decision-making during the development of the Shared Lives for Mental Health Crisis Project.

Recovery approach

The Wales Strategy for Mental Health (385) (Together for Mental Health) takes a rights-based approach and explicitly promotes the recovery model, as well as the empowerment and involvement of service users, at an individual, operational and strategic level. All Shared Lives services operate in line with the recovery approach, with the stated goal being provision to users of: "an ordinary family life, where everyone gets to contribute, have meaningful relationships and are able to be active, valued citizens" (386). Each service user's personal plan includes a detailed assessment of the individual's needs and personal (382) Skills that improve autonomy and confidence are developed and maintained, in line with the recovery approach.

Service evaluation

The Care and Social Service Inspectorate for Wales carried out a full inspection of the Southeast Wales Scheme in 2018, looking at quality of life, quality of care, and quality of leadership and management. It found a well-run service with carers who were carefully matched and able to offer support that met individuals' needs. Care planning was good, with a well-trained, motivated and skilled team. Effective structures and systems were also in place to ensure that care met identified needs (*382*).

In England, the Care Quality Commission, which regulates all Shared Lives Schemes, has consistently rated these services as providing the safest and highest quality form of care. In 2019, the Care Quality Commission rated 96% of all 150 Shared Lives schemes across the UK as "Good" or "Outstanding", including the Southeast Wales scheme (387-389).

A qualitative evaluation conducted through the Shared Lives Plus online platform in April 2019, found that 97% of respondents who used Shared Lives said they felt as if they were part of the family of their carers most or all of the time, 89% felt involved with their community, 83% people felt their physical health had improved, and 88% said emotional health had improved. Most said the support from their Carer had also helped them have more choice in their daily life and improved their social life (390).

Since its creation in September 2019, the Shared Lives crisis scheme has supported 59 individuals, with an average length of stay of 15 nights (391). These service users rated their patient experience using a Patient Experience Questionnaire, with an average score of over nine on a 10-point scale, which

is significantly higher than experience ratings of in-patient hospital care. People using the crisis service also complete the Recovery Quality of Life outcomes assessment. In a recent evaluation comparing quality of life outcomes for 44 of these service users compared with 15 control group participants, significant improvements were shown in their quality of life post discharge. People who used the Shared Lives Mental Health Crisis scheme had fewer admissions to acute inpatient units post-discharge than before they were admitted, and show fewer accident and emergency contacts and fewer onward referrals within mental health services, suggesting that Shared Lives is associated with a pattern of reduced service use over time (391). Individual testimonies about South East Wales Shared Lives also are highly positive (392-398).

Costs and cost comparisons

Service users of the Southeast Wales Shared Lives scheme undergo a means assessment and may be required to pay an assessed charge for their care and support. For the mental health crisis service, however, there is no cost to the individual. Carers receive between £340-£588 per week for residential care (approximately US\$ 475–820)^y, depending on the level of support. An independent report calculated that, on average, the "net cost of long-term Shared Lives arrangements was 43% cheaper than alternatives for people with learning disabilities, and 28% cheaper for people with mental health needs, saving an average of £26 000 (approximately US\$ 36 300)^z and £8000 (US\$ 11 170)^z per year respectively" (399). A different estimation stated that "by going into a Shared Lives home, rather than residential care or an alternative, an annual average saving of £13 000 is made for each person by councils" (400).

The Shared Lives Mental Health Crisis scheme costs $\pounds 672$ per week (US\$ 940)^r, whereas one week of in-patient hospital care amounts to $\pounds 3213$ (US\$ 4485)² in South East Wales. In combination with data suggesting improved outcomes, this suggests that Shared Lives for Mental Health Crisis is a highly cost effective (or high value) intervention. The organization's overall track record has contributed to the Welsh government's commitment to fully fund the Shared Lives for Mental Health Crisis scheme.

y Conversion as of March 2021.

 $z\$ Conversion as of February 2021.

Additional information and resources

Website:

Shared Lives <u>https://www.caerphilly.gov.uk/sharedlives</u> Shared Lives for Mental Health Crisis <u>https://abuhb.nhs.wales/about-us/public-engagement-consultation/transforming-adult-mentalhealth-services-in-gwent/</u>

Videos:

Shelley Welton & Simon Burch's Story: Setting up the service https://www.youtube.com/watch?v=8F55lboVbhg

Lindsey and Shaun's Digital story, Matching and introducing carers and services users https://www.youtube.com/watch?v=XTVmkn5NYRM&t=1s

Shared Lives for Mental Health Crisis: <u>https://youtu.be/auWBkPqUFz4</u>

Contact:

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2.7 Conclusion

The wide range of mental health services showcased in this document provided very different examples of good practice, however, all of them have arisen out of a realization that people are often not well-served by conventional care services and systems. The services presented have sought to find new ways of responding to people – ways that make human rights a central concern and work from a positive recovery approach. They are testimony to the fact that with imagination, creativity, commitment and leadership, real progress can be made in mental health care in very different settings across the world.

Although there are great differences between these services and the contexts in which they operate, there are also several commonalities:

- nearly all services showcased seek to help individuals and families articulate their experiences and requirements in their own words rather than using the language of diagnoses;
- they seek to address people's needs in a holistic manner across all areas of their life rather than making medication the central focus of their work;
- they are all responsive to feedback from the individuals and families that they work with, welcoming challenges and criticism, and changing and developing over time; and
- they work within their communities, emphasizing the importance of understanding and responding to mental health conditions and crises within their local contexts.

In highlighting these particular examples, it is not suggested that the showcased services are the only services that incorporate good practice, nor that they are perfect and without limitations. While these services demonstrate that it is possible to respect legal capacity and promote non-coercive practices, participation, community inclusion and a person-centred recovery approach, they each have done so in their own ways. In some cases, their strategies are similar, in other cases very different. None, though, are fully compliant with the CRPD and all could be improved. Further, few services have concrete outcome data, even in high-income countries, and the quality of evaluation data varies considerably across services. This particular limitation applies to most mental health services worldwide, as outcome evaluations have not been a central focus to date. While these services each provide positive examples of ways mental health care can be delivered differently, they cannot on their own provide the comprehensive range of services and supports that many people need in order to live full and inclusive lives in their communities. For this to happen it is important that services within the health system closely collaborate with social sector services.

Section 3 demonstrates the importance of housing, education and training, employment, and social protection interventions, if full community inclusion is to be achieved. While the mental health services described in this guidance provide some support in these areas, it is not their primary area of focus. In some instances, though, they have worked to overcome limitations by collaborating with other services and organizations, both governmental and non-governmental, to provide a more comprehensive response to the needs of individuals and families.

In addition, while these services all incorporate a human rights approach and seek to avoid coercive interventions in their own work, they are each part of a wider mental health system which often has different agendas and priorities. For example, all of these services are situated in countries where national laws allow for coercive practices. Also, some of the services have established narrow admission

criteria, in which people in crisis are excluded from benefiting from the service. Others are simply unable to cope with more challenging situations, referring people who are going through a difficult crisis to parts of the conventional service in which coercive practices still operate. These challenges emphasize the inherent limitations of a standalone approach to delivering mental health services. The reality of mental health work is that it is often complex and challenging and no single form of intervention or service will always be appropriate or successful.

The ideal situation is one in which a full range of services and supports is available to individuals and families within a connected network that promotes the positive values and principles outlined in this document. Section 4 sets out some important examples of efforts to create such a comprehensive network of services. While none of these networks has abolished coercive practices entirely, they have made substantial and genuine progress towards this goal.



Towards holistic service provision: housing, education, employment and social protection The previous section documented and described individual community-based mental health services from around the world that were selected as good practice examples. These services are strongly committed to delivering mental health interventions and supports in a way that is consistent with human-rights and the recovery approach, and they consistently consider ways to improve and achieve a higher standard of quality of care and support. In their different ways, they strive to respect individuals' legal capacity, to use alternatives to coercive practices, to foster community inclusion, to ensure the full participation of people with lived experience in all decision-making processes, and to adopt a recovery-based perspective on mental health.

As highlighted earlier, mental health and wellbeing are influenced by multiple social, economic and environmental factors, and have far reaching consequences in all aspects of our lives. As such, mental health services alone are not always sufficient to bring about a real transformation in the lives of people with mental health conditions and psychosocial disabilities. Today, many people in these groups have fewer opportunities in education and employment, and face discrimination when it comes to housing or social benefits. Having access to the full enjoyment of these services on an equal basis with other individuals, is a fundamental human right, as well as being an essential component of living a meaningful life and participating fully in one's community. As such, it is important to develop services that engage with these important life issues in a substantial way and ensure that all services and supports available to the general population are also available, accessible and of good quality for people with mental health conditions.

This section describes considerations for housing, education, employment and social benefits, and showcases several services from around the world that tackle these issues faced by people with mental health conditions and psychosocial disabilities.

3.1 Housing

Adequate housing is a human right that everyone is entitled to without discrimination. The CRPD encompasses the right to housing for persons with disabilities including the right to a secure home and community (401). Housing is an important determinant of mental health and an essential part of recovery. Unsafe and precarious living arrangements can exacerbate poor mental health and perpetuate a vicious cycle of exclusion (402). Studies also show that meeting the housing needs of people with mental health conditions and psychosocial disabilities is more protective against early mortality from natural and other causes, including suicide, than provision of any other needed service (403). Additionally, the quality of housing contributes to a person's perception of control, choice and independence – which are all factors intrinsic to recovery (404). Thus, addressing adequate housing is not only a human rights imperative, but also a public health priority.

The importance of providing support "for securing housing and household help" was identified as a necessary precondition for people with disabilities' ability to live and fully participate in the community in the 2016 report of the Special Rapporteur on the Rights of People with Disabilities (405). This situation is far from being achieved. People with mental health conditions and psychosocial disabilities are more likely to face multiple barriers to access and remain in stable, quality housing. Obstacles include stigma, discrimination, poverty and the lack of available facilities (406).

As a result, many people worldwide face homelessness and a life on the streets at some point in their lives (407, 408). For example, in Rio de Janeiro, Brazil, many people diagnosed with schizophrenia reported that they had been homeless at some point in their lives (409). A survey from Chengdu, China, also found that a significant proportion of people with schizophrenia had experienced a period of homelessness during follow-up (410). Similar results were reported by a study in Ethiopia (411).

While more precise and stronger research is needed, many studies have demonstrated a much higher prevalence of mental health conditions and/or psychosocial disabilities in street and shelter homeless populations than in the general population both in low- and middle-income countries (412), such as Ethiopia (413) and Colombia (414) and in higher-income countries (407) including the USA (415), France (416) and Germany (417). Because of the overrepresentation of people with mental health conditions among individuals who are homeless, it is essential that holistic service provision include housing support.

For many years, it was assumed that people needed treatment for their "mental health condition" first, if they were to be able to function in independent housing (*418-421*). The "housing first" approach moves away from this paradigm, by de-linking housing and mental health care. This approach, which started in 1988 in Los Angeles, California, and has expanded throughout the USA and various other countries, prioritizes providing permanent and affordable housing to people who are homeless, thus ending their homelessness and serving as a platform from which they can pursue personal goals and improve their quality of life. "Housing first" works on the principle that people's basic necessities such as food and shelter need to be addressed first, before attending to mental health issues. The approach is also based on the principle that people should be able to exercise choice in housing and support services selection and that this choice helps to ensure that people retain their housing and improve their lives (*422*). In this way, the "housing first" model it breaks the vicious cycle between poor mental health and homelessness.

Evaluations of the housing first approach have consistently shown that having access to housing without pre-conditions of treatment acceptance or compliance reduces homelessness because it enables people to obtain housing quicker and retain it for longer periods of time than treatment-dependent housing (423). There is also evidence to support the beneficial effects of the housing first approach on people's quality of life, including dimensions such as community adjustment and social integration, and some aspects of health (424, 425). As the research base is growing in favour of this approach (424, 426), the "housing first" model is now expanding across European countries and has even become national policy in Finland (427).

Behind effective and useful housing support lies the understanding that peoples' experience of living with a mental health condition or psychosocial disability is unique, and susceptible to change over time. This means that housing opportunities and any support services provided should be as diverse as possible to respond to each individual's needs, for example, in terms of the level of support provided, the location of assistants location (on-site or not), type of structure (group or individual) and level of permanence (strong or limited emphasis on moving out) (428).

The level of support, including the amount and type provided should depend on an individual's choices, preferences and needs. Some housing support services may only have staff coming in for a few hours per day or week to check in. Where additional support is needed, staff can be more present, with residents taking care of their day-to-day living for example, cooking, cleaning and work. Finally, some supported housing options have staff present at all times to provide care and assistance with daily living skills, including meals, paying bills, transportation and health care. For example, the Home Again services provided by The Banyan in Chennai (see section 2.6.2) is a type of supported housing that provides low to high levels of support in order to help people transition from institutionalized care (e.g. long-term hospitalization) to independent living in the community, by giving them the option of cohousing with others in a home-like environment.

Services are also differentiated as to whether assistants live in the housing facility or not. In some housing support services, such as the KeyRing Supported Living Networks, assistants do not live in the home of the person using the services (see section 2.6.3). Members choose where and with whom they live, and the housing contract is made in their name. Still, people using this service have access to support by connecting with their community-worker or any other peers in the network if and when they feel the need. There is also a helpline available so that members can reach someone for support at all times. In other housing services which often require higher levels of support, assistants live with the people using the services.

It is also possible to distinguish between group housing options, shared with other mental health service users, and individual housing options which includes generic community housing (not mental health specific). As an example of group housing, the "Protected Homes" (*Hogares Protegidos*) in Peru provide housing for up to eight residents with mental health conditions and psychosocial disabilities without family or community support, who temporarily live together in a house within the community (*429*, *430*). An example of shared housing that is not specific to mental health is the permanent supportive housing development led by "The People Concern" and "Fly Away Home", in Colden, Los Angeles, which provides housing to 32 formerly homeless individuals and families, including people with mental health conditions and psychosocial disabilities (*431*). In total, there are eight units, each with four bedrooms, as well as a unit for the unit manager. Tenants share a living room, kitchen and bathroom, and have their own individual private bedrooms (*432*). In addition to providing housing, The People Concern

also provides a set of support services on-site to ensure that programme participants are supported to remain housed. The property is built with plenty of community and outdoor space to encourage interaction among tenants. This aim is to provide housing to 20,000 people who are homeless in Los Angeles by 2028 by developing similar housing solutions in one third of the time and one third the cost per person, via a scalable and replicable development model (including modular construction, shared living units, etc.).

Finally, some housing services emphasize the need to move on to more independent housing arrangements in the future, while others do not. For example, the Shared Lives service in Wales is a scheme in which an adult who needs support and/or accommodation can move in, and stay with, an approved Shared Lives carer, for as long as they both wish (see section 2.6.4) (374). In some cases, carers and users have been living together for decades. Others do not constitute long-term options, and people are encouraged to move out after a specific period of time or when their situation has changed.

Overall, people's needs for housing should always be assessed. There is a wide range of options for housing support that can and should be provided according to people's needs. Regardless of their type and form, it is important to ensure that supported housing options do not reproduce institutional values and practices. As the Committee on the Rights of Persons with Disabilities has stressed, although institutionalized settings differ in size, name and set-up, they share certain defining elements. These elements include: isolation and segregation from independent life within the community, paternalistic approaches in which service users lack control over their own day-to-day decisions which are instead made by staff, lack of choice over with whom they live, rigidity of routine irrespective of personal will and preferences, supervision of living arrangements, obligatory sharing of assistants with others and no or limited influence over the choice of who one is assisted by on a daily basis (74). While institutional settings significantly reduce people's opportunities to make their own choices and interact with others, supported housing options, on the contrary, aim to expand them.

3.2 Education and training

Education constitutes an essential building block of human and economic development and has wideranging impacts on health, employment, poverty and social capital (433, 434). As such, it has been at the forefront of international guiding documents such as Sustainable Development Goal 4 (435) and the CRPD (436).

Access to good quality education opportunities is not uniform across different groups. Many adults with mental health conditions and psychosocial disabilities have had their education halted or interrupted during childhood, adolescence or early adulthood (436-438). In low- and middle-income countries, studies show that people with mental health conditions have experienced heightened levels of exclusion in education (439, 440). They have lower rates of initial enrolment in school, are more likely to face discrimination and stigma in education and are more likely to drop out and leave school early (441). This is also the case in many high-income countries. For instance, a 2019 systematic review on childhood disability and educational outcomes in the USA showed that people with mental health conditions and/or psychosocial disabilities consistently had lower graduation rates and higher dropout rates (442). Another study showed that they had lower chances of completing a post-secondary education degree (443).

This education gap carries important implications in adulthood for people with mental health conditions and psychosocial disabilities, by affecting their future prospects for employment, income and standard of living (444). The lack of educational opportunities constitutes an upstream barrier to their full inclusion and participation in the community and contributes to perpetuating a cycle of social and economic exclusion (438).

In addition to providing access to good quality mental health services and supports (436), it is essential to provide adequate and quality education as well as lifelong learning opportunities (445), to ensure that individuals can get the qualifications or knowledge necessary to have a job or a livelihood that corresponds to their interests, wishes and needs. To that effect, it is essential that schools and universities are built on inclusive approaches to education, in which curricula and school settings adapt to the needs of every learner, including persons with disabilities (440, 446). In addition, appropriate health and social support need to be provided, alongside varied teaching methods and/or reasonable accommodations within the mainstream education system. This can include online classes, lighter schedules, individual assistance, peer support or assistance in navigating the school system.

Additionally, supported education services exist in some places to provide assistance to adults with mental health condition and psychosocial disabilities to go, or return, to school (444, 447). Those services, while diverse in the type and level of services they provide, generally support individuals to identify their educational goal, (re)enter an education programme of their choice, coordinate with other mental health services and other community-based resources, and cope with the difficulties related to studying and navigating the school system (444, 448, 449). Many also provide one-to-one and/or group skill-building activities to develop transversal skills that can be helpful in an education setting (for example, time management or emotional regulation). Some supported education programmes are available as part of an educational curriculum, while others are independent, community-based services or work in partnership with the school systems. While more evidence is needed to rigorously assess the impact of supported education programs, there is preliminary evidence to suggest that such services can help individuals build better self-esteem, progress towards their education goals and develop a sense of hope (444).

Ledovec is a recovery-based organization that has been providing supported education services in the Czech Republic since 2006. Depending on the person's needs, support can begin before, and continue throughout the study period. Support offers are varied, and include activities like choosing a suitable school, preparation for any entrance examination, support in coping with the ordinary study duties and dealing with stress. Ledovec workers can mediate discussions with the school staff and provide assistance in implementing rights and personal interests at school, and also assist individuals in preparing their transition from a school to a working environment. Families, as well as education professionals close to the person are included in the process, and peer support groups are organized to ensure that a strong support system is woven around the person. Finally, Ledovec raises awareness on mental health conditions in the education system and creates pluri-disciplinary support networks made of professionals from the educational, social and medical sectors to advocate and remove educational barriers in Czech society for people with mental health conditions and psychosocial disabilities.

Beyond education as offered in schools and universities, there is a growing movement to establish "recovery colleges" in various countries - safe supportive spaces where people with mental health conditions can develop the skills, techniques and knowledge for recovery (450, 451). These colleges share some characteristics of formal education: registration, enrolment, term curricula, full-time staff, sessional teachers and a yearly cycle of classes; and some are actually located in mainstream adult education institutes (452). As such, while Recovery Colleges are not designed to help people to get a specific job at the end, the knowledge and skills that individuals may derive from this experience may be quite helpful for finding and maintaining a job (453). People may use the college as an alternative to mental health services, alongside support offered from mental health services, or to help them move out of mainstream mental health services altogether. In Kampala, Uganda, Butabika National Referral Hospital has established the on-campus Butabika Recovery College (BREC) where people with lived as well as professional experience of mental health conditions co-design and co-deliver regular teaching sessions on recovery-related topics. Most teaching sessions focus on "what helps" and "what hinders" recovery although BREC also offers skills-based teaching sessions. Students of the college are mostly users of Butabika inpatient and outpatient services, though BREC is also open to family members and hospital staff. The co-production of the courses ensures that people with lived experience bring their expertise to the design, development and delivery of the courses offered (454).

Individuals may want to undergo specific vocational training to learn practical skills or trade, which in turn can be helpful to get a particular job (see section 3.3). Often, these training opportunities don't require the prerequisite of a diploma or specific qualification. For instance, ENOSH - the Israeli Mental Health Association, provides a range of community-based mental health rehabilitation services, one of which is vocational mental health training. The programme focuses on three areas: bicycle mechanics, culinary skills and public speaking. The programme is spread over five months and provides a psycho-educational training that aims to improve personal recovery and occupational skills. The training process includes six parts: enrolment, building a personal plan, professional training, internship, graduation with a diploma, and support with employment opportunities. Participants in this initiative engage in empowerment and mentoring processes, and benefit from professional training and hands-on experience (455) that directly leads to employed at bicycle repair shops in the open labour market or continue their supportive employment at ENOSH's Bicycle Repair Shop. Since 2014, 233 people have graduated from the programme and an evaluation of the Ramat-Gan branch showed that 61% of graduates were employed, 29% were provided with supportive employment and only 10% remained unemployed (456).

Individuals may also wish to study for the satisfaction and meaning of learning without a specific job, or outcome in mind. Learning should be considered as an important aspect of recovery in itself, as it is about acknowledging each individuals' strengths and potential, enhancing access and inclusion, and nurturing a sense purpose and meaning (457).

Finally, while many adults with mental health conditions and psychosocial disabilities may not have been able to receive an adequate and quality education during their childhood and adolescence, developing and preserving initiatives that bridge the education gap in adulthood is essential to ensure that individuals, can benefit from the personal, social and professional benefits of learning, if they wish. Mental health services should therefore routinely ask about education disruption and future aspirations and facilitate referrals to appropriate services in the community.

3.3 Employment and income generation

Most people, including those with mental health conditions and psychosocial disabilities, want to engage in meaningful work (458, 459). Having access to paid employment can not only provide financial stability and facilitate access to basic needs such as housing, it can also improve one's quality of life by adding some daily structure and a sense of achievement, purpose, autonomy and contribution to society (460, 461). Work can be also linked to a sense of identity and status, and can contribute to strengthening one's social network (73). As such, having access to voluntary or paid meaningful employment is intrinsically linked to recovery.

Despite the right of persons with disabilities to work, on an equal basis with others (462), discrimination around the world against people with mental health conditions and psychosocial disabilities persists to this day (463) and unemployment rates among this group are consistently higher than the general population, with known detrimental effects on well-being (464, 465). In OECD countries, people with mild to moderate conditions such as anxiety and depression are twice as likely to be unemployed than the general population (465, 466), and those who are employed tend to report more precarious contracts and lower payrates (465). Additionally, a cross-survey of 27 countries with varying income levels reported unemployment rates averaging at 70% among participants who had received a diagnosis of schizophrenia (467). The gap in employment rates can be attributed to several factors, such as stigma and discrimination, the lack of meaningful support, individuals' fear of losing access to social benefits, or the difficulty of dealing with mental health conditions in early adulthood without appropriate support (often a transition period into employment or future training) (459, 467-469).

Various approaches to supporting people with mental health conditions and psychosocial disabilities to enter or re-enter employment have been developed throughout the world. Historically linked to institutional care, sheltered approaches in which people are given work in protected environments with other people with disabilities, have been predominant (470). However, this kind of approach is gradually disappearing because of the generally poor quality work offered by such employment (poor working conditions, repetitive nature of the work, low salaries, no prospects for professional development etc.), and also because of the very low rates of transition to the open-labour market, and the difficulty of creating a financially viable structure in a non-competitive setting (470). This setting also leads to the segregation and marginalization of people with mental conditions and psychosocial disabilities from the community.

Other approaches are based on beliefs that people out of the labour market need to receive some training before accessing any form of employment. This approach can take various names but is commonly known as vocational training. People usually receive training courses (on generic or specific work skills, personal development, or specific social or cognitive skills etc.), participate in workshops to get acquainted with employment expectations, and/or receive counselling (471) (see section 3.2). The approaches are particularly useful when they are targeted to help individuals find a job that is meaningful to them.

Some services provide a period of **transitional employment** before helping the person obtain employment in the open market. This can be considered a stepwise process in which people gain professional experience in programmes specifically for those with mental health conditions and psychosocial disabilities, which can be then used as a stepping-stone for future prospects of employment (*471*).

The Clubhouse model is a recovery-based example of a service providing vocational training and transitional employment opportunities before providing support to access open-market employment. Its approach involves a period of preparation before members attempt to return to competitive employment (194). This period of preparation is founded on creating a "work-ordered day" and a co-management system in which Clubhouse members have shared responsibility and ownership for the good functioning of the service (planning for groceries, cooking, managing Clubhouse funds, handling new applications and other). This approach builds the self-esteem and competencies of members who are then better acquainted with what is expected in a paid position. The Clubhouse also supports members in identifying and accessing transitional employment that has meaning for the person concerned and assists them to progressively return to the job market (194). Transitional employment positions are time-limited (usually between six to nine months), during which "the Clubhouse develops and maintains a relationship with the employer, [and] provides onsite training and support" (194).

Some mental health services have promoted the creation of **social enterprises** that provide employment for people with psychosocial disabilities. These enterprises compete with other businesses in the open market, pay their workers the going rate for their work, and provide decent conditions and security (470). (see the example of Trieste in section 4.1.3). In Hong Kong, the New Life Psychiatric Association, which was formed and is owned and managed by a group of individuals who have received a diagnosis of a mental health condition, has created several social enterprises in various domains like catering, retail, and ecotourism (472). These combine training and employment to "establish a viable, ongoing business that can generate income". The profit is then reinvested to achieve the social mission of the enterprise, which is to provide training to people with health conditions in real work settings and support them to gain necessary skills and confidence for open employment and community integration (472). As such, each social enterprise serves as a real work training site and provides training placements for service users who work as trainees. As people improve in their work skills and capabilities, they are promoted to senior trainees. With further progress, the association's placement officers support them to find employment in the open market.

Another example of a social enterprise employing people with mental health conditions and psychosocial disabilities is the Parivartan Café, located on the grounds of the Ahmedabad Hospital for Mental Health, in Gujarat, India. The café has been running successfully since October 2017. It is managed by people with lived experience and provides vocational training to others. The aim of the café is to ensure that people with mental health conditions and psychosocial disabilities have more employment opportunities and also to create positive mental health awareness within the community itself. A monthly honorarium of 3000 Indian rupees (US\$ 41)^{aa} is provided, in addition to free meals. This honorarium is 50% higher than the official daily minimum wage. Employees have the support of a psychologist, who helps them with anything they may need, from dealing with difficulties in their jobs, to discussing their own health and wellbeing.

While vocational training and transitional employment follow a "train then place approach", another way to provide employment support for people with mental health conditions and/or psychosocial disabilities is through a "place then train" approach. This is often called **supported employment** and has a very strong empirical evidence base (471). These programmes do not provide training before employment but instead prioritize accessing employment in the open market. They then provide support and training, if necessary, while the person is engaged in work (470). These programmes have been

shown to have good or better outcomes than vocational training rehabilitation, in terms of gaining competitive employment (473). People in supported employment also earned more and worked more hours per month than those in pre-vocational training and vocational training (473).

Individual placement and support (474) is a specific model of supported employment with an extensive evidence base from many countries (475-482). Individual placement and support is based on a number of principles, defined by a fidelity scale (483). It focuses on conducting a rapid job search (rather than focusing on training or counselling first) in a competitive employment setting with no artificial time limit and equal pay for co-workers with similar duties. It also works to develop job opportunities for people by reaching out to employers, ensuring that client preferences guide decisions, providing individualized time-unlimited supports and helping people to access social benefits (474). A systematic review of 27 randomized controlled trials demonstrates that this approach leads to higher competitive employment rates when compared to traditional vocational rehabilitation across all studied settings (484).

Another common and important approach to employment and income generation is the development of small businesses and livelihood programmes to provide opportunities for people with mental health conditions and psychosocial disabilities. For example, the organization Basic Needs is an international NGO, now known as CBM Global, that provides support for people with mental health conditions and/ or a diagnosis of epilepsy to access or return to work, alongside a range of other services such as improving access to treatment, development of community-based mental health services, etc (485). They work with local partners and ensure that livelihood is considered an integral part of individuals' recovery process. In one of their projects, Basic Needs Ghana, they have supported 650 people in Northern Ghana to secure livelihoods in the area of their choice, which included vegetable farming, livestock rearing, gardening, and apprenticeships in tailoring and dress-making (486).

Finally, efforts also need to be made to support people with mental health conditions and psychosocial disabilities in their work environment, and also to support their return to previously held employment. This may require support and accommodations to be made at and by the workplace (487, 488). Overall, there are a large variety of ways to provide support for employment. Because each individual's requirements are different, work schemes considered should best fit a person's aspirations at that point in time. Some people may find a stepwise approach to employment more helpful and build-up their confidence and skills through volunteering or any other form of community-based involvement. Others may prefer to start directly in their preferred employment and benefit from work accommodations (such as flexible working, home working, lighter schedules, sick leave and graduated return to work arrangements etc.). Still others may not feel they are ready for work, or they may not wish to work at all, and some may feel comfortable with an entirely independent employment contract.

3.4 Social protection

There is a well-established, two-way relationship between financial hardship and poor mental health (489). Living in poverty and conditions often associated with poverty, such as poor housing, insufficient nutrition, violence, lack of access to health and social supports amongst others, increases the risk of developing a mental health condition and psychosocial disabilities. People with mental health conditions and/or psychosocial disabilities are also more likely to drift into or to remain in poverty because of the discrimination they face.in employment and education (465) (see section 3.3). Higher rates of unemployment also mean fewer opportunities to access contributory schemes such as social insurance (490).

More people with mental health conditions report being in debt compared to people without similar conditions (491). Additionally, while employment is generally a positive factor when it comes to mental health, this is not always the case and some people may find it harder to work during some stages of their lives due to their condition or disability. The struggle to secure a stable source of income can induce a lot of stress and undermine or worsen one's mental health. As a result, social protection programmes and benefits can provide a lifeline for people who are unable to provide for themselves, temporarily or for longer periods of time, and as such constitute an essential aspect of recovery (492).

The right of persons with disabilities to an adequate standard of living and social protection without discrimination on the basis of disability is a key provision in the CRPD (493) and includes both the social protection programmes available to the general population (such as pension systems, job-seekers allowances, and all other mainstream social protection schemes) and schemes targeting people with disabilities specifically. Both are crucially important to ensure the full inclusion of individuals with mental health conditions and psychosocial disabilities on an equal basis with others in society. This section, however, focuses on issues related to disability-specific benefits.

Despite the human-rights standards set by international law, the practice in many countries demonstrates that people with mental health conditions are, in fact, discriminated against in relation to disability-specific social benefits (494, 495). In OECD countries, for instance, current waves of policies which aim to tighten assessment processes and narrow the eligibility criteria for disability benefits disproportionately affect people with mental health conditions (494, 496, 497). In Britain, for example, a study estimated that that claimants with a mental health condition were 2.4 times more likely to lose their entitlement to a disability living allowance than those with a non-mental health related condition, such as diabetes, neurological or musculoskeletal conditions (498).

Another form of discrimination stems from the fact that it can be particularly difficult for people to navigate the complex application processes and eligibility assessments inherent to many social protection systems (499, 500). For instance in India, some argue that "many who would qualify for [disability] benefits are prevented by their disability from obtaining the disability certificate without assistance" (501). A survey from the UK showed that four-fifths of people with mental health conditions and psychosocial disabilities who had made welfare claims struggled to find the required information to submit in support of their claim, and nearly all of them found the application process difficult (500). In that same study, nine in ten participants (93%) said that their mental health deteriorated in anticipation of a medical assessment (500), which goes to show that assessments and application processes are extremely stressful and can have considerable impacts on people already struggling with poor mental health (502). Furthermore, as access to disability benefits often relies on medical

assessments, psychiatrists act as a gatekeepers for persons with mental health conditions and psychosocial disabilities. This can act as a disincentive to access social protection benefits. Having a record of a mental health condition also acts as a disincentive for applying for benefits in that it can disqualify people from obtaining many types of employment.

In many countries benefits are contingent only on variables such as impairment type, individual or household resources, or estimated capacity to work, rather than being based on needs (503, 504). This takes a reductionist approach to disability that obscures the fact that by definition, disability exists because of the environment in which the person is situated and the societal barriers that they face. For instance, focusing only on impairment type fails to address the fact that individuals with similar conditions may have widely different needs in terms of type and intensity of care and support needs, depending on their living arrangements and life aspirations. Moreover, in many countries, to qualify for social benefits, the person must satisfy a means test, which often does not take into account the significant disability-related costs persons with mental health conditions and psychosocial disabilities face to achieve the same standard of living as others (505).

Furthermore, focusing on an evaluation of work capacity completely overlooks the widespread stigma and discrimination within the employment sector and the resulting difficulty in finding employment experienced by many job-seekers with mental health conditions and psychosocial disabilities (506). Under this approach, individuals are certified as being "unable to work" in order to access social protection programmes, which is in direct contradiction with the right to work recognized in the CRPD. Most people with mental health conditions and psychosocial disabilities would be actually positioned to work if labour markets were inclusive and people were provided with support and workplace accommodations (488). Additionally, fear that starting a job and earning an income would reduce entitlement to benefits may also further marginalize people and prevent their full inclusion in society (503). Against this background, there is a need to move away from the "incapacity to work" approach, particularly amongst young people, and promote an adequate and flexible combination of income security and disability-related support to promote economic empowerment and employment (490).

Overall, recent evidence suggests that conditionalities within social protection programmes – in which access to benefits is dependent on people agreeing to meet certain obligations (for example, mandatory, work focused interviews, training and support schemes, or job search requirements) – are largely ineffective and inappropriate for people with mental health conditions and psychosocial disabilities, and "in many cases, it triggers negative health outcomes" (507). Such conditional benefits can also contribute to creating "welfare stigma", whereby people receiving social protection are stigmatized and discriminated against for being benefit recipients (508, 509). This dynamic was highlighted by a study in Latin America, in which social benefits recipients diagnosed with bipolar disorder reported higher levels of self-perceived stigma compared to non-recipients (510).

There are many ways to ensure that social benefits are tailored to the needs of the individual and thus support their inclusion in society. One of these ways is to provide an unconditional component to social protection. For example, in Sweden, a 2015 study found that providing a monthly unconditional cash allowance of US\$ 73 for nine months to people with mental health conditions and psychosocial disabilities led to significant improvements in their perceived quality of life and social networks, and statistically significant (but clinically modest) decreases in depression and anxiety symptom severity compared

to a control group (511). In a review of social protection systems and mental health, Senior et al. concluded from current evidence that: "introducing an unconditional component of the welfare system is likely to improve claimants' mental health (and consequently their ability to work) without reducing their desire to work" (502).

There is also a need to develop a source of funding that follows people with mental health conditions and psychosocial disabilities, based on their expressed needs. A good example of this is the concept of Personal Health Budgets, which are allocations of money that individuals are able to spend on the services of their choosing (*512*). This holistic, person-centred approach to care and support empowers individuals to use funding in possibly new and innovative ways that goes beyond traditionally commissioned services (*512*). Personal health budgets presume individuals are the experts on their own lives and well-being, and allow them to take control of the services and supports they may wish to receive, which facilitates a more meaningful, integrated, inclusive and fulfilling life for recipients. After its implementation in the UK, there has been positive evidence and feedback to support its increased use (*513-515*).

The city of Trieste, in Italy, has implemented a successful example of individual health budgets for people who need highly personalized care and support to fully exercise their right to housing, employment and social inclusion (see section 4.1.3) (516). The 160 participants identified their goals and needs in personalized care plans, on which their health budget depends. The latter can be used to meet housing, employment, or social relationships needs, thus fostering a holistic vision of care and support. This needs-based approach enhances individuals' level of autonomy and increases the personalization of care. Through the health budgets, "a whole range of community resources is implemented in an integrated way, [and] services based on a personalized care plan shift from rigid, preconceived programmes to flexible and diversified ones" (516).

In 2015, the Government of Israel, the Joint Distribution Committee, and the Ruderman Family Foundation, partnered to set up "Israel Unlimited", a personal budget pilot program, which benefited 300 people with a range of disabilities in 2019 (517). In this program, participants are connected with a care coordinator with whom they identify their life goals and how to get there (518). Once they have a plan, participants receive an allocation of money based on what has been discussed, to achieve their life goals. As Avital Sandler-Loeff, director of the programme reported, "here, we allow people to choose the lifestyle they want. It means taking the person's dreams and aspirations and seeing how we can help them get there" (519). As such, supported decision-making is an essential part of their work. They also work with service providers and families to deconstruct preconceived beliefs that individuals with mental health conditions and disabilities are unable to make decisions for themselves (518). Beyond the positive feedback this project has received from participants, preliminary findings also suggest that it cost 20-30% less than the current disability benefit system in Israel, while empowering people to decide on their care and support (518).

More generally, it is fundamental to ensure that people are provided adequate support to access and make decisions with regards to the social benefits that they are entitled to, in line with human rights requirements. Initiatives such as Personal Ombudsman (see section 2.5.5) can play a key role in supporting individuals to navigate complex benefit systems. The USP-K Nairobi Mind Empowerment peer support group, an association registered with social services and the National Council for Persons with Disabilities, provides a good example of how a peer support organization may assist people in accessing social protection, tax exemptions and economic empowerment programs (see section 2.4.2).

The support group helps members to register as having a disability and once successfully registered, information is provided around disability benefits and other funding opportunities that the person may now be able to access. These could include education grants, trade tool grants and waivers on local markets operations fees for those in informal employment. The group will also discuss what kind of services the person may want or need, and how they can be supported to access them. Providing tailored advice about welfare benefits to people with mental health conditions and psychosocial disabilities can actually cut the cost of health care by reducing the lengths of hospitalizations, preventing homelessness and preventing relapse of mental health conditions (*520*).

3.5 Conclusion

Ensuring that individuals with mental health conditions and psychosocial disabilities have access on an equal basis with others, to housing, education, employment, and social protection is fundamental for the respect of their human rights, and for their recovery. The next section highlights some examples of countries around the world that have established networks providing a variety of integrated mental health services but also a range of other key services, and that collaborate with services from other sectors in the community to provide comprehensive support to people with mental health conditions and psychosocial disabilities in all aspects of their lives.


Comprehensive mental health service networks

In several places around the world, individual countries, regions or cities have developed service networks which address the social determinants of health and the associated multiple challenges that people with mental health and psychosocial conditions face every day in all aspects of their lives. Crucially, these networks are making efforts to go a step further and work to rethink and reshape the relationships between services and the people who come to them for help. These networks of services have, in some cases, been explicitly inspired by a human rights agenda and have worked to establish recovery-oriented services. While they are focused on delivering a diversity of mental health services, they also recognize the importance of addressing key social determinants and actively collaborating with other sectors such as housing, education and employment. Many are also seeking to create the conditions for genuine partnerships with people with lived experience to ensure their expertise and requirements are integral to the services being provided. Several examples of mental health networks are provided in this section; some well-established, structured and evaluated networks that have profoundly reshaped and reorganized the mental health system, as well as some networks in transition, which have reached significant milestones.

Showcasing these networks is not meant to imply that human rights standards are being met in all the network services at all times. This is not the case in any part of the world. However, these networks provide inspiring examples of what can be achieved with political commitment, determination and a strong human rights perspective underpinning actions in mental health. These examples are living proof that policy makers, planners and service providers can create a unique system of services that people with mental health conditions and psychosocial disabilities want to use and find helpful, and that produce good outcomes, protecting and promoting human rights.

4.1 Well-established mental health networks

Well-established networks have been built over decades and are constantly making strides to ensure that the rights of the people they serve are fully respected, and that the highest attainable standard of health is achieved for all. Common features among these networks include: a strong and sustained political commitment to reforming the mental health care system over decades, so as to adopt a human rights and recovery-based approach; the development of new policies, laws, budgets and an increase in the allocation of resources which reflect political will; and the development of community-based mental health services, which are integrated and connected with multiple community actors from diverse sectors including the social, health, employment, judiciary and other sectors.

4.1.1

Brazil Community Mental Health Service Network

A Focus on Campinas



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. Operating under Brazil's unified public health system (SUS), the network of comprehensive services, including the communitybased mental health centres, are a product of the powerful psychiatric reforms initiated during the late 1970s, which shifted the focus of treatment from hospitals to communities, within a supporting legal and regulatory framework. Campinas, a Brazilian municipality in São Paolo State, provides a model of how this works at a local level, where all services are provided through this model, following the closure of the city's psychiatric hospital in 2017.

Coordination of services and foundation principles

In Brazil, community-based mental health care is delivered nationwide through a comprehensive network of services guided by human rights principles and a community-based approach. The network reflects the individual, family and community. How the network is configured in any particular area of Brazil reflects the unique needs of that area. Community-based mental health centres (*Centro de Atenção Psicossocial* (CAPS)) and community-based primary health care centres (CBHCs) are the primary coordinating mechanisms in the network. These services are complemented by the others in the network, including specialist services providing mental health support to CBHCs, street outreach teams, deinstitutionalization strategies, mental health beds in general hospitals and emergency and urgent services. A detailed description of a CAPS III is provided in section 2.3.2.

Key services and how they operate

Community-based mental health centres (CAPS)

Community-based mental health centres are the cornerstone of the community-based mental health network in Brazil. The CAPS approach is rights-based and people-centred, and their primary goals are to provide psychosocial care, promote autonomy, address power imbalances and increase social participation. CAPS provide mental health care support to individuals with severe or persistent mental health conditions and/or psychosocial disabilities, including during challenging and crisis situations. As a network cooordinating body, CAPS also offer support to other mental health and general health services to fulfill their role in the broader community-based mental health network. In addition, CAPS develop and implement strategies to link with other community resources and services in health, education, justice and social assistance, with the aim of promoting and guaranteeing rights.

CAPS are denominated according to catchment area, operating hours and target population. Depending on the size of the population and area covered, CAPS I, II and III levels exist for the adult population, with specific services for children and adolescents (CAPSi) and for problems and needs associated with substance use (CAPSad). A CAPS III is open 24 hours a day, seven days per week, providing overnight accommodation if needed. They can be accessed for respite, to take time away from difficult situations, during challenging and crisis situations, or any other situation when an individual feels that they may benefit from additional, constant support (*184*). In Campinas, there are 14 CAPS, six of which are CAPS III, with the remaining CAPS services focused on children or people with problems and needs associated with substance use. All CAPS follow three guiding principles:

1. Open door policies – A person can simply walk in to the centre to make an initial meeting; people are free to come and go throughout the daily life of the CAPS, participating in the activities offered or simply use it as a place to connect and meet with others, as a place of respite, or to participate in group activities.

2. Community engagement – CAPS are active in the community, working to fully engage with and understand the community they serve and the individuals who live there. They identify and activate community resources and create partnerships to carry out mental health care initiatives.

3. Deinstitutionalization – CAPS were designed and developed to replace psychiatric hospitals and other institutionalization structures (184). All CAPS have the capacity and responsibility to attend to complex, challenging and crisis situations, offering care and support with community-based practices. As a principle, CAPS do not refer individuals to psychiatric hospitals.

In addition to common guiding principles, CAPS, also share commonalities in their practices. These include person-centred recovery plans for all individuals, psychosocial rehabilitation practices with a key focus on active citizenship, identifying actions to empower individuals in their daily life, their community, in the service itself and mental health more broadly, providing individual and group activities and providing support to families as well as the individual.

Community Based Health Centres (CBHC)

Community Based Health Centres are considered the first contact point for people to enter the Brazilian public health system, providing basic community care across general practice, paediatrics, gynaecology, nursing and dentistry (*521*). Family Health Teams link the community with CBHCs. In Campinas, there are 66 such centres, approximately one CBHC for every 20 000 inhabitants. All CBHCs in Campinas are linked with, and receive support from a CAPS.

Multi-professional teams with training in mental health (Núcleo de Atenção à Saúde da Família (NASF))

NASFs are multidisciplinary teams with a wide range of specialist expertise, including in mental health, that provide direct general support to Community Based Health Centres (CBHC) and Family Health Teams. NASFs discuss clinical cases, undertake shared consultations, collaborate in the development of person-centred recovery plans, and deliver prevention and health promotion activities. NASFs also support capacity-building of CBHC professionals in mental health. By supporting individuals with less severe or less complex mental health needs, the community's CAPS can focus on providing care and support to individuals with more complex mental health needs. NASFs are particularly important in municipalities with under 15 000 inhabitants. These municipalities, which represent about 60% of Brazil's municipalities and about 12% of the total Brazilian population, are too small to be served by a dedicated CAPS. Within these municipalities, CBHCs and NASF teams are the mainstay of mental health care and support (*184*).

Street Outreach Teams (Equipe de Consultório na Rua)

Street Outreach Teams are part of the CBHCs, providing support and health care to the homeless community. They provide general mental health support as well as support to individuals with mental health conditions, psychosocial disabilities, and problems and needs associated with substance use. Street outreach teams are in constant dialogue with CBHCs, Family Health Teams and CAPS (*184*). They do not refer people to psychiatric hospitals or other services where coercion, restraint or seclusion may be used. The two Street Outreach Teams in Campinas provided support to approximately 476 individuals per month in 2020.

Mental health beds at general hospitals (Leitos de saúde mental em Hospitais Gerais)

Some general hospitals have a limited number of dedicated mental health beds, which can be accessed at the request of a mental health network service, such as a CAPS. In Campinas, hospitalization is generally used for support during a crisis situation, depending on its severity and the needs of an individual. However, this service remains linked to the main community-based network. In this way, if an individual is admitted to a mental health bed in a general hospital, the hospital team and the team from the referring service (for example, a CAPS) collaborate on the person's recovery plan.

Emergency and urgent services

Urgent and emergency mental health care is part of the emergency services network of the general health system. As a general guideline, these services work together with CAPS when an individual with mental health needs presents at one of the services.

Independent living facilities (Serviços Residenciais Terapêuticos)

The mental health network in Brazil includes deinstitutionalization strategies specifically designed for individuals who have been discharged from psychiatric hospitals or custody hospitals after long periods of hospitalization. Independent living facilities are houses located in the community that provide an independent accommodation option to individuals who, upon discharge, have no possibility of returning to the family home, and do not have family or other support networks available. Psychosocial rehabilitation is provided through a close partnership between the individual, the independent living facilities and the CAPS, with the objective of promoting autonomy, social inclusion and guaranteeing rights. Campinas has 20 independent living facilities which accommodate 139 people, all of whom are recipients under the "Going Back Home" programme. – a deinstitutionalization to strengthen a person's autonomy by ensuring they have resources to make their own choices. The monthly amount paid at federal level is R\$ 412 (US\$ 73)^{ab}.

Cross-network initiatives

Services within the network also engage in cross-network initiatives that are transformative in terms of the individual, the community and a wider perception of, and engagement with mental health and psychosocial disability. Examples include:

- Community centres (Centro de Convivência (CECO)) These community-based centres are open to all, including people with psychosocial disabilities, cognitive disabilities, older adults, and children and adolescents with social vulnerabilities. Within the municipality of Campinas, CECO activities reflect two main themes – coexistence (group activities, public meetings, promoting the understanding of differences between people) and partnerships with public institutions and civil society that contribute to inclusion and autonomy.
- Work and income generation initiatives These initiatives promote the right to work and provide training
 and qualifications for work. They promote social inclusion and autonomy, increasing personal power
 and improving people's living conditions. These initiatives follow a solidarity economy approach. The
 municipality of Campinas has two services focused on the Solidarity Economy and the generation
 of work and income, promoting autonomy, social inclusion through work, and participation in social
 associations and cooperatives.
- Cultural initiatives The mental health network in Campinas has a number of collective and crossnetwork projects that include the participation of individuals who use mental health services, as well as professionals and family members from different CAPS, independent living facilities, community centres and beyond, in initiatives including radio programmes, publications and sports initiatives.

Impacts and achievements

In comparing the community-based mental health services and strategies that replaced psychiatric hospitals in Brazil, community-based mental health services were found to be more effective and efficient (522). A 2019 study demonstrated a correlation between increasing CAPS and primary health centre coverage with decreased psychiatric hospitalization rates (523). A 2015 systematic review of studies on the mental health services in Brazil reported satisfaction with the services that were developed as a substitute to institutionalization (e.g. CAPS), citing positive attributes such as: welcoming and humanizing attitudes, breaking social isolation, improvement in clinical conditions, and overall quality of life and mental health support (522). It also reported improvement in self-confidence, emotional health, quality of sleep, and the capacity to handle difficult situations (522).

A prospective cohort study involving 1888 CAPS users found that CAPS practices were effective in supporting people in challenging and crisis situations (524). After attending CAPS, 24% of users that they were crisis-free; 60% experienced crises less frequently and 70% with less intensity. The longer the time attending the CAPS, the greater the time elapsed since the last psychiatric hospitalization. CAPS were also found to favour the expansion of individuals' autonomy as well as a proactive approach and sense of co-responsibility in recovery (525). The implementation of the CAPS system has also been found to reduce the risk of suicide by 14% (526).

Family members also have reported satisfaction with the service, the quality of care and the support that they receive (*527*, *528*). NASFs have been effective in supporting mild and moderate mental health needs, preventing excess demand on specialist services (e.g. CAPS) (*529*, *530*). The use of NASF teams in a rural area was also found to increase individual engagement with activities proposed by the health services and health needs were more comprehensively attended to (*531*). Supported living services such as the independent living facilities have been found to support individuals who had experienced long-term hospitalization, increasing their sense of power and autonomy, social participation and ability to establish relationships (*532*, *533*). Similar findings support the benefit of financial programmes such as "Going Back Home" in supporting people to return to the community after extensive periods of hospitalization (*534*, *535*)

Useful figures

- At the beginning of 2020 there were 3070 CAPS across all Brazilian regions (536). The annual health budget in Campinas in 2019 was approximately R\$ 1.2 billion (about US\$ 207 million)^{ac}. The community-based mental health network was allocated 6.6% of this total budget, equivalent to approximately R\$ 80 million (about US\$ 14 million)^{ac} (537, 538).
- Using the example of the Campinas network, the cost of the community-based mental health network in 2019 was approximately R\$ 67 per capita, (US\$ 12), based on an approximate population of 1.2 million and excluding cost of mental health beds in general hospitals and the wider (non-mental health) costs of CBHCs.
- In a cross-sectional study, 95% of Campinas CAPS users interviewed reported not having had any psychiatric hospitalization after starting to attend the CAPS; 73% reported seeking the CAPS in a crisis situation, while no one turned to a psychiatric hospital. This supports the premise that community-based networks are able to replace the functions of psychiatric hospitals (539).

Innovative features

- The community-based mental health network in Brazil is an example of how a country can implement scalable services and initiatives built on human rights and recovery principles, to meet the unique mental health needs of each community.
- The network has been negotiated at all levels, and with all stakeholders of the mental health system, including individuals who use the services, family members, civil society movements and mental health professionals (540), fostering buy-in and commitment.
- These networks are continuously evolving to meet new challenges, as a result of dialogue among the stakeholders.

Additional resources

Websites:

https://www.gov.br/saude/pt-br http://www.saude.campinas.sp.gov.br/

Videos:

Morar em Liberdade: Retratos da Reforma Psiquiátrica Brasileira - FIOCRUZ (portuguese)/ Living in Freedom: Portraits of the Brazilian Psychiatric Reform - FIOCRUZ (english) <u>https://www.youtube.com/channel/UCD2xLN_GleJRWqOs8yWLDPQ/videos</u> Memórias da reforma psiquiátrica no Brasil - FIOCRUZ (portuguese)/Memories of psychiatric reform in Brazil - FIOCRUZ (english) <u>http://laps.ensp.fiocruz.br/</u> Rádio 'Maluco Beleza' - Campinas (portuguese)/Radio 'Maluco Beleza' - Campinas (english) <u>https://www.youtube.com/watch?v=ujRDWeL_cnM</u>

Contact:

Coordination of the Area of Mental Health, Alcohol and other Drugs, Brazil <u>saudemental@saude.gov.br</u>

Coordination of the Technical Area of Mental Health, Municipal Health Secretariat, Campinas, Brazil, <u>dptosaude@campinas.sp.gov.br</u>

Serviço de Saúde Dr. Candido Ferreira, Campinas, Brazil, contato@candido.org.br

4.1.2

East Lille community mental health service network

France



The mental health network of East Lille promotes the concept of "citizen psychiatry". Serving a population of 88 000 in the south-east region of the Lille metropolitan area, the network has been built over 40 years of mental health system reorganization and reform. The East Lille network demonstrates that a shift from inpatient care to diversified, community-based interventions for people with mental health conditions and psychosocial disabilities can be achieved with an investment comparable to that of more conventional mental health services. The approach supports respect of human rights of individuals who use mental health services, and their empowerment – even while operating in a more restrictive national legal context.

Coordination of services and foundation principles

The East Lille mental health network is made up of a range of community-based mental health services that maximize independence and promote citizenship. All services work together, including sharing access to health records, to create a coherent care pathway for each individual across the network. An important emphasis is enhancing a person's quality of life, their social network, their achievements and their strengths.

The Public Mental Health Institution Lille Métropole (*Etablissement Public de Santé Mentale Lille Métropole* (EPSM)) is responsible for the day-to-day administrative management of the network, and regional oversight and planning mechanisms are in place. Six municipalities of the East Lille metropolitan region comprise the Intermunicipal Association for Health, Mental Health and Citizenship – a forum for community stakeholders to meet, discuss and plan services and activities. It is chaired by the mayors of the local authorities and is co-led by the East Lille mental health network. Activities are organized according to four main themes including: prevention and health promotion, culture, housing allocation, maintenance and planning, and the local health context – which aims to ensure that regional priorities are implemented.

Key services and how they operate

Local medical-psychological services (Services Médico-Psychologiques de Proximité (SMPP))

Based in two dedicated ambulatory EPSM services and integrated into 12 other health related facilities, SMPPs are the first point of contact for people with the mental health network in East Lille. Professionals include: nurses, psychiatrists, psychologists, psycho-motor therapists^{ad}, social workers, peer support workers, and an adapted sport coach who works with people with special needs and disabilities. A person is referred to a SMPP by their general practitioner. Referral is followed by an assessment of both mental and physical health needs within 48 hours. Each assessment is then discussed by a multidisciplinary team, which identifies care and support needs. Consultations take place at a range of venues, such as a social and support centre for youths where they can directly access the SMPP without a doctor's referral. There is no waiting list, and the service can also undertake home consultations.

ad Psychomotor therapy is defined as a method of treatment that uses body awareness and physical activities as cornerstones of its approach. It is widely used in a number of European countries, including France.

Mobile crisis and home treatment team (Soins Intensifs Intégrés dans la Cité (SIIC))

SIIC provides crisis response and intensive care at home for up to 15 people at a time. The team is multi-disciplinary and available 24 hours a day, 7 days a week^{ae}. All workers in the service are sensitized to using the recovery approach, the rights of service users, and handling crises without coercion. When all of these resources are considered, there is nearly one full-time equivalent worker for each individual seeking care (0.96 FTE ratio) (541).

Jérôme Bosch Clinic (Clinique Jérôme Bosch)

Ten beds and a multidisciplinary team are available for people with mental health needs at the Jérôme Bosch Clinic situated in a General Hospital. Hospitalization, and especially forced admission, is avoided as much as possible in the East Lille network. At any given time, there are seven people in the clinic who remain for seven days on average ([Medical information service], [EPSM Lille Métropole], unpublished data, [2020]). Upon admission, both written and verbal information about an individual's rights and obligations is provided. A person can nominate a trusted person for personal support during their time at the clinic. The clinic relies on the support network of the person in order to help with negotiation, safety and avoiding conflict. To facilitate these connections there are no fixed hours for visits (*542*) and two rooms have a second bed for support people who want to stay overnight at the clinic. Practical and general health needs during a person's time at the hospital are discussed, along with mental health. All health professionals receive specific training to prevent instances of conflict and violence. Any use of restraints is considered to be a major adverse event in care, and is investigated in order to ensure a continuous process of improvement, which also invites input from service users and their families. Seclusion is never used in the hospital or other East Lille mental health services.

Therapeutic host families

One special feature of the Lille network is the existence of a system of "therapeutic host" families who welcome individual mental health service users as a member of their family. It is an alternative to the traditional patient/caregiver relationship and hospitalization. Host families receive training in their role as a host as well as training on mental health issues, the recovery approach, and the rights of people with mental health conditions and psychosocial disabilities. They are also trained on ways to help with agitation and crisis avoidance.

Intersectoral family and systemic therapy centre - specialized external consultation centre

The intersectoral family and network therapy centre (Don Jackson) is a service that delivers psychotherapeutic interventions for families and couples.

ae Psychiatrists, nurses, psychologists, special educators, psychomotor specialists, peer supporters.

Rehabilitation and supported living services and initiatives

The mental health network in East Lille has a comprehensive set of complementary initiatives to support individuals who use mental health services to lead meaningful lives and actively participate in their communities.

- Habicité Habicité is an Assertive Community Treatment (ACT) (543) team, staffed by nurses, social workers, peer supporters and psychologists, that provides long-term, intensive support to 80 individuals with mental health conditions to stay in their homes within a recovery framework. The service also offers a range of communal housing, with 13 apartments providing group housing for up to 26 people. Access to housing has recently been democratized by including community representatives in the process. The service is now also based on the "housing first" philosophy, meaning unconditional access to housing and support (423).
- Frontières This service focuses on enhancing social inclusion and wellbeing through physical, artistic, cultural, creative and professional activities. Initiatives include the Service d'activités d'insertion et de soins intégrés à la cite, providing activities for people with mental health conditions or psychosocial disabilities. There is also a "Sagacités" system that supports people who wish to attend community activities with people outside of the mental health system. This support can either be focused on specific activities or take the form of intensive coaching. Peer support groups can also be offered if people have a common project or interest. The service also facilitates access to employment through partnerships with local actors and stakeholders. An occupational therapist is available to develop career and professional plans, and a psychologist is available for supporting, motivating and evaluating a person's competencies at work.

The East Lille network has established active links with many other community-based services and organizations over the years, networks which involve social and cultural institutions, elected officials, user and family support groups, and various other health sector partners, such as general practitioners, pharmacists and private nurses. It uses these links to assist people who are using mental health services to re-establish their place in the community (544). Several support groups are also available to service users to promote inclusion in the community and active citizenship.

Impacts and achievements

An important achievement of this network can be seen in the steadily decreasing rate of hospital admissions, from 497 admissions in 2002 to 341 admissions in 2018, despite the considerable increase in the number of people receiving care in the network over the same period, from 1677 people in 2002 to 3518 people per year in 2018. The average length of stay at the in-patient unit also decreased from 26 days to seven days over the same period.

An independent assessment team conducted a WHO QualityRights evaluation (545) in September 2018 across all of East Lille's mental health services. Three of the potential five themes were fully achieved: i) the enjoyment of the highest attainable standard of physical and mental health, ii) freedom from coercion, violence and abuse, and iii) the right to live independently in the community. The remaining two themes: (iv) the right to an adequate standard of living and v) the right to legal capacity and personal liberty and security, were partially achieved (541). The existing French legal framework was found to be an important barrier for the full achievement of these latter two themes.

Additional resources

Website:

https://www.epsm-lille-metropole.fr/recherche?field_tags=All&search_api_fulltext=G21

Videos:

Les SISM, c'est quoi ? Avril 2014, https://youtu.be/D7_1SQSiNb4

Contacts:

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Useful figures

- In East Lille hospitalization represents only 28.5% of expenditures on mental health, compared to 61% nationwide in France (541).
- Overall costs for mental health services also are lower in East Lille than the surrounding metropolitan areas, with an average per capita cost of €132 (US\$ 158)^{af} per annum.
- The average cost per person using the services has been decreasing steadily from 2013–2017, from €3131 (US\$ 3759)^{af} to €2915 (approximately US\$ 3480)ff per year (541). These figures include costs associated with the whole care pathway, from the initial consultation to hospitalization (541).

Innovative features

- The East Lille mental health network demonstrates that it is possible to provide human rights and recovery-oriented services even within contexts in which mainstream practices and legislation at the national level are still heavily oriented towards institutionalization, with considerable human rights restrictions.
- The network has successfully reached and engaged local politicians, authorities and community
 organizations in the decision-making about the design and delivery of East Lille's network
 of services to promote the active engagement of people with mental health conditions and
 psychosocial disabilities in the community, and the sustainability of the service.

4.1.3

Trieste community mental health service network

Italy



Since the closure of its large psychiatric hospital in the 1970s, the city of Trieste has been a pioneer in implementing community-based mental health care. Anchored around an open-door approach, Community Mental Health Centres operate 24 hours a day, seven days per week, providing users with a hybrid set of options for day care and overnight stays, at a fraction of the cost of hospital services. Unique features of the wider network include personalized health budgets as well as supported work and training opportunities through social enterprises. In 2018, the network covered a population of approximately 236 000 people (546) providing services to 4800 individuals that year (547).

Coordination of services and foundation principles

The Trieste mental health service is founded upon on a human rights-based approach to care and support with a strong emphasis on de-institutionalization. Community Mental Health Centres (CMHCs) are the main point of entry into the Trieste mental health services, while the General Hospital Psychiatric Unit (GHPU) is mainly used for emergencies during the night.

Staff at CMHCs play a crucial role in ensuring the coordination of all of the network's services. They actively engage and collaborate with health and welfare services, the judicial system, cultural institutions, regional and city authorities, and other community organizations such as peer and social networks. They connect people to the different community initiatives, services and opportunities. For example, each person using a CMHC is assigned a small multidisciplinary group of staff, who become specifically responsible for their care and support. The General Hospital Psychiatric Unit is also in direct contact with the CMHCs in order to support people to move into community-based care as soon as possible.

The system in Trieste is managed by the Department of Mental Health within the Giuliano Isontina University Health Authority (Azienda Sanitaria Universitaria Giuliano Isontina), covering Trieste and the neighbouring territory of Gorizia. The Department of Mental Health has responsibility for the budgeting, planning and delivery of services. In accordance with its "whole person, whole system, whole community" approach to mental health care, the University Health Authority directly funds a wide range of independent partners in the non-profit sector, including social enterprises, cooperatives and volunteer associations.

Key services and how they operate

Community Mental Health Centres: developing a set of multidisciplinary, flexible, and mobile services in the community

The four CMHCs in Trieste operate around the clock, and accept all referrals coming from a population of about 60 000 inhabitants per centre. There are no waiting lists to access the centre, and people can walk in anytime between 08:00 and 20:00. Anyone who enters or telephones a CMHC receives a response usually within one to two hours.

The centres provide both day care and overnight stays, with on average, six beds available to welcome a person in crisis. The average stay is 13.8 days (548). Throughout their stay, individuals are encouraged to continue ongoing activities in which they may already be engaged and can host visitors on an informal basis. People can also come intermittently to the centres for individual and group therapy sessions and meetings, medication support, informal contact with others, or sharing a meal together. All of the CMHCs have an open-door policy and there are no physical barriers such as locks, keys or codes.

CMHCs also provide outreach activities, home visits, crisis support at home, and support for individuals to access education, employment, social or leisure-related services in the community. Staff members make scheduled visits to people's homes or meet people in public spaces to ensure that they are supported as much as possible in a community-based environment. About 50% of the staff work takes place in the centres, and 50% in the community.

General Hospital Psychiatric Services and Unit (GHPU) as a last resort: providing short-term hospitalization

There is one general hospital unit in Trieste which has six beds. The rapid crisis response organized by the CMHCs results in very few hospital admissions. As such, the GHPU is mainly used for emergencies at night; most people stay for less than 24 hours, with the average stay being 1.7 days (548), before being referred as quickly as possible to the CMHC in their own area. There is an explicit policy of "open door – no restraint" in the GHPU (546, 549, 550) and all staff members are trained in the use of negotiation and de-escalation strategies in order to avoid the use of coercion.

Community inclusion support services and initiatives: ensuring full inclusion and participation in the community

The mental health network in Trieste has a comprehensive set of rehabilitation and supported living services that work in partnership with a wide range of non-profit organizations, such as social cooperatives, volunteer and "social promotion" associations, including those of peers and carers. These rehabilitation and supported living services aim to ensure that people can live a meaningful life and participate fully in the community.

The supported living services, provided through several small flats for individuals and small groups of up to five people, cater to about 100 people every year. There is also a recovery house, which has space for about four to six people to stay, usually for six months. The rehabilitation and supported living services collaborate with a network of approximately 15 social cooperatives, which provide training and employment to approximately one-third of mental health service users in the city. In 2018, there were 292 individuals supported by the city's mental health services who were receiving work-grants as trainees, in activities ranging from catering, maintenance of public gardens, to hotel services (547). Additional activities run by volunteer and peer associations are organized across various social spaces of the city, and focus on defined areas such as sports, peer support, art expression and anti-stigma initiatives.

Among the city's residents, about 160 people per year receive subsidies, in the form of personalized health care budgets in order to access services and cover expenses for housing, education, training, employment, as well as personal care and leisure needs (549, 551). Personalized health care budgets can also help fund education and vocational training. To decide on a funding allocation, a plan is developed which includes a person's identified goals, and is discussed and agreed upon in collaboration with the person. Family may be involved, with the individual's permission.

Impacts and achievements

Research over the years has demonstrated important outcomes for the services in Trieste. The first follow-up study after the reform law (1983-1987) showed better psychosocial outcomes for 20 people with a diagnosis of schizophrenia in Trieste and Arezzo compared to 18 other Italian centres (552). The number of people subjected to involuntary treatment each year has dropped from 150 in 1971 to

18 in 2019. That translates into a rate of 8.11 per 100 000 population (548), one of the lowest rates in Italy (553). Significantly, Italy also had the lowest overall rate of involuntary hospitalization among 17 western European countries in 2015, or 14.5 people per 100 000 population, compared to highs of 189.3 in some other countries; this has also been a consistent finding since 2008 (53).

In 2005, a survey conducted by Trieste's Department of Mental Health in 13 centres found that the crisis care provided by the CMHCs resulted in faster crisis resolution as well as the prevention of relapses, and better clinical and social outcomes at two-year follow-up (554-556). The findings also underlined the importance of trusting therapeutic relationships, continuity and flexibility of care, and service comprehensiveness. Additionally, the survey found that there had been a 50% reduction in emergency presentations at the general hospital psychiatric unit between 1984 and 2005 (557). Other research points to high rates of service user satisfaction with the work of the CMHCs (558).

A 2014 study of 27 people with complex needs who used the services, found that there was a high rate of social recovery at five-year follow up: nine participants secured competitive jobs, 12 achieved independent living, and the overall score on the Camberwell Assessment of Needs (559) dropped from 75% to 25%. There was also a 70% reduction of days of admission, and only one person dropped out (549, 560).

In 2018, it was estimated that the cost of the network of mental health services put in place amounted to 37% of the cost of the old psychiatric hospital, adjusted for current levels of expenditures (547).

Additional information and resources

Website: www.triestementalhealth.org

Videos:

BBC News, Trieste's mental health revolution: 'It's the best place to get sick' <u>https://www.bbc.com/news/av/stories-49008178</u>

Report from the LA-Trieste Delegation: December 11, 2017: <u>https://youtu.be/gnYydKZzIGM</u> Episode 8 - Lived experience in Trieste, a mental health system without psychiatric hospitals, with Marilena and Arturo:

https://www.spreaker.com/user/apospodcast/episode-8-lived-experience-in-trieste-a-Roberto Mezzina, 2013, https://youtu.be/UnMSHQDrByl

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Useful figures

- Trieste has one of Italy's lowest rates of involuntary hospitalization for mental health conditions, with 8.1 people per 100 000 population (*561*), and Italy has one of the lowest rates in Europe, with 14.5 per 100 000 (*53*). The number of people subjected to involuntary treatment in Trieste dropped from 150 in 1971 (*562*) to 18 in 2019 (*548*).
- Mental health budgets are overwhelmingly invested in community services and interventions; these represent 94% of the budget, while hospital services received 6% (2014) (549).
- With the overall transformation of services from the 1970s until today, several studies have shown that the outcomes for people using the services have significantly improved and that the costs of providing care and support have diminished (552, 554-556, 560).
- In 2018, it was estimated that the cost of the network of mental health services put in place amounted to 37% of the cost of the old psychiatric hospital, adjusted for current expenditures (547).

Innovative features

- 160 people benefit from a Personalized Health Budget to access an individualized program of activities as well as various housing, education and social services.
- The mental health service collaborates with a network of approximately 15 social cooperatives, which provide employment to approximately one-third of mental health service users in the city.

4.2 Mental health networks in transition

More recently and across the world, an increasing number of countries such as Peru, Lebanon, Bosnia and Herzegovina, and others, are making concerted efforts to develop and expand their mental health networks and to offer community-based, rights-oriented and recovery-focused services and supports at scale. While more time and sustained effort is required, important changes are already materializing.

A key aspect of many of these emerging networks is the focus on **the rapid development and expansion of community-based mental health centres**, which aim to bring 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. One such example is Peru's expansion of community mental health centres, as shown in Box 1 below. Community-based mental health centres often serve as a first point of entry into the mental health care system, and usually act as a central component of the network. Through these centres, individuals can access a wide range of outpatient, outreach and primary-level mental health services, which vary across countries. Among others, services can include group or individual therapy, the distribution of medication or treatment, access to peer support, at-home visits, etc. These centres not only deliver services but are also involved in providing support for the coordination of other mental health services in the network and in fostering recovery by connecting individuals to opportunities to engage with community life. Beyond their aim of providing mental health care and treatment, many strive to include social inclusion and participation in their mission.

Box 1. Peru - A Mental Health Network in Transition

Peru – A focus on expanding community mental health centres



In Peru, for example, there has been a considerable push over the last decade to create community mental health centres (CSMCs, the Spanish acronym) across the country, each serving a population of approximately 100 000 individuals (563). Since 2015, 155 CSMCs have been established, and the Ministry of Health expects to expand coverage to 281 centres nationwide by the end of 2021 (564). CSMCs have three functions: to provide treatment and care to individuals with mental health conditions (including psychosocial and pharmacological interventions); to implement community-based promotion and prevention activities for mental health; and to strengthen non-specialized primary health care services on mental health care (training, supervision, capacity-building and strengthening the referral systems from non-specialized primary health care services to CSMCs).

The community health care centres are not the only important aspect of reform. They are complemented by the development of protected community "halfway houses" (*Hogares Protegidos*), and the establishment of mental health units in general hospitals, all of which have as their foundation a strong policy and strategy for UHC.

To date, 11 halfway houses have been established, five of which are based in Lima (565, 566). With an explicit orientation towards respect for human rights, the halfway houses provide accommodation and around the clock care and support for small numbers of people who would otherwise be living in the country's large psychiatric hospitals. Each house has space for eight residents. The halfway houses are designed for people who need high levels of support and weak family support systems (429). They also aim to improve individuals' capacity to live independently in the community. The

Peruvian Ombudsman's Office has noted that these interventions could be further strengthened to provide clear paths toward independent living and to avoid the risk of re-institutionalization (567).

The development of mental health units in general hospitals also acts to shift the focus of mental health care away from the large psychiatric hospitals as part of the deinstitutionalization process. The mental health units in general hospitals offer periods of short-term hospitalization with a maximum stay of 45 days (568). Mental health inpatient units have currently been established in 32 general hospitals in the country. By 2021, the target of the Ministry of Health is to have mental health units in 62 hospitals (566).

It is important to note that these transformations in the mental health system towards communitybased networks have been made possible by a set of landmark national law and policy reforms. In particular, Law 29889 was passed in 2012 to transform the existing mental health system into a community-based health care model, and to assert the right of all people with mental health conditions and psychosocial disabilities to access the highest attainable standard of care (569).

Around the same time, Peru also committed itself to UHC, and developed a health insurance scheme which included mental health services as part of the benefits package. In addition, a results-based budgeting programme was created in 2014 establishing a ten-year financing framework for mental health action, which permitted a sustained increase in the resources available for mental health care reform activities. For example, the Peruvian national budget for the fiscal year 2020 allocates 350 million Peruvian sol (S/) (approximately US\$ 94.8 million)^{ag} to mental health, an increase of S/ 70 million (approximately US\$ 19 million)^{ag} over the 2019 allocation (570).

More recently, in 2018, the Civil Code was reformed in a landmark move, removing obstacles to legal capacity based on disability, which also ended civil guardianship of adults with disabilities, and prevented the restriction of personal legal capacity based on psychosocial, intellectual and cognitive disabilities (571). Furthermore, Law 30947 was passed in 2019 consolidating a community-based model of mental health care (568). Its regulations, adopted in March 2020, include key provisions recognizing the right to legal capacity and informed consent of service users as well as the role of supported decision-making in the context of the mental health provision (572). Those reforms and political engagement have played an important role in shaping the development of services and how they operate.

In many countries, great progress is being made to diversify and integrate mental health services within the wider community. Many of these networks have taken a **multidisciplinary approach to care and support and promote a holistic framework** for the provision of mental health care. This approach requires active engagement, collaboration and coordination of mental health services with other community actors, including welfare, health, and judiciary institutions, regional and city authorities, as well as cultural, sports, and other services, initiatives and opportunities in the community. Through this holistic approach to care and support, individuals can receive support in all aspects of their life important for their mental health and well-being including, employment, housing, relationships, etc. Partnering with civil society organizations, including for example, organizations of people with mental health conditions and psychosocial disabilities is an important aspect of creating a fully-fledged mental health network, as the example of Bosnia and Herzegovina shows, in Box 2 below.

ag Conversion as of March 2021.

Box 2. Bosnia and Herzegovina - A Mental Health Network in Transition

Bosnia and Herzegovina – comprehensiveness of mental health centres and community linkages



Since the 2010s in Bosnia and Herzegovina, the mental health network has been strengthened by the fact that mental health services are intricately weaved into the wider social, employment and housing sectors. For instance, the local areas of Drin and Bakovici in the Municipality of Foinica, provide sheltered housing for people who need a lower level of support and are recovering well, thus fostering independent living. Currently, Bakovici provides housing to 50 individuals within 13 housing units and there are 74 people using Drin's seven houses in the local community. These services receive funding from the social service sector of individual cantons (for regular activities), from the federation level from the Ministry of Labour and Social Policy (for infrastructure costs) and through donations, humanitarian and income generation projects (573).

There has also been an increase in the number of rehabilitation services, which have been built in cooperation with social work centres administered and funded by the social sector, healthy aging centres in Sarajevo and associations of users of mental health services. Preventative and promotion programmes in the community mental health services have also increased and they are required to make up 30% of the community mental health services. All centres cooperate with schools through educational workshops and visits by mental health professionals to schools, but also through provision of mental health services when needed. In some centres the staff also engage in preventative activities aimed at supporting older people either at their local communities or in the care homes.

More generally since the 2010s all mental health services have been required to use a case management approach, which involves the coordination and delivery of evidence-based, biopsychosocial interventions, using a collaborative approach which connects service users to services and resources available in the community (574). Person-centred and recovery-oriented services, including case management and other approaches such as occupational therapy, self-help groups, improved work with families and caregivers and preventative programmes are fully covered by health insurance. As such, inter-sectoral cooperation has increased and is at the core of the reform efforts in the country.

The availability of mental health care services in the community has also increased. For example, the number of community mental health centres has increased from 51 in 2010 to 74 today, covering approximately 60% of the population (575). In the last decade, many interventions have focused on developing the capacity of community mental health centre multidisciplinary teams for the provision of innovative, responsive, recovery-oriented and gender-sensitive mental health services.

An important strength of the expanding mental health network in Bosnia Herzegovina has been the collaboration of organizations of persons with mental health issues for service provision and on advocacy initiatives. Some of the organizations are recognized as alternative providers of community mental health services and many of them are closely linked and supported by the Community Mental Health Centres.

Traditionally over the last decades the standard approach of many countries has been to provide mental health services in large specialized hospitals often associated with poor care outcomes and human rights violations. An increasing number of countries are making efforts to profoundly **reform their hospitals to ensure that a sustainable process of deinstitutionalization and a human rights-based approach can be achieved.** Any responsible process of deinstitutionalization needs to be accompanied by a set of comprehensive reforms for the entire mental health care system, including the development of alternative community-based services, as well as a shift in the workforce mindset towards person-centred care, rights-based support and the recovery approach. The countries tackling hospital-level care are therefore making efforts to reduce hospitalizations, close down large psychiatric hospitals, and in parallel, create opportunities for support in general hospitals, in primary health care centres, or in specialized settings in the community such as community mental health centres, group houses, and people's homes. Box 3 below illustrates Lebanon's comprehensive approach to quality improvement and promotion of a person-centred recovery approach in hospital-based care.

Box 3. Lebanon - A Mental Health Network in Transition

Lebanon – quality improvement and the recovery approach in hospital-based care



In Lebanon, the Ministry of Public Health initiated a comprehensive set of transformations in mental health care (576, 577), focused on quality improvement and the promotion of a person-centred recovery approach. The reform efforts are the result of political commitment to improve the quality of mental health care countrywide. To that effect, the National Mental Health Program was created in 2014 within the Ministry of Public Health, and a five-year strategy for mental health (2015-2020) was launched in collaboration with international, national and civil society partners. Many of these improvements are being channelled through the WHO QualityRights Program.

In February 2019, the Al-Fanar Psychiatric Hospital in Lebanon was closed down following reports of human rights abuses. Violations spanned inadequate standards of living, lack of hygiene, and suboptimal treatment including coercion and neglect (*578-580*). In response, the Ministry of Public Health issued two decisions: Decision No. 271/1 concerned the assessment of the health status of patients transferred from Al-Fanar Hospital (*581*); and Decision No. 270/1, concerned the quality of care and human rights in the field of mental health, using WHO QualityRights (*582*).

Hospitals must now comply with high accreditation standards based on the stepped-care model and recovery approach (583). Every hospital receiving people with mental health conditions is required to: recruit a multidisciplinary team (including psychiatrists, psychologists, social workers and mental health nurses); establish a link with at least one primary health care centre; and undergo continuous evaluation including the examination of mental health reports and indicators of hospital performance.

Lebanon has also undertaken widespread efforts to conduct comprehensive service assessments and staff trainings on mental health, human rights and recovery, using the QualityRights assessment and training tools. The training of a national pool of assessors began during the pilot phase in 2017, and as of July 2020 there was a national team of more than 40 assessors of mental health services in the country, comprising mental health professionals, social workers, lawyers and service users. The goal is to ensure that these services in hospitals provide short-term support and quality care, and that they are able to link to the community services. In 2017, two pilot assessments took place, and three assessments of mental health facilities took place in 2020 prior to the COVID-19 pandemic and associated lockdown. Of these three facility assessments, work on one improvement plan is currently underway, with the improvement plan process of the other two facilities temporarily halted in accordance with lockdown measures.

Connected to the work at hospital level is a growing network of four community mental health centres with trained multidisciplinary teams, who act as referral points for the specialized care of persons with mental and substance use conditions. To ensure a continuum of care, these community mental health centres are linked to a primary health care centre that is part of the national network, as well as to a general hospital that has a mental health in-patient unit. Some are also linked to substance use treatment centres.

Another key feature of emerging mental health networks is the recognition that the 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. To that effect, networks that support and empower civil society groups and user movements to play significant roles at all levels of service planning, delivery and evaluation are critical. Some examples are highlighted in Box 4. **Box 4.** Lebanon, Peru and Bosnia and Herzegovina - Strengthening civil society and meaningful participation

Lebanon, Peru and Bosnia and Herzegovina – strengthening civil society organization and meaningful participation of people with lived experience



In Lebanon in line with the Mental Health and Substance Use Strategy (Lebanon 2015-2020, strategic objective 1.4.3) (577), the National Mental Health Programme at the Ministry of Public Health, in collaboration with partners, is currently facilitating the creation of independent service users associations. Working towards proper representation of persons with lived experience is essential to achieve their full participation in the development, implementation and evaluation of mental health policies for Lebanon. As of 2020, the establishment of the first Service User's Association is underway, with help and support from a network of civil society organizations, international NGOs and partners, as well as technical support from the National Mental Health Programme. Within the programme, the participation of service users has been an integral element in implementing the Mental Health Strategy, so that their participation is a consistent component in policy-making activities and national advocacy activities, including the design, implementation and review of nation-wide campaigns.

Within the QualityRights programme in Lebanon, representation and participation of persons with lived experiences was taken into account in the recruitment and training of QualityRights assessors. Of the pool of 40 trained QualityRights assessors, eight are service users or persons with lived experiences, including service users who previously worked as peer supporters. In addition, the participation of persons with lived experiences and service users was ensured in the recruitment of participants in QualityRights capacity-building training sessions and in a master Training of Trainers in early 2020.

In Peru, organizations of persons with psychosocial disabilities have been active in promoting legal and policy reform. For example, Alamo Association, an organization of persons with psychosocial disabilities and their families, played an important role in the drafting and adoption of the Law 29889 of 2012, which triggered the implementation of a community-based mental health model, and the 2018 landmark reform on legal capacity, for which Alamo participated in the Congressional Committee in charge of reviewing the Civil Code to recognize the legal capacity of persons with disabilities. Similarly, the newly created Coalition for Mental Health and Human Rights, composed of persons with lived experience and allied organizations, made significant contributions in the drafting of the regulations of the 2019 Mental Health Act to ensure a rights-based approach to disability. Despite these positive examples of impact, the participation of persons with mental health conditions and psychosocial disabilities in the design, implementation and monitoring of mental health policies is still limited and fragmented (584). In recognition of this, the Peruvian Ministry of Health is promoting the creation and participation of service user organizations as part of the actions to strengthen the services provided in community mental health centres (585). As part of these efforts, a National Association of Users and Family Members (Ayni Peru) was created in 2019, which will complement and articulate efforts with other regional and local organizations. As one research project suggests (586), these organizations could be further strengthened by incorporating discussions on human rights and supported decision-making as part of their agenda.

In Bosnia and Herzegovina, there are over a dozen associations of persons with mental health issues who have formed and registered as civil society organizations, some of them employing professionals and providing services such as daily centres with psychotherapy, occupational therapy and other regular activities (587). What is common across these organizations is that they provide psycho-education to their members and their families, support the development of life skills, especially following longer hospitalizations, provide group therapy, counselling, occupational and music therapy, support in exercising users' entitlements to social welfare, and organize different trainings such as self-advocacy. People with mental health conditions and psychosocial disabilities have also taken an active part in advocacy and campaigns to address stigma, for example the nationwide campaign – "A Person is Person". This campaign aimed to raise awareness around mental health and people with mental health conditions, portraying people in their everyday lives as part of the community.

4.3 Conclusion

As demonstrated throughout this section, mental health services need to be considered as part of a comprehensive and integrated network of services and systems. The services made available to individuals with mental health conditions and psychosocial disabilities should reflect the diversity and complexity of every person's needs. More generally, it is a human rights requirement that all services are accessible to the general population should also be available to individuals with mental health conditions and psychosocial disabilities. The paradigm shift reflected in the CRPD calls for a holistic approach in which mental health care represents just one of the various aspects leading to social inclusion.

The various examples given in this section illustrated that these networks of services recognize the importance of housing, employment, education, social protection and other supports in the services that they provide. The integration of health and social services fulfils a central role in promoting recovery, community inclusion and the full realization of the human rights of people with psychosocial disability. This integration needs to be reinforced and strengthened, everywhere. In this context, ongoing efforts are required to build strong collaborations with the social and non-profit sectors. Finally, a strong and sustained political commitment to continuous development of community-based services that respect human rights and adopt a recovery approach, is essential to build such comprehensive networks.

While this section showcases some of the transformation that has taken place around the world in mental health and sheds light on good practices for well-established and transitioning networks, it is not intended to provide an exhaustive representation of all the progress that is being made both within those countries and in the rest of the world. Most importantly, the development of any mental health system and network of services needs to be sensitive to the local context. Although this section highlights some common features and important steps to achieving human rights and recovery-oriented mental health networks, each country will need to take into consideration its own specificities for the reform process. All countries, however, should ensure that human rights, and the recovery approach remain, without compromise, at the heart of any reform endeavour.



Guidance and action steps

There is an opportunity to place human rights at the centre of mental health systems and, in doing so, to expand service provision and improve services. The 2030 *Agenda for Sustainable Development* (588) and international human rights frameworks, including the CRPD, represent commitments and agreed obligations of governments everywhere to uphold human rights, build inclusive societies and to leave no one behind. These commitments and obligations represent a unique opportunity to mobilize action, attention and resources to enhance mental health and social support services that respect rights. The Word Health Organization has responded to this challenge in a comprehensive way through its global programme of work and through the WHO Comprehensive Mental Health Action Plan 2020–2030 which forms the basis of many of the suggested action steps for countries outlined below.

Governments, health and social care professionals, NGOs, OPDs and other civil society actors and stakeholders can make significant strides to improve 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 UHC and broader social systems in countries whilst protecting and promoting human rights. The actions that can be taken in countries span policy, law, the service model and its delivery, health workforce, financing, information systems, the community as well as the direction and type of research being undertaken. Different actors and stakeholders in countries will take on different roles and responsibilities depending on the specific local context, with governments taking a lead role on the majority of actions with the exception of advocacy and other civil society-related areas.

5.1 Policy and strategy for mental health

By placing human rights and recovery approaches at the forefront of strategic policy and system issues, new directions for mental health policy and strategy have the potential to bring substantial social, economic and political gains to governments and communities. This will need to be underpinned by strong collaboration between the health and social sectors and an inclusive process for developing and implementing policy and strategy. It also requires a shift in thinking to encompass a human rights model which recognizes the importance of health interventions (from diagnosis through to psychological and pharmacological interventions) but does not focus solely on these to the detriment of other key life areas and determinants of health such as housing, education, income, inclusion, relationships, social connection and meaning.

Grounding policy in a human rights-based approach, as recommended by the WHO Comprehensive Mental Health Action Plan 2020–2030, also requires explicit reference to the principles of non-coercion, respect of legal capacity, the right to live in the community, the recovery approach, and how these principles will be implemented in a meaningful and systemic way throughout the whole health and social system. The paradigm shift from a purely biomedical model towards the practical implementation of a human rights model based on the CRPD needs to be the foundation of all policies and strategies related to mental health and requires integration throughout all relevant policy and strategy areas, rather than simply being a token line of text or single paragraph. Box 5 below describes some of the profound changes necessary for mental health policy, strategy and systems.

Box 5. Key directions for policy, strategy and systems

Key directions for mental health policy, strategy and systems (589)

Integrating a human rights-based and person-centred recovery approach requires meaningful changes to policy, strategy and system issues, including:

- i. strengthening engagement of civil society in particular the participation of people with lived experience and their organizations in decision-making processes for policy making and implementation;^{ah}
- **ii.** reorganization of services and redistribution of resources to shift care away from psychiatric hospitals into the community in order to successfully achieve deinstitutionalization;
- **iii.** articulation of the range of community-based services for mental health (including crisis response services, community mental health centres, hospital-based services, community outreach services, peer support services and supported living services) that will be developed according to human rights and recovery principles and evidence, and expanded throughout the country, including through the integration of mental health into general health services;
- **iv.** outlining roles and responsibilities of health and social sectors in order to comprehensively address the support needs of people with mental health conditions and psychosocial disabilities;
- v. workforce development to nurture a strong, trained multidisciplinary workforce (including community workers, health workers, specialized mental health professionals and peer supporters) whose knowledge and understanding of human rights and recovery principles is applied in their daily work to support people with mental health conditions and psychosocial disabilities;
- vi. budgets and financing based on evidence-based practices and human rights rather than old outdated models;
- **vii.** quality improvement including accreditation and monitoring of services to ensure human rights are respected;
- **viii.** information systems to evaluate and better inform policy and system improvements that align with human rights;
- **ix.** implementation of prevention and promotion initiatives responding to the social determinants of heath; and
- **x.** strengthening community understanding of mental health including through advocacy, combatting stigma and discrimination, and improving mental health literacy.

A critical policy area concerns the interface and collaborative relationships established between health and social sectors (education, housing, employment and social protection). Through the creation of joint policy and strong collaboration between health and social sectors, governments are better able to address the key determinants of mental health and provide a more comprehensive response to care, support, and community inclusion. Strong coordinated leadership from multiple sectors, with accountability processes and a means to allow coordination throughout the system are necessary to make the collaboration work – from the policy level through to practical implementation at the service level on the ground.

ah Increased funding is required to ensure the availability of community-based services and to support the process of transition from institution to the community.

The entire process of developing, articulating and implementing policy and strategy requires the active participation of all stakeholders, including people with mental health conditions or psychosocial disabilities who have traditionally been absent from the dialogue in these areas. Each stakeholder brings a unique contribution to the discussion: people with mental health conditions and psychosocial disabilities know from experience the types of services and support interventions which are helpful; families and other supporters bring their own perspective around support needs for their relatives and also themselves; mental health and social care workers are able to offer their expertise through years of training and experience working to support people with mental health conditions and psychosocial disabilities; NGOs have the links and capacity for sustained attention and outreach in the community; and human rights advocates, OPDs, lawyers, police and many others have unique experiences, perspectives and useful contributions to make.

Key national actions to integrate person-centred and human rightsbased approaches

The major steps on the path towards placing human rights and recovery approaches at the forefront of mental health policy, strategy and system issues will require that countries undertake the following actions:

- explicitly promote a shift towards comprehensive, person-centred, holistic, recovery-oriented practices that consider people in the context of their whole lives, that respect people's will and preferences in treatment, are free from coercive practices and that promote people's rights to participation and community inclusion in national mental health policies and strategies;
- integrate the human rights, person-centred and recovery-based approach into all key policy, strategy areas and system issues;
- create enabling environments which value social connection and respect in education, employment, social and other relevant sectors;
- articulate in policy and strategy how the mental health system and services will interface with social services and supports for all people with mental health conditions and psychosocial disabilities and the accountability mechanisms and processes to make that happen in practice;
- firmly commit to deinstitutionalization in policy and ensure this is accompanied by a strategy and action plan with clear timelines and concrete benchmarks, a moratorium on new admissions to psychiatric hospitals, the double funding of institutions and human rights-compliant community services during the process of deinstitutionalization, the redistribution of public funds from institutions to community services over time, and the development of adequate community support, such as economic assistance, housing assistance, employment opportunities as well as relevant training, home support and peer support;
- describe in policy and strategy how different types of human rights-oriented, community-based services will be provided – including crisis response services, community mental health centres, hospital-based services, community outreach services, peer support services and supported living services, and how they will respect legal capacity, non-coercion, lived experience, participation, recovery principles and community inclusion;
- commit to supporting the provision of peer support within services (590) and within the community (591) preferably by independent peer support organizations not managerially linked to the mental health service;
- recognize, state and formalize in policy the central importance of lived experience for policy development and implementation, and include strategies – such as regular round table discussions with policy makers – to closely consult and partner with NGOs and other civil society actors, in particular people with mental health conditions and psychosocial disabilities and their organizations, for this purpose; and
- commit to monitor and end human rights violations and present a system-wide strategy for doing this.

5.2 Law reform

National laws and regulations specifically related to mental health have direct and significant impacts on the degree to which people are able to enjoy and exercise their rights. As highlighted in the WHO Comprehensive Mental Health Action Plan 2020–2030, a significant effort is needed by countries in order to bring legal frameworks in line with the requirements of the CRPD. The CRPD and its human rights-based approach to disability emphasizes the universal nature of human rights, challenging mental health law as it exists today. The CRPD rejects all forms of discrimination on the basis of disability and embraces a support paradigm which demands a transformation in the way mental health services and other related services are provided. Substitute decision-making, coercive practices and institutionalization must be replaced by support in exercising legal capacity, independent living in the community, and other human rights (37). Promoting the principles of the CRPD requires a major overhaul of laws related to mental health and other laws directly impacting the lives of people with mental health conditions and psychosocial disabilities, for example those governing voting, marriage, employment and education, amongst others.

Within the health care context, law reform can play a crucial role in increasing access to health care and ensuring the rights of persons with mental health conditions and psychosocial disabilities are realized on an equal basis with others, including the right to equal recognition before the law and to legal capacity, to informed consent, to hold or withhold information in medical records, the right to confidentiality, access to justice, to access support in making decisions, the right to liberty and security of person, to community inclusion and to freedom from exploitation, violence, abuse, and from torture or cruel, inhuman and degrading treatment or punishment. Legislation concerning medical liability or medical malpractice should be further reformed in order to avoid practitioners resorting to the use of seclusion and restraints as a means to avoid risk of harm, and instead to promote the respect of people's rights (34).

Reform of laws specifically related to actions in other sectors are equally crucial to prevent discrimination in education, employment, social welfare, housing, health, justice, marriage and contractual arrangements, amongst others. Several global surveys of legislation on employment, voting, marriage, parental rights, legal contracts, and property-related rights have highlighted the extent to which people with psychosocial disabilities are actively and severely discriminated against and denied their rights in each of these areas (463, 592-594). In some countries being a person with mental health conditions or psychosocial disabilities can also lead to health insurance being denied (595).

Concurrently, discriminatory language used by laws and regulations must be reformed. Currently there are many countries who still use the term 'unsound mind', 'lunacy', 'idiot' and 'cretin' amongst other derogatory terms, as a basis to restrict the participation in social and public life – the civil and political rights – of people who have received a diagnosis related to their mental health. In India, for example, a 2012 review found that around 150 old laws in India, still operational, use terms such as 'unsound mind', 'physical and mental defect', 'incapacity', 'physical and mental infirmity' to deny people with mental health conditions and psychosocial disabilities their right to exercise their legal capacity (596).

A number of countries have already undertaken landmark legal reforms towards improved alignment with the CRPD, as shown in Box 6 below.

Box 6. Landmark legal reforms

Law reform – Colombia, Costa Rica, India, Israel, Italy, Peru, Philippines

Many countries have adopted landmark legal reforms which demonstrate how different elements of national laws and regulations can work to respect, protect and fulfill the rights of people with mental health conditions and psychosocial disabilities.

Italy pioneered deinstitutionalization during the 1960s and the 1970s and enforced a watershed law reform in 1978, Law No. 180 (597), also known as the Basaglia Law. This law, later included within the General Health Law No. 833, represents a first example of successful human rights-focused legal reform, despite the continued but limited use of involuntary treatment. The Basaglia Law established a ban on building new mental health hospitals and on admitting new patients to the existing ones, which were gradually closed. The law also placed strict limits on involuntary treatment and prompted the development of a network of decentralized community-based services.

In the last five years, Costa Rica (2016) (598), Peru (2018) (599) and Colombia (2019) (600) have completed important legislative reforms which removed barriers to the exercise of the legal capacity of persons with disabilities. The Peruvian reform, in particular, has been internationally recognized and is considered a milestone in the implementation of Article 12 of the CRPD (571). The Legislative Decree No. 1384 removed all obstacles to legal capacity based on disability from the Civil Code, the Civil Procedural Code and the Notary Act. It also ended civil guardianship of adults with disabilities. This reform means that grounds relating to psychosocial, intellectual and cognitive disabilities can no longer be used to justify any form of restriction on legal capacity. Moreover, building on this reform, the 2020 Mental Health Act regulations include a series of provisions that recognize the legal capacity of service users and the role of supported decision-making in the context of the mental health services (*601*).

Several other countries have also taken positive steps towards the incorporation of a human rights approach in their mental health legislation. Although they are not complete in terms of their alignment with the CRPD, they represent the best examples to date of countries which have adopted more progressive legislation related to mental health. For example, in 2017, India adopted a new Mental Health Act (*602*) which included a series of key provisions to protect the rights of persons with mental health conditions and psychosocial disabilities, such as the recognition of the right to access mental health care, the possibility of making advance directives or appointing a nominated representative, the decriminalization of suicide, and the prohibition of seclusion and solitary confinement. Similarly, the Philippines adopted in 2017 its first Mental Health Act (*603*) incorporating advance directives, supported decision-making and deinstitutionalization.

Legal reform can be also instrumental in facilitating access to community-based services and support. For example, in Israel, the Rehabilitation in the Community of Persons with Mental Disabilities Law of 2000 (604) provides persons with mental health conditions and psychosocial disabilities with a package of services and programmes which includes supported housing, employment, adult education, social and leisure time activity, assistance to families, dental care and case management.
Key national actions to integrate person-centred and human rightsbased approaches

In reforming mental health law to align with the CRPD and other international human rights standards, countries need to take some crucial steps. These include:

- actively engage persons with mental health conditions and psychosocial disabilities and their organizations in law reform processes in order to ensure that laws and regulations promote and protect their rights and meet their needs and requirements;
- introduce capacity-building for key stakeholders including decision makers (members of parliament, senators, local, regional and national legislatures etc.) before the initiation of the law reform;
- establish law review processes to identify legislation that needs to be abolished, modified or adopted to align national legislative frameworks, including mental health laws, with the CRPD;
- remove all discriminatory provisions in law related to education, employment, social welfare, housing, health, justice, the right to have a family, and to participate in political and public life;
- repeal guardianship and other substitute decision-making legislation and replace with laws that recognize legal capacity and promote supported decision-making, including the use of advance plans and best interpretation of will and preference;
- establish laws and regulations that promote the rights of people with mental health conditions and psychosocial disabilities to make care and treatment decisions for themselves and, in line with the CRPD, include throughout advance planning documents (that cannot be over-ruled by services during crisis) and supported decision-making options;
- ensure that laws require that admission and treatment are always based on the free and informed consent of people using services, including medication, ECT and other irreversible interventions, such as sterilization;
- include in health and mental health laws and regulations provisions that provide alternatives to involuntary admission, treatment and other coercive practices including seclusion and restraint
- include in laws and regulations provisions that provide for support and accommodations, including supported decision-making, safe spaces of respite and de-escalation strategies, during crisis or emergency situations;
- set out procedures in law and regulations for determining people's will and preference or best interpretation of will and preferences if the person is not able to communicate them;
- modify civil and criminal legislation to ensure that regulations on the legal liability and the duty of care of service providers and families do not encourage or result in coercive practices (34);
- build in accountability mechanisms to report, retrain, dismiss, or penalize staff who breach human rights;
- establish mechanisms and laws to monitor services for people with mental health conditions and psychosocial disabilities, including robust systems to investigate complaints, and ensure meaningful participation of persons with psychosocial disabilities and their organizations in such activities; and
- ensure provision of free legal aid services that are available and accessible.

5.3 Service model and the delivery of communitybased mental health services

Until now, when people have referred to community-based mental health care, the intention has been that care should be provided in the community where it can be more easily accessed as people get on with their lives. However, what is also essential is that care and support is personalized, inclusive, comprehensive and rights-based, and actively contributes to independent living and community inclusion. Further, community-based mental health care is not a single entity but involves a range of services and interventions in order to provide for the different support needs of people, in particular crisis support, ongoing treatment and care, and community living and inclusion. The range of services includes, but is not limited to, crisis response services, community mental health centres, hospital-based services, community outreach services, peer support services and supported living services. How these services are operationalized can be vastly different by region and country; services can overlap in terms of the care and support activities that they provide, and the same type of service may operate in vastly different ways using very different principles in different locations. For example, a community-based mental health centre in one location may provide many functions such as crisis response, community outreach, and ongoing treatment and care, however in another location or region a different centre may serve a much narrower function with other functions being provided by other services. Notably, services may be completely absent or minimal in many countries and regions.

No matter how well mental health services are provided, they alone will not be sufficient to support all people with mental health conditions and psychosocial disabilities, particularly people who are living in poverty, who do not have housing, education and a means to generate an income. Having access to these resources, opportunities and rights is crucial to supporting people to live a meaningful life and participate fully in their community. As such, it is important to ensure that mental health services and social sector services engage and collaborate in a very practical and meaningful way. The ultimate aim is for countries to develop their own network of mental health services to comprehensively address the main functions of crisis support, ongoing treatment and support and community inclusion. This requires careful consideration of the type of services to be included in the network, how these complement each other and work together, and how they will interface to work seamlessly with social and other sectors.

In all countries, families, carers and support persons as well as community networks, may be able to provide some of these functions, providing support for many people. This support can be invaluable. For example, family support has been shown to reduce hospitalization rates and duration (605, 606), reduce mental health crises, and improve recovery (607-611). However, in most low- and middle-income countries, families and informal carers are the only source of support for people with mental health conditions and psychosocial disabilities, leading to various problematic situations, from gender-based inequalities due to the feminization of caring responsibilities, to the loss of autonomy and privacy on the part of those receiving support. Therefore, formal services provided by government sectors will always be required to complement the support provided by families and communities. Further, families and carers themselves should also benefit directly from the support of services. This has been shown to promote the mental health of the family members and caregivers, reducing stress and anxiety symptoms (610), and improving physical health (612-614).

Traditional and faith-based healers and organizations are often the first point of contact for many people, particularly in low- and middle-income countries. While they can play an important role in providing care and support, there are many documented instances of chaining and other coercive measures being practiced by these service providers (*107*, *615*, *616*). Any network of services for people with psychosocial disabilities therefore needs to work towards ending coercive practices such that only the positive aspects of care and support are retained.

The development of a network of community-based services does not need to start from scratch. In spite of all the problems and challenges currently faced by mental health systems everywhere, many services in countries are providing care and support that people find meaningful and helpful, that promote hope and recovery, and that respect their dignity and rights. A key task for countries is to identify their good practice services, improve them where there are gaps and expand them throughout the region and country.

WHO has developed the QualityRights assessment tool kit (see Box 7) which can be used to assess the quality and degree of alignment with human rights principles of all types of mental health services and social care homes in line with the CRPD (6), including hospitals, crisis services, outreach services, supported living services and community mental health centres. In addition, WHO has developed a transformation tool (617) to support countries to transform and improve services based on gaps identified through the QualityRights assessment. A key feature of the guidance concerns processes for changing the service culture and power dynamics which are pre-requisites for achieving the human rights-based approach in mental health and social care services (617).

Box 7. WHO QualityRights assessment tool kit

WHO QualityRights assessment tool kit to assess and improve quality and human rights in mental health and social care facilities

The <u>WHO QualityRights assessment tool kit</u> enables countries to assess their services against standards derived from the CRPD, covering issues related to legal capacity, informed consent to treatment, supported decision-making, advance directives, and freedom from violence, coercion and abuse, as well as promoting community inclusion (6). Since its publication in 2012, assessments of one or more mental health services have been carried out in at least 47 countries (*618*).

In the European region, as part of the WHO Regional Office for Europe project on adults with mental health conditions, psychosocial and intellectual disabilities living in institutions in the European Region, QualityRights assessments were conducted in 75 facilities across 24 WHO Member States throughout 2017 (*619*).

From 2014 to 2016, widescale assessments of mental health services were also undertaken throughout Gujarat in India, by the state's Ministry of Health and Family. These assessments were accompanied by other actions including the development of individualized improvement plans in each of the services and the rollout of a comprehensive capacity-building programme using WHO QualityRights tools and methodologies (*620, 621*). The Gujarat experience showed significant positive impact in services throughout the State. Over a 12-month period, the quality and human rights

conditions in services improved substantially, with important advancements noted on standards around legal capacity and informed consent. In addition, staff in the services showed substantially improved attitudes towards people using services and the latter reported feeling significantly more empowered and satisfied with the services offered (*621*). The video below highlights aspects of the Gujarat capacity-building experience using WHO QualityRights tools.

WHO: Providing "QualityRights" in mental health services (Gujarat, India) <u>https://youtu.be/phd_PoHuL9c</u>

In Lebanon, a ministerial decision has mandated that all psychiatric hospitals and in-patient mental health wards within general hospitals and social care organizations be subject to an assessment concerning the quality of care and human rights using the WHO QualityRights framework (*582*). As part of its overall comprehensive mental health system reform, a large pool of 20 service assessors – including mental health professionals, social workers, lawyers and people with mental health conditions and psychosocial disabilities – has been established and has undergone a WHO QualityRights training programme (*622, 623*). Five services have already undertaken assessments and several have continued on to develop and implement improvement plans using the QualityRights service transformation module. These services are already showing significant impact on the lives of people using the services. The video below highlights aspects of the process of service transformation and improvement in Lebanon.

WHO: Improving mental health care in Lebanon: <u>https://www.youtube.com/watch?v=TIIB_LgEYpc</u>

Moving towards a culture change aligned with WHO QualityRights will allow existing services to evolve and new services to develop, with more imagination and flexibility (15). Many of the services highlighted in this guidance might act as inspiration for such developments. The intention is not to build exact replicas of the services described, but to learn from how they developed, how they work with the values and principles of the CRPD and how they incorporate a recovery approach. What is most important is to create services that are guided by the principles supporting legal capacity, coercion free services, participation, the recovery approach and community inclusion while at the same time ensuring that the services are rooted and embedded in the community that they service.

Key national actions to integrate person-centred and human rights-based approaches

In order to develop a community mental health system that is truly person-centred, recovery-oriented, human rights-based and responsive to the full range of needs and requirements that individuals may have, countries will need to undertake the following actions:

- develop a network of community-based mental health services for a region or country to provide critical functions of crisis support, ongoing treatment and care and community living and inclusion, and which interface with social sectors and initiate the process of deinstitutionalization in countries where institutions remain;
- develop person-centred, inclusive, comprehensive and rights-based mental health services within this network (crisis response services; community mental health centres; hospital-based services; community outreach services; peer support services and supported living services);

- ensure services provide adequate support to families, carers and other support persons;
- provide families, carers, and support persons with education, knowledge, and tools to support the recovery process;
- ensure due consideration for the role and support provided by traditional and faith-based healers and
 organizations within the country, capitalizing on the positive aspects of the care and support they
 provide while at the same time working to stop the use of coercive practices;
- align community-based mental health services with international human rights standards, in particular the CRPD; services that use alternatives to coercive responses, respect legal capacity, promote participation, community inclusion and recovery approaches;
- introduce service level policies and practices against the use of forced medication, and other coercive practices including physical, mechanical and chemical restraint and seclusion; and introduce those that utilize supported decision-making, advance plans, and recovery plans;
- foster a positive service culture by addressing attitude and culture change within services, offer training to build the knowledge and skills of service staff in order to promote the human rights of people using the service; and ensure that service development, design and delivery are always informed by the experience and expertise of people with lived experience;
- create services that provide different treatment and support options, covering a holistic recoveryoriented approach and which provide information on treatment options including benefits and potential harms of each, thereby enabling full informed consent;
- ensure that all services and supports that are available to the general population are also accessible to and inclusive of persons with mental health conditions and psychosocial disabilities, and responsive to their needs; for example, social protection programmes, housing, childcare, family support, sports clubs, etc.;
- collaborate with social services to enable the provision of affordable and supportive housing, education, employment and income generation opportunities, and support for integration in all aspects of community life for people with mental health conditions and psychosocial disabilities;
- actively collect and respond to independent and anonymous feedback from the users of the services to understand their views, what was helpful, what was not helpful, specific complaints and what the service could do better to support them;
- implement regular independent assessments of services using the WHO QualityRights assessment tool kit (or similar) and take action to address any identified gaps using the guidance and training for transforming services (6, 617);
- provide for independent advocacy services so that people using services can raise alarms or complaints about breaches of human rights or person-centred approaches, without fear of negative impact on their ongoing care; and
- ensure that services are available, accessible and culturally acceptable for all the individuals and groups of individuals who need specific mental health support without discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status.

5.4 Financing

Many countries do not adequately invest in mental health resulting in limited access and poor quality service provision. Further, in many low- and middle-income countries, mental health is often not included or is extremely limited in the package of services provided through their public health systems or covered through health insurance schemes. Psychiatric hospitals continue to receive the greatest proportion of health care expenditure on mental health. WHO's 2017 Mental Health Atlas reports that 80% of mental health budgets in low and middle-income countries go to mental hospitals and 35% in high-income countries (5).

Costing analyses have demonstrated that hospitalization costs often exceed the costs of equivalent treatment, care and support in the community, as the following examples show. In Israel, for instance, hospitalization for one night for an adult costs 476 Israeli shekel (\square) (US\$ 145)^{ai}. In comparison, supportive housing in the community costs between $\square 40-394$ (US\$ 12–120)^{ai} per day depending on the intensity of support provided (624). Similarly, in Maryland, USA, the mean cost for treatment in residential crisis services (homes in the community that provide acute care for persons who would otherwise be treated in a short-stay psychiatric inpatient unit), is US\$ 3046 whereas the cost for hospitalization in a general hospital is US\$ 5549 (44% higher) (625). In Peru also, the average unit cost per outpatient consultation at specialized mental health hospitals was estimated at US\$ 59 compared with US\$ 12 for standard outpatient consultations at community mental health centres – a five-fold savings (566). In another comparison, a single psychiatric admission in Nigeria costs US\$ 3675 – the equivalent of 90 outpatient visits (626).

Instances in which perverse incentives may operate to maintain and reinforce negative practices in mental health need to be modified. Such perverse incentives may include the following examples.

- Higher payments to hospitals or reimbursements for people using hospital services may be paid (either from public health financing or from health insurance) for inpatient and outpatient services that instead could have been delivered at a lower cost in community-based settings. For example, in Turkey, treatment in mental health hospitals incurs a 30% higher payment than a mental health unit in a general hospital (627). Similarly, a US study of 418 hospitals found that the average amount charged per hospitalization in psychiatric services was 2.5 times greater than the actual cost to deliver care and that having health insurance cover was associated with longer stays (628).
- Health insurance or national health system reimbursement schemes may not be aligned with the evidence for treatment and interventions. Health insurance drives a need for diagnosis and favours simple and discrete interventions (such as medications) rather than more complex interventions that may be beneficial. This has the effect of limiting treatment options and choice. When health insurance or national health system reimbursement schemes are not aligned with evidence they reinforce bad practices and limit the choices of other evidence-based interventions. For example, in many low-, middle- and some high-income countries, people have much better access to psychotropic medications, for free or at a relatively low cost, relative to non-medical forms of treatment such as psychotherapy (629). There are, however, notable efforts to increase the availability of alternatives, for example, the training and placement of 820 psychosocial counsellors in 425 comprehensive health centres in Afghanistan during the period 2007-2019 (630).

ai Conversion as of March 2021

aj Conversion as of March 2021

Higher payments to services for procedures that need to be delivered within a hospital (such as ECT) act as a perverse incentive encouraging their use even in situations where this use is not supported by evidence and clinical indications^{ak} (631). For example, in Germany, the use of ECT means an extra payment of €271 (US\$ 328)^{al} to the service per day (632).

Changes to the types of services and interventions that are financed by governments and reimbursed through health insurance schemes will play an important role in diminishing the use of coercive practices and introducing and prioritizing person-centred, recovery and human rights-based services and practices in countries.

Many good practice, community-based services that align with recovery and human rights-based approaches are being led and managed by NGOs in the not-for-profit sector. This opens up opportunities for governments to contract NGOs to deliver (or continue to deliver) services instead of government health services trying to provide all these services directly. There are many examples of countries across the world using a mixed approach in which governments provide mental health services directly as well as through contracting NGOs. There are many examples of NGO-provided services which are funded by the government directly, including several mentioned in this document such as Afiya house USA; the network of services in Bosnia and Herzegovina and Hand in Hand Georgia. Implementing this type of shift requires close coordination and integration, otherwise NGOs can be easily marginalized, and the overall effect can increase fragmentation of the mental health care system.

Careful attention should be paid to the potential rigidity of some contractual schemes that require strict criteria to be met by services in order for funding to be approved. Sometimes the lack of flexibility in criteria is incompatible with the flexible approach required by a person-centred recovery approach. For example, health insurance funding for a peer support service that reimburses recovery planning but not the transport costs to meet service users, presents important barriers to the delivery of that service and its uptake.

Many countries have successfully used shifts in financing policy and strategy as a powerful lever for mental health system reform, as shown in Box 8 below.

ak The use of ECT should be limited to very rare cases (only for catatonia and treatment-resistant severe depression), and only when full informed consent in given. This should include information about the controversial nature of the procedure and the possibility of serious adverse effects. ECT should only be used with appropriate anesthesiology support.

al Conversion as of March 2021.

Box 8. Financing as a lever for reform in Belgium, Brazil, Peru and countries of West Africa

Using financing as a critical lever for reform in Belgium, Brazil, Peru and countries of West Africa

Historically, Belgium, and especially Flanders, has had a very large number of psychiatric hospital beds. One of the key objectives of the mental health reform in Belgium, therefore, was to phase out psychiatric hospital beds and instead offer more outpatient care options, in particular through creating mobile teams to provide care to people in their home environment.

The reform has involved the entire country and health sector – not just public hospitals. In Belgium the vast majority of hospitals are private, not-for-profit institutions and the closing of psychiatric hospitals by the government would have required providing the organizing bodies of these institutions considerable financial compensation. For this reason, an alternative decision was made to use financial incentives to encourage hospitals, on a voluntary basis, to make the required shift to reduce beds and increase community services.

In relation to financing, the government agreed to fully fund all hospital beds that were to be closed (at a level as if they had been fully occupied). The fact that beds were closed – without any loss of funds – freed up the time of the available clinical staff so that they could serve on the mobile teams that were being established.

Over a four-year period, the community mobile teams also received a significant financial contribution by the government to facilitate their creation; with the medical supervision of the team and the fees for the home visits by psychiatrists, being fully covered by government funds. This also ensured that home treatment was made available completely free of charge to the end users of the communitybased mobile outreach service.

In Belgium, mental health care is organized in regionally defined networks and not every region had the same number of hospital beds and hence possibility to create mobile teams through the closure of beds and use of staff time to work as part of the community mobile outreach teams. In these situations, the government provided additional financial resources to allow the sufficient recruitment of staff for the mobile teams. In addition to the creation of the community mobile outreach teams, the same mechanism of financial incentives also allowed the strengthening of other aspects of hospital services, in particular, the crisis response services.

Belgium ([de Bock P], [Service public fédéral (SPF) Santé publique], personal communication, [2020])

Brazil

Universal health care is a constitutional right in Brazil provided under the country's Unified Health System which includes provision of Brazil's community-based mental health network. From early 2000 substantial changes were made to how the mental health budget was used in Brazil in order to finance the development of community mental health services and to implement a policy of deinstitutionalization. Institutional structures and services have been replaced by a communitybased network of services through incremental resource reorientation (633, 634). Mental health spending increased by 51.3% from 2001 to 2009 (635). Of the federal financial resources allocated to mental health in 2002, psychiatric hospitals accounted for almost 80% of expenditure, with community-based mental health services accounting for the remaining 20%. In contrast, by 2013 nearly 80% of the mental health budget went towards community-based services compared with 20% for hospital expenses (*184*).

Peru

In 2012, Peru included mental health services in the benefit package of its Comprehensive Health Insurance scheme, as part of the national efforts toward achieving UHC. In addition, a revised reimbursement fee schedule was implemented for mental health providers and services to cover the cost of service provision at community mental health facilities and specialized psychiatric hospitals. This led to the increased provision of mental health services in the community and helped reduce patients' out-of-pocket payments for mental health services from 94% in 2013 to 32% in 2016. In 2014, a ten-year financing framework that uses a results-based budgeting programme based on pay-for-performance (*Presupuesto por Resultado*) was established to direct and expand reform efforts. In this framework the budgets are assigned by the Ministry of Economy and Finance based on the attainment of predetermined indicators related to the screening and treatment of mental health conditions, as well as community interventions (such as family and community support and training) (566, 636).

West Africa

Governments are the main duty bearers for provision of equitable, quality health care that promotes dignity and rights, but gaining political support, policy change and investment for a transition from inadequate or outdated services is often a challenge in resource-poor settings with many competing priorities. Local and international civil society organizations and NGOs often play a catalytic role in this process. Their independence, access to financing, and lack of bureaucracy enables them to move faster than formal systems. Such non-state actors often work by establishing innovative programmes that can demonstrate progressive change and are aligned to international recommendations including human rights standards, for example addressing access to services, promoting participation or challenging coercive practices. Ideally such a reform is carried out in a partnership approach with government and local civil society organizations (through a public private partnership), so that a gradual transition to local ownership and financing is built into programme strategy, avoiding the risk of brief, time-limited projects that cannot be sustained or scaled.

One example of health system strengthening work that has attempted to play this catalytic role, as well as leave a legacy of sustained reform, is the work that the Christian Blind Mission (CBM) has done in West Africa since 2005. Their programmes in Burkina Faso, the Gambia, Ghana, Liberia, Niger, Nigeria and Sierra Leone also worked within government systems and ministries of health, providing financial, technical and other support to strengthen health information systems and medication supply chains. At the same time, by working through local NGO partners and building local civil society Mental Health Stakeholder Coalitions, including people with psychosocial disabilities, a strong advocacy voice was developed and empowered to hold governments accountable, successfully facilitating policy and legislation reform, and increasing investment in many of these countries (637, 638).

Key national actions to integrate person-centred and human rightsbased approaches

In order to create and adequately fund a person-centred, recovery-oriented, human rights-based system of mental health care and support, it is critical that countries undertake the following finance-related actions:

- substantially increase the budget for mental health within health and social protection sectors.
- use budgets to reshape services by linking budgets with human rights-based programmatic objectives and investing in community services and supports which are evidence-based, human rights-based, person-centred and that promote recovery, which could include reimbursements for social prescribing (to enable general practitioners, nurses and other health and care professionals to refer people to a range of local, non-clinical supports in the community) (639) and the development of recovery plans and advance plans, with the full engagement of service users;
- invest in the social sector to provide education, housing, employment opportunities and social protection schemes for people with mental health conditions or psychosocial disabilities;
- eliminate discrimination against people with psychosocial disabilities in health insurance in particular, the denial of health insurance based on disability must be legally prohibited and regulations adopted to ensure that insurance plans and premiums are fixed in a fair and reasonable manner (640) – and ensure the availability of health insurance for mental health care and support over the long term, not just for acute admissions;
- remove incentives to maintain psychiatric hospitals and social care institutions and incentivize their closure in a planned systematic way to ensure that former residents have the supports they need to lead meaningful lives in the community;
- eliminate financial incentives for interventions and treatments which are not evidence-based or compliant with international human rights standards and introduce incentives for evidence-based community-based mental health services;
- use financial incentives to implement non-coercive approaches and a more comprehensive range of treatments and supports that allow for a holistic, person-centred recovery approaches for care and support including psychotherapy;
- prioritize, in the basic package of mental health services provided by the public mental health system, those good practice, community-based mental health services that operate on the principles of recovery, legal capacity, community inclusion and freedom from coercion, as an alternative to institutionalization or an over-reliance on specialist care; and
- include and integrate NGO-delivered services that promote recovery, rights and good outcomes within the umbrella of services that are contracted and managed by government and covered by health insurance schemes.

5.5 Workforce development and training

The workforce in health and social care sectors directly impacts the type and quality of services provided. The development of the workforce itself depends on a myriad of factors including recruitment, motivation, retention, education, training and continuing professional development amongst other factors, which have been well described in WHO publications (641, 642).

Moving towards services and interventions that promote a person-centred recovery approach and that meet the international human rights standards set by the CRPD, requires significant changes to the attitudes, knowledge, competencies and skills of service providers in health and social care services. Negative assumptions and false beliefs held by health professionals and service providers (as well as policy makers and the community at large) about people with mental health conditions and psychosocial disabilities need to be overcome to address stigma and discrimination in the health care context. In addition to clinical training needs such as that provided by WHO's mhGAP Intervention Guide (643), educational and training initiatives which introduce a more balanced, person-centred and recovery-based approach – as opposed to solely focusing on a biomedical model – are central to achieving transformative change. Such initiatives would have the added potential benefit of reducing fear and stigma and the belief that people with mental health conditions or psychosocial disabilities are potentially (or actually) dangerous (43, 644-646).

Human rights education is rarely provided to service providers within the health and social sectors (647), but is much needed given that service providers can (and do) restrict rights (648, 649). Health care professionals need to be trained on human rights-based approaches that address the intersecting forms of discrimination that affect persons with mental health conditions and psychosocial disabilities. In addition, medical and health professional and educational institutions should review their curricula to ensure that the education they offer adequately reflects the health care needs and rights of persons with disabilities (640).

In an effort to change staff attitudes, beliefs and practices towards a human rights-based approach and service culture, WHO has developed a set of face-to-face training tools on mental health, disability, human rights and recovery (see Box 9). **Box 9.** WHO QualityRights Training Materials on mental health, disability, human rights and recovery

WHO QualityRights Training Materials

The QualityRights face-to-face training modules have been developed in collaboration with more than 100 national and international actors including: disabled people's organizations, NGOs, people with lived experience, family and care partners, professionals working in mental health or related areas, human rights activists, lawyers, and others. The modules are designed to change mindsets around mental health and practice and cover the following key topics:

Core training

- Human rights (650)
- Legal capacity and the right to decide (38)
- Mental health, disability and human rights (44)
- Recovery and the right to health (651)
- Freedom from coercion, violence and abuse (10)

Specialized training

- Recovery practices for mental health and well-being (652)
- Strategies to end seclusion and restraint (40)
- Supported decision-making and advance planning (325)

Evaluation tools

- Evaluation of the WHO QualityRights training on mental health, human rights and recovery: pretraining questionnaire (653)
- Evaluation of the WHO QualityRights training on mental health, human rights and recovery: post-training questionnaire (654)

WHO QualityRights training materials are available at: <u>https://www.who.int/publications/i/item/who-qualityrights-guidance-and-training-tools</u> Evaluation tools are available at: <u>https://qualityrights.org/resources/evaluation-tools/</u>

While focused, intensive training is needed in order to change attitudes and practices, any meaningful and sustainable change in the field of mental health can only happen if mindsets and practices of staff are changed on a wide scale. Sporadic training events, even if intensive, often reach limited numbers of people and because of this are not able to change the status quo that exists within the community at large.

In order to reach the scale required, a WHO QualityRights online e-training programme and platform on mental health, disability, human rights and recovery has been developed and is currently being rolled out to reach, engage and train many more people within a much shorter period of time, without logistical concerns, and at a fragment of the cost of face-to-face training. Among other countries, the Governments of Ghana and Kenya have embarked on a nationwide rollout of this training, as shown in Box 10. The e-training has been well-received by participants. The learning content of the e-training platform is based on the full set of QualityRights face-to-face training materials. **Box 10.** WHO QualityRights e-training on mental health and disability : eliminating stigma and promoting human rights

WHO QualityRights e-training on mental health and disability: eliminating stigma and promoting human rights

In 2019 both the Government of Ghana and the Government of Kenya embarked on nationwide rollouts of the WHO QualityRights e-training on Mental Health, Disability, Human Rights and Recovery. In Ghana, from the national launch of the QualityRights e-training in February 2019 to the February 2020, around 17 000 people enrolled in the 15-hour, 6 module course and around 9000 people successfully completed the full course to obtain their WHO certificate. In order to sustain and incentivize capacity-building in the long term, several professional organizations registered QualityRights e-training as part of their Continuous Professional Development, including the Medical and Dental Council, Psychology Council, Allied Health Council, Nursing and Midwifery Council, Pharmacy Council and Ghana College of Nurses and Midwives). Further, the Ghana College for Nurses and Midwives integrated the training into their regular curriculum. Moreover, the QualityRights e-training certificate has become a prerequisite requirement for all staff at the Accra Psychiatric Hospital to receive a promotion.

Meanwhile in Kenya, just over one year after the official national QualityRights e-training launch in November 2019, around 3500 people had enrolled, 3000 had completed a core module on human rights and 800 had successfully completed the full 8 modules to receive their certificates. In addition, in July 2020 the government of Kenya launched its roadmap for mental health in a report entitled "Mental Health and Well-being: Towards Happiness & National Prosperity" and the WHO QualityRights initiative and e-training underpinned many of the recommendations for transforming the mental health system and was included as a core strategy to address stigma and discrimination, to improve access to mental health services and to strengthen human resources for mental health.

In the Western Pacific, the Philippines officially launched the e-training in Filipino on World Mental Health Day, October 10, 2019, at the Third Public Health Summit of the Department of Health. The e-training is one of the core interventions in the country's Strategic Plan of the Philippine Council for Mental Health, for the implementation of the new Mental Health Act.

In 2019–2020, Turkey, Estonia, Czechia and Bosnia and Herzegovina translated and launched the QualityRights e-training programme in each of their respective countries and languages. This has facilitated national capacity-building of thousands of health professionals and other key stakeholders in each country.

The creation of the Spanish and French versions of the QualityRights e-training in 2021 will allow the large-scale uptake of QualityRights in French and Spanish speaking countries throughout the world, notably throughout Latin America.

A 2019 evaluation examining attitude change for participants completing the e-training course, conducted by the Institute of Mental Health, University of Nottingham, specifically demonstrated significant improvements in attitudes and practices towards a human rights-based approach in mental health including those related to the need to end force and coercion in mental health care and to provide information and choice as well as respect people's decisions concerning treatment ([Dilks H, Hand C, Oliveira D and Orrell M],[Institute of Mental Health, University of Nottingham], unpublished data, [2019]) (655).

Feedback received on the QualityRights e-training platform

The QualityRights e-training has been well-received by participants from Czechia, Estonia, Ghana, Kenya, Turkey and other countries, as the following quotes from participants clearly illustrate.

"Life changing!"

"Coercion, violence and abuse at work must end NOW!!!"

"Am most grateful to this special training for helping me to upgrade my professional knowledge about human rights."

"Wow. Learning has indeed taken place. I pray to resolve from making the final and only decision for my patients without caring for their legal capacity."

"Very educative, it got to a point I bowed my head because I felt ashamed of how on numerous occasions I used substitute decision instead of supportive decision. I seriously think all health workers especially mental health workers in Ghana can help respect these rights a lot."

"It has been a real life transforming experience, practices I previously thought to be acceptable(normal) are actually grave violations of basic human rights. I have already begun speaking to people about changing their mindset and will continue to advocate for QualityRights for people in my community and beyond. Thanks for the priceless knowledge you have bestowed upon me."

Key national actions to integrate person-centred and human rights-based approaches

In order to successfully integrate a person-centred, recovery-oriented and human rights-based approach in mental health, countries must widen their focus beyond the biomedical model in order to change and broaden mindsets, address stigmatizing attitudes and eliminate coercive practices. To do so, countries will need to prioritize the following actions:

- provide education and training to build structural competencies of health and social care workers
 as part of pre-service and ongoing training which allow them to understand and recognize the
 importance of social determinants of mental health, including poverty, inequality, discrimination
 and violence, and adequately respond to these factors when providing care and support;
- redesign undergraduate and graduate course curricula in medicine, psychology, social work and occupational therapy, among other areas, to incorporate education and training on human rights, disability and person-centred, recovery approaches in mental health and social care;
- provide internships and learning placements in services that promote human rights and personcentred, recovery approaches;
- provide Continuing Professional Development (CPD) that incorporates training modules on human rights, disability and person-centred, recovery approaches in mental health;
- require that professional accreditation include training on human rights, disability and personcentred, recovery approaches in mental health as a pre-requisite for certification;
- provide, as part of the education curriculum and ongoing training programmes for health and social care professionals, training on how to support people wanting to reduce or come off psychotropic drugs;
- co-produce and co-deliver education, training materials and training courses by people with lived experience, for health and social care workers, NGOs, OPDs, the police and other groups in the community; and
- ensure WHO QualityRights training modules and e-training are provided in undergraduate, graduate and continuing professional development curricula as part of the overall effort to improve awareness, knowledge, attitudes and practices of practitioners in health and social care.

5.6 Psychosocial interventions, psychological interventions and psychotropic drugs

International human rights standards underscore the importance of access to evidence- and human rights-based interventions, including psychosocial and psychological interventions, and psychotropic drugs. However, it is of the utmost importance that these be seen as interventions that may, or may not, be helpful to a particular individual at a particular point in their life. Their use must always be discussed, their limitations and possible negative effects explained clearly, and their ultimate use based on individual's will, preferences and informed consent (656).

Current practice in all parts of the world, however, places psychotropic drugs at the centre of treatment responses for people with mental health conditions and psychosocial disability. Major concerns have been expressed about the very high prescription rates from primary health care providers in high income countries (15, 657-660). Evidence shows that while psychotropic drugs can help people to manage symptoms and different forms of distress, it is essential that they are not overused or abused and that service providers and people prescribed these drugs are fully informed of their impacts – both positive and negative including the potential for withdrawal effects. For instance, recently increasing concern has been expressed about the negative effects of antidepressants, including the serious withdrawal syndrome that can occur when people stop these drugs (661-663). This is particularly concerning given that they are being widely and increasingly prescribed in many countries (11-13) and that evidence for their efficacy is mixed and even contested (664-666). Although many people benefit from antipsychotic (neuroleptic) drugs similar evidence about their harmful effects, for example, the metabolic syndrome seen with long-term use, reinforces the need for cautious responsible prescribing (667, 668). In this context it is essential that psychotropic drugs are only prescribed when people considering their use have been made aware of these issues and have given their informed consent. People wishing to come off psychotropic drugs should also be actively supported to do so, and several recent resources have been developed to support people to achieve this.

Psychosocial interventions (for example interventions supporting people with housing, employment, education, training and social protection), psychological interventions and peer support should be explored and offered in the context of a holistic, person-centred, recovery and rights-based approach. It is essential that services have access to different recovery tools that can broaden the treatment approach and provide a more personalized approach to individuals and the distress that they are experiencing (see Box 11). Some examples include recovery plans and frameworks (75, 652), as well as advance plans (325).

Box 11. The recovery approach in mental health– WHO resources and tools

The recovery approach in mental health- WHO resources and tools

WHO has developed key tools for promoting the recovery approach in the area of mental health.

1. The WHO QualityRights Person-centred recovery planning for mental health and well-being selfhelp tool guides people through the process of setting up a recovery plan for themselves. The tool has been designed so that people can use it on their own or in collaboration with others. For example, it can be used as a framework for dialogue and discussion between people using services and service providers or other supporters.

The self-help tool starts by introducing what recovery is and what it means for people in their lives. The tool then takes people through an exercise of identifying their dreams and goals, how to create a wellness plan as well as planning ahead for difficult time or crises during their recovery journey. People using this self-help tool are taken through a series of self-reflective exercises that encourage an understanding of self, and how to draw on their network of support.

The WHO QualityRights Person-centred recovery planning for mental health and well-being self-help tool is available here https://www.who.int/publications/i/item/who-qualityrights-self-help-tool.

2. The WHO QualityRights specialized training module on the recovery practices for mental health and well-being is designed for use by a wide range of stakeholders including people with lived experience, health and mental health managers and professionals, families, NGOs, OPDs and many others working in health and social sectors. The module provides comprehensive training on practical ways to introduce a person-centred recovery approach to services providing mental health care and support. It provides a detailed introduction to the recovery approach and how it differs from approaches within more traditional services.

The training highlights the importance of understanding what "getting better" or "recovery" means for each person, as well as key skills for working with them to achieve this. Through a series of case studies and exercises, trainees are shown how people can be supported, through their recovery journey, to identify and harness their strengths, goals and aspirations, explore opportunities, exercise choice and maximize inclusion and autonomy in their communities. Although the module focuses on mental health and social services, the recovery approach is equally relevant to all people overcoming difficulties and/or loss in their life, with or without disabilities.

The WHO QualityRights specialized training module on the recovery practices is available here https://apps.who.int/iris/bitstream/handle/10665/329602/9789241516747-eng.pdf.

Many different forms of psychological intervention are available and have shown to be effective including interpersonal therapy (669, 670), cognitive behaviour therapy (671-673), dialectical behavior therapy (DBT) (674), and mindfulness-based interventions (675-677). In addition, the competency of providers of psychological interventions in developing an alliance with a person seeking support has been found to be important in terms of outcomes (678), as is the cultural understanding between explanations given by the therapist and the world view and expectations of the person. This cultural connection provides emotional and cognitive space within which healing can occur (679). It also strengthens confidence and trust within the therapeutic relationship. WHO has made available various tools and resources concerning psychological and social interventions, as described in Box 12.

Box 12. WHO resources for psychological interventions

WHO resources for psychological interventions

WHO has developed a range of different tools and materials around psychological and psychosocial interventions, including the following resources.

Problem Management Plus (PM+): Individual psychological help for adults impaired by distress in communities exposed to adversity. (Generic field-trial version 1.1) (680) https://www.who.int/mental_health/emergencies/problem_management_plus/en/

Group Problem Management Plus (Group PM+): Group psychological help for adults impaired by distress in communities exposed to adversity (generic field-trial version 1.0) (681) https://www.who.int/publications/i/item/9789240008106

Group Interpersonal Therapy (IPT) for Depression (WHO generic field-trial version 1.0) (682) <u>https://www.who.int/mental_health/mhgap/interpersonal_therapy/en/</u>

Thinking Healthy: A Manual for Psychosocial Management of Perinatal Depression (WHO generic field-trial version 1.0) (683) <u>https://www.who.int/mental_health/maternal-child/thinking_healthy/en/</u>

Doing What Matters in Times of Stress: An Illustrated Guide (684) https://www.who.int/publications/i/item/9789240003927

EQUIP: Ensuring Quality in Psychological Support (685) https://www.who.int/mental_health/emergencies/equip/en/

With the rapid expansion of technology, online mental health tools and apps are becoming increasingly popular. A cautionary warning is required to ensure that these are not used as a panacea for widespread responses to mental health issues and distress, but that they take a comprehensive approach to understanding mental health, including social factors and determinants, and do not lead to widescale propagation of understandings of mental health solely focused on biomedical approaches, or undermine the responsibility of governments have to provide accessible, acceptable, comprehensive human rights-based community mental services and supports. The development of these apps should also be informed by research, based on evaluation of effectiveness and feedback from user experiences and quality standards in terms of data privacy and safety. When people experience extreme states and emotional distress, the need for people to establish meaningful therapeutic relationships cannot be underscored enough.

Key national actions to integrate person-centred and human rightsbased approaches

In order to ensure that all mental health services, interventions and supports are compliant with international human rights standards, countries will need to undertake the following actions:

- implement a systematic approach to obtaining free and informed consent for all mental health interventions with consideration for all people using services, and respect peoples' right to refuse any or all interventions;
- ensure that psychosocial interventions address the full range of needs that a person may have, spanning relationships, peer and social networks, work and income, education and training needs, housing, and discrimination;
- make a range of both non-pharmacological and pharmacological treatment options available and offered by health services taking into account the importance of non-pharmacological approaches and options;
- ensure the availability of psychological tools, interventions and psychotropic medication in countries;
- explicitly discuss with all people considering treatment, the potential beneficial and harmful effects of medication and its impacts on physical health, as well as psychological interventions, and the pros and cons of both;
- provide guidance and support to people wanting to reduce or come off psychotropic drugs;
- evaluate and monitor the use and costs of psychotropic medication, psychological interventions, and other treatments in mental health and social services in primary care; and
- use advance plans, make sure that these are accessible and communicated to other key people and that they are enforced to ensure that each person's will and preferences are respected with regard to treatment and support offered.

5.7 Information systems and data

Mental health information systems are essential for a well-functioning mental health system. For policymakers and planners, information systems provide a mechanism for understanding the mental health situation, monitor it over time, assess whether goals and objectives are being achieved and help inform choices, improvements, and future courses of action. Data can also be used to inform people who use mental health services and the community about the service's compliance with quality and human rights standards, and service outcomes. This information should be presented in an accessible format and openly and readily available to the public.

Given the important impact of social determinants on mental health, indicators are required at population and service level both within and outside the health sector. In order to reflect the diversity of information required, much of the data required for indicators may need to be collected from different sources within health, social and other relevant sectors. Suggestions for data that could potentially be collected to inform a human rights based approach are presented below. Although it is unlikely that all these data can be collected, countries should nevertheless review, determine and prioritize which data are important and feasible to collect on a routine basis. Additionally, periodic surveys or other means can be used to supplement efforts to collect data on specific issues of interest. A number of tools to facilitate data collection are presented in Box 13.

At population level and from a human rights perspective, countries can consider collecting national level data disaggregated by sex and age on:

- the proportion of the mental health budget allocated to community-based services and support, in comparison with budget allocated to psychiatric hospitals and beds;
- budget allocated to specific forms of treatment including psychotropic drugs, psychosocial interventions and psychological therapies;
- mortality rates of persons with mental health conditions and psychosocial disabilities, by type and cause;
- suicide rates and suicide attempts among persons with mental health conditions or psychosocial disabilities;
- rates of poverty, income level, employment, education, housing, social protection, and disability support of persons with psychosocial disability versus other disabilities, versus the general population;
- number and proportion of homeless people with mental health conditions and psychosocial disabilities;
- number and proportion of people with mental health conditions and psychosocial disabilities in prisons;
- morbidity and mortality associated with treatments, interventions, comorbidities, lack of access to and equity in health care;
- prescription rates and costs for psychotropic drugs;
- number and proportion of people receiving psychological and psychosocial interventions;
- number and proportion of people under guardianship or other substitute decision-making mechanisms;
- rates of involuntary hospitalization;

- number and proportion of people receiving support for decision-making;
- number and proportion of people with legally enforceable advance plans or directives;
- proportion of services meeting quality and human rights standards the QualityRights assessment tool kit can be used to measure this; and
- number and proportion of health practitioners and staff of health, psychiatric, mental health, social care and supported living services, and institutions trained on the rights of persons with disabilities.

Box 13. Tools for data collection on mental health and psychosocial disability

The Washington Group short set of six questions to assess disability (686)

The short set of six questions on disability formulated by the Washington Group on Disability Statistics is the most widely recognized method for disaggregating data by disability in national surveys and censuses in an internationally comparable manner. The questions cover six domains of functioning: seeing, hearing, walking, cognition, self-care, and communication. However, psychosocial disability is one area where the short set under-identifies people. To remedy this situation, the extended questionnaire (686) includes four questions on anxiety and depression, in addition to three cognitive questions, which aim to capture psychosocial disability. The Washington Group on Disability Statistics continues to explore better ways to measure psychosocial functioning. *The Washington Group Short Set on Functioning (WG-SS)* is available here: https://www.washingtongroup-disability.com/question-sets/

The WHO Model Disability Survey (MDS) (687) and how it reflects psychosocial disabilities

The MDS is a general population survey developed by WHO and the World Bank in 2012. The MDS is grounded in the *International Classification of Functioning, Disability and Health* and includes both a household and an individual questionnaire in a modular structure. The objectives of the MDS are to determine the current prevalence and distribution of disability in the population, and identify the barriers and inequalities faced by persons with different levels of disability.

The MDS understands disability as the outcome of the interaction between a health condition and barriers faced in the environment in which the person lives. Disability is also understood as a matter of degree (mild, moderate and severe levels of disability), rather than a matter of type (visual, hearing, physical or psychosocial disability). As disability is not solely an attribute of persons due to the presence of visual, hearing, physical and psychosocial impairments, the MDS does not focus on counting people with these disabilities. However, in Module 5000 – health conditions and capacity – information is collected on the presence of health conditions, including mental health and neurological conditions. MDS includes depression, anxiety and dementia, but countries can expand the list if they are specifically interested in particular conditions. Depending on the sample size, it is possible to analyse the data broken down by a health condition(s). The *WHO Model Disability Survey* is available here: https://www.who.int/disabilities/data/mds/en/

Countries can also consider collecting service level data (which can be aggregated and reported at national level) on the number and proportion of people with mental health conditions and psychosocial disabilities disaggregated by sex and age, who are:

- currently residing in institutions (e.g. psychiatric inpatient settings, residences for persons with intellectual disabilities, etc. from large scale facilities to group homes) (688);
- currently residing in secure / forensic units;
- undergoing forced interventions (including medication, ECT, psychosurgery, sterilisation without consent);
- subjected to seclusion;
- subjected to physical, mechanical or chemical restraints;
- subjected to involuntary admission in social care services, psychiatric institutions and other settings;
- accessing key services which, depending on the country's organization of services, could include: (i) community-based mental health centres (ii) crisis services (iii) hospital-based services (iv) outreach services (v) supported living and home support services and (vi) peer support services;
- with legally enforceable advance plans;
- with therapeutic recovery plans; and
- who have died in mental health services and institutions.

In addition, data can be collected and disaggregated by sex and age for each individual using services, through an exit survey that asks about:

- any use of coercive practices including forced treatment such as medication, seclusion and restraint as well as any subjective perceptions of having been coerced;
- any experience of violence, abuse or neglect;
- respect for opinions/decisions/preferences concerning medications, treatment and autonomy;
- support to develop an advance directive and whether existing advance directives expressing will and preference were upheld;
- support to develop, revise, and implement a recovery plan;
- attention to factors related to community inclusion as part of a recovery plan, whether inpatient or outpatient; and
- peer support offered within the service or outside the service.

Key national actions to integrate person-centred and human rightsbased approaches

In order to effectively plan, monitor and evaluate the creation and implementation of a human rightsbased approach to improve the mental health and well-being of specific communities and the population as a whole, countries will need to undertake the following actions:

- collect data at national and service levels and report on mental health indicators which reflect social determinants of mental health and human rights of people with psychosocial disability;
- disaggregate data where appropriate by sex, age, gender, race, ethnicity, disability and other variables relevant to the national context;

- review, discuss, prioritize and agree upon feasible indicators at population level from national level data highlighted above;
- review, discuss, prioritize and agree upon feasible indicators at service level, from the data highlighted above;
- collect key information from people using services to understand the quality of care and respect for human rights from exit surveys;
- specify means and methods for data collection for selected indicators;
- use data to inform the health and other sectors about the state of mental health and human rights, the impact of policy, strategy and interventions to address this and improvements required based on findings, which includes the use of data to:
 - » understand morbidity and mortality caused by treatment and interventions being used or the lack of access to treatment and services;
 - » understand which populations are disproportionately impacted by human rights violations and coercive practices;
 - » understand the cost-effectiveness of services and approaches in order to ensure available resources are spent efficiently;
 - » inform the community about the quality, human rights and outcomes linked to the mental health services being provided, making any data and reports available in an accessible format and readily available; and
- make data collected by government health services available to civil society for transparent accountability and monitoring of services and make use of the data collected by civil society to validate government-collected data.

5.8 Civil society, people and the community

While this guidance focuses on building health and social systems that integrate person-centred, human rights-based, and recovery-oriented approaches to community mental health services, it is important to recognize that taken alone, these efforts are insufficient to achieve the intended results. Wider efforts are required to create inclusive societies and communities where diversity is accepted and the human rights of all people are respected and promoted. Several community-level actions that can contribute to this goal are described below.

Addressing negative stigmatizing and discriminatory attitudes of whole communities

It is fundamental to take action in relation to changing negative and stigmatizing attitudes or mindsets and discriminatory practices not just within health and social care settings, but also within the community, involving all sectors and diverse community stakeholders including: people with mental health conditions and psychosocial disabilities themselves, family members, government departments and services, NGOs, OPDs, educational and training bodies, workplaces, researchers and academics, teachers, the legal profession, the police force, the judiciary, cultural, traditional and faith based healers and organizations, as well as journalists and the media. Addressing stigma and discrimination in this way has the added benefit of promoting diversity, acceptance and inclusiveness and thus can contribute towards creating more cohesive and harmonious communities which can, in turn, promote the health and well-being of their members.

Awareness raising campaigns and human rights training are essential actions to address stigma and discrimination. Generally they work best when they involve personal contact with persons with disabilities themselves (689, 690). Through these actions it is essential that people with mental health conditions and psychosocial disabilities become aware of what their rights are so that they can claim them. Family members and carers also need to understand these rights so that they too can respect them and also support their relatives in accessing rights. A wide group of community stakeholders such as those listed above also need to have an understanding of human rights and mental health that should be introduced through basic awareness programs and professional development training. Two compelling examples of programmes that challenge mental health stigma and discrimination are highlighted in Box 13 below.

People with lived experience have a unique role in designing and implementing awareness campaigns, with good outcomes. One such example is Time to Change Global, a programme which challenged mental health stigma and discrimination in Ghana, India, Kenya, Nigeria and Uganda, highlighted in Box 14. Other innovative approaches include the WHO QualityRights face-to-face training modules (see Box 9) and WHO QualityRights e-training programme (see Box 10). WHO has also published key practical guidance documents on how to develop, implement, monitor and evaluate advocacy campaigns addressing mental health, disability and human rights (*691*).

Box 14. Challenging mental health stigma and discrimination

Conversations Change Lives: Anti-stigma toolkit

Time to Change Global was a programme which challenged mental health stigma and discrimination in Ghana, India, Kenya, Nigeria and Uganda. People with lived experience were responsible for developing and communicating the campaign's key messages. The programme was a partnership between UK mental health charities Mind and Rethink Mental Illness, international disability and development organization Christian Blind mission, and five country-level partners: Mental Health Society of Ghana (MEHSOG), Grameena Abyudaya Seva Samsthe (GASS), Gede Foundation, Basic Needs Basic Rights Kenya (BNBR) and Mental Health Uganda.

Programme partners developed Conversations Change Lives (692), a global anti-stigma toolkit rooted in the voices of people taking action to end mental health stigma and discrimination. The toolkit aims to capture a snapshot of what stigma looks like in the five programme locations – Accra in Ghana, Doddaballapur in India, Abuja in Nigeria, Nairobi in Kenya and Kampala in Uganda. The toolkit does not present a "right way" to take on anti-stigma work – instead, it helps readers to consider different approaches and new solutions. As well as providing a snapshot of what stigma looks like, the toolkit covers three key themes: how to talk about mental health, how to include people with lived experience and how to identify and reach the right audience(s).

Each of these sections shares learning and reflection and sample tools and materials alongside case studies and examples from the five locations.

For more information see: <u>https://time-to-change.turtl.co/story/conversations-change-lives/</u>

The Speak Your Mind campaign

"Speak Your Mind" is a nationally driven, globally united campaign that aims to catalyze greater national government action on mental health by uniting civil society efforts and reframing mental health as an important issue at the national and global level (693). The emphasis is on encouraging people with lived experience to fully engage in the development and delivery of mental health policies and practice nationally and internationally.

In recent years, national coalition campaigns have achieved important wins. For example, thanks to the efforts of Sierra Leone campaigners, the Government announced a review of the Lunacy Act of 1902 in order to protect and promote the human rights of people with mental health conditions and psychosocial disabilities. The government of Nigeria banned the dangerous pesticide 'Sniper' which was implicated in the majority of suicides in the country. The government of Tonga announced its first-ever National Mental Health Policy and tripled its mental health budget.

The campaign is active in 19 countries, including English, Spanish and French speaking countries.

For more information see: www.gospeakyourmind.org @gospeakyourmind #SpeakYourMind

Supporting the development of civil society

In order that whole communities enjoy good mental health, it is important to have an active civil society contributing to decision-making at political, social and community levels, as the degree of a community's well-being is also related to its governance. The political empowerment and strengthening of civil society increases the engagement of local people and communities in defining problems and generating and implementing solutions (694)

Countries who have ratified the CRPD have an obligation to create the conditions for an active civil society which engages in policy making and advocates for the full participation of people with mental health conditions and psychosocial disabilities and their organizations, as a movement to be listened to and reckoned with. Government respect and support of movements of people with lived experience creates an environment which allows people to have a stronger voice to demand that their rights and interests are respected. Civil society groups can play a key strategic role in advocating for human rights and for policy, services and other actions that are more responsive to their needs (694).

In the majority of countries, people with mental health conditions and psychosocial disabilities face barriers to participation in policy decision-making (22). This failure can be explained partly by the absence of organizations of people with psychosocial disabilities in many parts of the world. When such organizations do exist, they often lack funding, human resources and sufficient support. This stands in contrast to civil society engagement in issues such as HIV/AIDS where in many countries, those most directly affected have had an important voice in policy development and the allocation of resources. Their advocacy efforts have been extremely effective in changing the public health response from a traditional one detrimental to human rights (such as mandatory testing, travel restrictions and isolation) towards a public health response based on a human rights perspective in implementing HIV prevention, care, and support instead. Active ingredients of this success were the empowerment of people who were HIV positive and their participation in all advocacy activities (695, 696). Adapting elements of these advocacy efforts in the area of HIV could be an important means of promoting the health of people with psychosocial disabilities and empowering them to fight for their rights.

A strong civil society also helps create more effective, efficient, and accountable programmes and services. For example, organizations of people with psychosocial disabilities, lived experience and those who have experienced abuse within mental health services, hold a unique perspective that can help ensure that the mental health system and services address their needs and respect their human rights. As such, they can play an important role as advisors to government on mental health related policy, laws and regulations; reforming and transforming mental health and social services; and other measures to better protect people's human rights.

Civil society can play a number of other important roles such as: (i) conducting advocacy campaigns to change attitudes and negative practices, including engaging with the international human rights system to call governments to account; (ii) providing education and training on mental health, disability and human rights, and (iii) the direct provision of services including: crisis support services, peer support, livelihood (income generation) initiatives and personal assistance, in which direct support is provided to people on specific issues for which they wish to receive assistance. WHO has published practical guidance on how civil society movements in countries can take action to advocate for human rights-based approaches in the mental health and social sectors in order to achieve impactful and durable change (255). Box 15 presents a number of active, worldwide networks of civil society organizations of people with mental health conditions and psychosocial disabilities.

Box 15. Civil society organizations of people with psychosocial disabilities

International and regional civil society organizations of people with psychosocial disabilities

There are several networks of people with mental health conditions and psychosocial disabilities operating at the international and regional levels, which can provide valuable information, guidance and alliances to help reform mental health systems and services in line with a human rights-based approach.

World Network of Users and Survivors of Psychiatry (WNUSP) (697), originally founded in 1991 as the World Federation of Psychiatric Users, is the oldest international organization of users and survivors of psychiatry and people with psychosocial disabilities promoting and representing their human rights and interests. WNUSP played an important role in the negotiation of the CRPD and in subsequence advocacy leading to the development of international standards related to the rights of persons with psychosocial disabilities. WNUSP is a Member of the International Disability Alliance and has consultative status with the UN Economic and Social Council.

For more information, see: <u>http://wnusp.net/</u>

Transforming Communities for Inclusion – Asia Pacific (TCI – AP) (698) is an independent regional organization of people with psychosocial disabilities from the Asia Pacific region. Guided by the CRPD, TCI – AP advocates for the rights and full inclusion of people with psychosocial disabilities and enables human rights-based, CRPD-compliant community mental health and inclusion services. TCI – AP focuses on the pedagogy and the practice of Article 19 of the CRPD (Living independently and being included in the community) in Asia. The organization currently has participation from 14 countries, with emerging networks in many others. In 2018, TCI – AP adopted the Bali Declaration, endorsed by 70 people from the cross-disability movement (699).

For more information, see: <u>https://www.tci-asia.org/</u>

The **European Network of (Ex)Users and Survivors of Psychiatry (ENUSP) (700)** is an independent federation representing (ex)users and survivors of psychiatry. ENUSP promotes the human rights of people with psychosocial disabilities and user/survivor-controlled alternatives to psychiatry, free from coercion. ENUSP unites 32 organizations from 26 European countries and is a member of the European Disability Forum, the European Patients Forum and WNUSP. In recent years, ENUSP has been actively campaigning against the Council of Europe's draft additional protocol to the Oviedo Convention, which aims to regulate involuntary placement and treatment.

For more information, see: <u>https://enusp.org/</u>

The **Pan African Network of People with Psychosocial Disabilities (PANPPD) (701)** is a regional organization, founded in 2005, representing people with psychosocial disabilities in Africa. It aims to increase continental solidarity to promote and protect the rights of people with psychosocial disabilities. PANPPD operates as an advocacy platform for social justice, human rights, empowerment, social development, and full participation and inclusion of people with psychosocial disabilities. PANPPD promotes legal and policy reform, knowledge exchange and the capacity-building of their member organizations.

For more information, see: <u>https://www.facebook.com/pg/PANPPD/</u>

The **Redesfera Latinoamericana de la Diversidad Psicosocial** (Latin American Network of Psychosocial Diversity) (702) is a regional organization formed in 2018 by users, ex-users and survivors of psychiatry, 'mad people', and people with psychosocial disabilities, among others issues. Redesfera aims to promote the exchange of experiences, knowledge and alternative practices; the development of peer support groups; the knowledge and fulfilment of rights; the notion of 'mad pride' and the right to 'madness'; and law and policy reform in the region. Over the last year, Redesfera organized two cycles of webinars in order to foster the collective construction of knowledge from lived experience, and to inform about people's rights.

For more information, see: <u>http://redesfera.org/</u>

The **Global Mental Health Peer Network (GMHPN) (703)** is an international organization of persons with lived experience. GMHPN promotes human rights, empowerment, recovery, peer support and lived experience leadership. Since its establishment in 2018, the focus of its work has involved the building of a sustainable structure to develop a global leadership of people with lived experience, and to create a communication platform where the lived-experience community can share their views, opinions, perceptions and experiences. The GMHPN and its representatives are involved in various committees, partnerships, campaigns and projects. For example, GMHPN has launched "Our Global Voice" project with portraits of successful recovery stories.

For more information, see: <u>https://www.gmhpn.org/</u>

The media

Media coverage can also greatly influence public awareness and shape responses to mental health issues. It can help to reduce stigma and to educate, or conversely it can serve to increase prejudice through the promotion of stereotypes (704). Baseless and excessive focus on risk, harm, danger and crimes can link mental health conditions and dangerousness in the mind of the public (705). This is often compounded by the stigmatizing language and labels used in such reports (706). Journalists, therefore, have an important role in promoting a human rights and recovery agenda, by focusing on successful stories of recovery and respect of human rights (707).

Social media is increasingly the forum through which mental health issues are being explored, and offers people with mental and psychosocial disabilities a space to express themselves and to make connections (708). It has substantial potential for use in terms of education and the promotion of human rights and recovery, as well as the delivery of supportive interventions (709).

Key national actions to integrate person-centred and human rightsbased approaches

In order to create inclusive societies in which everyone's voice is heard and valued, and to improve the mental health and well-being of whole communities at the national level, countries will need to undertake the following actions:

- provide training on human rights in the context of mental health and psychosocial disability, for key influencers from all stakeholder groups in all sectors, including persons with lived experience themselves, the judiciary, schools, workplaces, faith-based organizations and civil society groups and for members of the community and the media – the QualityRights face-to-face training and e-training platform on mental health, disability, human rights and recovery can be used for this purpose in order to effectively reach all people;
- invest and support the establishment and sustainability of representative organizations of persons with mental health conditions and psychosocial disabilities;
- engage organizations of people with mental health conditions and psychosocial disabilities as advisors on policy, planning, legislation and service development to better protect human rights and achieve positive recovery outcomes, including community inclusion; and
- work with media to report responsibly on the work and lives of people with mental health conditions and psychosocial disabilities and educate actively against stereotypes and human rights violations.

5.9 Research

The biomedical paradigm has dominated psychiatric research in recent decades. In line with this paradigm, the focus has largely been on neuroscience, genetics and psychopharmacology. Thomas Insell, head of the National Institute of Mental Health (NIMH) in the United States of America from 2002 to 2015 (the largest funder of mental health research in the world) (*710*), said in an interview in 2017, "I spent 13 years at NIMH really pushing on the neuroscience and genetics of mental disorders, and when I look back on that I realize that while I think I succeeded at getting lots of really cool papers published by cool scientists at fairly large costs – I think US\$ 20 billion – I don't think we moved the needle in reducing suicide, reducing hospitalizations, improving recovery for the tens of millions of people who have mental illness" (*711*).

The extent of research examining human rights-based approaches in mental health is extremely limited. While there have been a few solid studies examining recovery practices including Individual Placement and Support (a model of supported employment) and the REFOCUS (*712, 713*) recovery intervention approach in several high-income countries, recent reviews of the literature indicate that there are too few overall and they are virtually absent in low- and middle-income countries (*714*).

Since 2015 there has only been one large comprehensive evaluation of a human rights-based approach in mental health. This was an evaluation of WHO QualityRights implementation in Gujarat, India (see Box 6 above) which involved the development and implementation of QualityRights service assessments and transformation plans; capacity-building for all stakeholders on human rights, the CRPD and the recovery approach; and the establishment of individual and group peer support for people using services, as well as peer support groups for people with lived experience and for families (*621*).

The lack of research exploring good practice human rights and recovery-oriented services and supports for mental health, and how services respect (or fail to respect) legal capacity, liberty and security of the person, including physical and mental integrity, is noteworthy in itself. In fact, very few of the good practice community-based services identified through research for this document had a strong quantitative or qualitative evaluation of impact, which in effect, limited the services that met the criteria for inclusion in this guidance. There needs to be a significant increase in investment in research and evaluation including assessing costs and outcomes for these types of services, alongside more efforts of services to collect evaluation data. In the context of research, qualitative methods should not be neglected because these are often able to describe, analyze and capture complex and subtle issues in comparison with quantitative research.

Additionally, more research is needed on the many promising interventions shown to be effective in reducing coercive practices through the use of de-escalation procedures, response teams, comfort rooms, individualized plans for responding to sensitivities, as well as interventions to promote legal capacity and autonomy (for example, different models of supported-decision-making interventions, advance directives and peer networks). Although there is evidence to support the effectiveness of many of these interventions (40, 546, 715, 716) there is also a striking lack of research on the social, economic and cultural issues impacting mental health and interventions that can address these More investment in research on the critical role that social environments play in the context of mental health also needed and can help move the agenda away from an understanding of mental health problems that regards people simply as collections of "symptoms" to be eliminated (717).

Although there are huge research gaps and an urgent need to rapidly step up our investment in the above areas, the evidence that we have already for the effectiveness of community-based services and interventions that promote rights (as demonstrated in chapter 3) is more than sufficient to promote action. There is no reason to wait for more research before moving towards improved human rights-informed alternative service models and changing cultural practices. Furthermore, human rights violations should be eliminated wherever they happen simply because they undermine human dignity and contradict internationally agreed conventions such as the CRPD. There is no evidence to justify coercive interventions that are undertaken with force have negative outcomes for those subjected to them (52). Coercive practices such as restraint and seclusion cause harm to physical and mental health and can lead to death (718, 719). People may take strong actions to avoid mental health care services because of their experience with forced treatment (51, 720).

People with mental health conditions and psychosocial disabilities can make notable contributions to research because of their expertise and experience. Emerging academic disciplines include survivor research. However, a recent comprehensive review of studies published in low- and middle-income countries (721) identified only one published study that had involved people with lived experience in the process of conducting the research (722). It is crucial that people with mental health conditions and psychosocial disabilities, including "survivor-scholars", "peer researchers" and "user researchers", have a leadership role in the design and implementation of research in this area. In fact, co-production has emerged as a specific methodology to ensure the inputs of people with lived experience in research design. Success will depend on a re-evaluation of many of the assumptions, norms and practices that currently operate, including a different perspective on what "expertise" means when it comes to mental health. Box 16 below highlights the strong political will of the Parliamentary Assembly of the Council of Europe in support of a person-centred, human rights-based approach and their call for additional research on non-coercive responses.

Box 16. Call for action by the Parliamentary Assembly of the Council of Europe

Call for funding and resources on alternatives to coercion and services that use these measures

In 2019 the Parliamentary Assembly of the Council of Europe stated, "The solution lies in the good practices and tools from within and outside the health system that offer solutions and support in crisis or emergency situations, and which are respectful of medical ethics and of the human rights of the individual concerned, including of their right to free and informed consent. These promising practices should be placed at the centre of mental health systems. Coercive services and institutional care should be considered unacceptable alternatives which must be abandoned. Yet, abandoning coercion does not mean abandoning patients and should not be used as an excuse to reduce the overall mental health budget. There should, instead, be more funding and resources for research on alternative responses" (723).

Parliamentary Assembly. Council of Europe. Ending coercion in mental health: the need for a human rights-based approach. 2019.

Strengthening research through the engagement of people with lived experience

The phrase "nothing about us without us" neatly sums up the vision that people with lived experience of mental health conditions or psychosocial disabilities must be meaningfully involved in every mental health action, including research. Engaging people with lived experience and expertise will profoundly strengthen and bring meaning to new research in this area. Several authors have highlighted the importance of engaging people with lived experience in both research development and implementation:

"Only a person with disability can truly set the ground base to what are their needs and participating in a research process that could lead to new changes for them should be considered crucial for success." (724)

"... co-production implies equality not just in the sense of persons or statuses but at the level of how knowledge itself is valued" (725).

Key national actions to integrate person-centred and human rightsbased approaches

A reorientation of research priorities will be necessary to create a solid foundation for a truly rightsbased approach to mental health and social protection systems and services. This will require countries and international and national research bodies to implement the following actions:

- increase investment and funding for both quantitative and qualitative research and evaluations of CRPD-compliant services and supports for people with mental health conditions and psychosocial disabilities (within mental health and social care systems) as well as research and evaluations on policy, law, services and training approaches to end coercion, respecting legal capacity and autonomy and reducing over-reliance on medication;
- incentivize research that focuses on the scale up of CRPD-compliant services and supports for people with mental health conditions and psychosocial disabilities and their integration into health and social systems, UHC and disability schemes in low-, middle- and high-income countries;
- redefine meaningful research outcomes to focus on and include outcomes related to participation and community inclusion, among other recovery dimensions, rather than solely focusing on clinical outcomes and symptom-based categories;
- incentivize research that focuses on interventions to address the social, economic and cultural issues impacting mental health at individual and population levels;
- promote research on the determinants of mental health and related implementation programmes;
- appoint people with mental health and psychosocial disabilities in leadership roles for setting the research agenda and developing and implementing mental health related research; and
- effectively communicate the results and findings of research to all stakeholders, including practitioners in health and social care, policy makers, civil society NGOs, OPDs and academia.

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Annex

Methodology

The aim of the methodology was to identify a diverse range of good practice services across geographical and economic contexts. The methodology was developed to be proportionate to project resources, scale and timeframes. It was recognized at the outset that the intention of the methodology was not to identify best practice services, but to identify good practices that illustrate what can be done and to demonstrate the wider potential of community-based mental health services that promote human rights and recovery.

Phase 1: Identification of potential services for consideration

Potential services for consideration were identified through four primary sources.

- 1. Literature reviews were completed in English, French, Spanish and Portuguese to identify potential services that had been identified or referenced in academic literature. Five key topics reflecting human rights and recovery approaches in mental health were identified and used to inform the unique and common key words used in each search (respect for legal capacity, alternatives to coercive practices, participation, community inclusion, and recovery approach). The most relevant databases for each language were selected, and date range limited to 2005–2017.
- 2. An internet search was completed in English, French, Spanish and Portuguese using the Google search engine to identify potential services with an online presence but who would not necessarily have been included or referenced in academic literature. The search format was "Country Name Mental Health Community Services" and was limited to the first 10 pages of results in "incognito" mode.
- 3. An e-consultation promoted through social media and WHO networks of collaborators including focal points for mental health in ministries of health and WHO collaborating centres, collaborating NGOS and OPDs, and other agencies of the UN system including the Office of the High Commissioner for Human Rights. The aim was to identify potential services whose primary language was not included in the above searches or that may not have had a presence in academic literature or on the internet. The criteria used to select services was specified in the e-consultation announcement.
- 4. Finally, relevant services known to the WHO were identified based on its work in countries over the years.

All searches used the same exclusion criteria: services for people with cognitive or physical disabilities, neurological conditions or substance misuse (but not specifically in the context of mental health) were excluded. Highly specialized services, for example those for treating eating disorders, were also excluded. Other exclusion criteria included e-interventions, telephone services (such as hotlines), prevention programmes, tool specific services (for example, advance planning), training and advocacy.

Phase 2: Initial screening against minimum human rights and recovery standards

Each service underwent an initial screening against five human rights and recovery-based criteria:

- **1.** respect for legal capacity: promoting autonomy, independent decision-making and fostering independence;
- 2. non- coercive practices: explicit reference to implementing services without coercion, force, restraint, etc.;

- 3. participation: peer support, users involved in the development or implementation of the service;
- **4.** community inclusion: direct links to community, offers additional services, cultural practice inclusion, development of networks; and
- **5.** recovery approach: supporting people to regain control, person-centred care, promoting meaningful relationships in life, hope for the future, and empowerment.

Services passed the initial screening phase if they demonstrated two of the five above criteria and were seen to embody human rights and recovery values through their mission, services and practices. A key consideration was if and how the service supported individuals with complex needs or those who may in some contexts be described as "difficult cases". Services that did not admit, provide support to or discharged/referred the majority of such individuals to non-CRPD compliant services were not included for further consideration. Allowances were made for services that appeared to meet the above criteria but where evidence was limited, particularly if from a low- or middle-income country or if the service represented a particularly novel approach.

Networks of services were distinguished from stand-alone services and identified separately. All networks of services identified came from previous or current QualityRights projects or collaborators.

Phase 3: Classification of services

Services were reviewed and classified according to service categories. Six service categories were identified:

- **1.** Crisis services
- 2. Hospital-based services
- 3. Community mental health centres
- 4. Outreach services
- 5. Supported living services
- 6. Peer support services.

Phase 4: Full screening of services within each service type

Services were reviewed in terms of number of criteria met, extent to which criteria was met (partially/ fully), good practice evidence base available (for example qualitative/quantitative data available). Services were ranked under each service type according to the criteria met and supporting evidence base available. Services from low-income contexts and under-represented geographical regions were prioritized where possible and/or appropriate, as well as services with evaluation data

Phase 5: Full write up of highest-ranking services within each service type

The highest ranking services within each service type were researched, reviewed and service descriptions completed in full. Additional information was sought from service providers as necessary. Complete service descriptions then underwent an internal review. Services either progressed or were eliminated at this stage. If eliminated, the next highest-ranking service in that service type was then selected to be reviewed in full (again with prioritization of low- and middle-income countries and those with availability of evaluation data). This phase was completed when good practices had been identified in all service type categories.

Phase 6: Validation of selected services as good practices

Services that progressed were reviewed in terms of evidence base and need for additional validation of that service. The extent to which services required additional validation was proportionate to the robustness of the available supporting evidence demonstrating good practice. Services with, for example, peer-reviewed research on the service, demonstrable qualitative or quantitative evidence of good practices (monitoring reports, service feedback, international or national level reviews and/or awards) underwent less additional validation of their service than services with less robust supporting evidence. Validation methods included field visits by local WHO QualityRights collaborators, interviews (in person during field visits or by distance) with service providers, service users and/or local services who work with the service of interest and/or requests for additional information. Services which successfully passed the validation phase were selected for inclusion in the final guidance document.

Limitations

A significant limitation of the methodology was limiting searches to four languages. Whilst this was attempted to be addressed through the e-consultation, it is unclear what additional services may have been identified if the literature review and online searches had been completed in more languages. Further, not all countries have the possibility to promote or publish data on their services, particularly in low- and middle-income countries, and this likely further limited the pool of services to select from. This limitation was partially addressed in the methodology by leveraging WHO collaborating networks to identify specific types and/or locations of services that would provide appropriate balance and representation to the overall selection of services included in this document. The services selected for showcasing in this document in no way imply that they represent the best practices in the world nor that there are no other good practices from other countries.

Fig. A1 below provides a summary of the methodology used for selecting good practice services for inclusion in this guidance.

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