Technical package

Comprehensive mental health service networks

Promoting person-centred and rights-based approaches





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Comprehensive mental health service networks: promoting person-centred and rights-based approaches

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

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Foreword

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

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

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however, in all countries, whether low-, medium- or high-income, the collective response has been constrained by outdated legal and policy frameworks, and lack of resources.

The COVID-19 pandemic has further highlighted the inadequate and outdated nature of mental health systems and services worldwide.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

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

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

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

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

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Executive summary

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

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

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

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

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

Key messages of this guidance

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

Introduction

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

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

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

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



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

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

Examples of good practice community mental health services

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

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

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

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

Significant social sector changes are also required

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

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

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

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

Scaling up mental health service networks

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

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

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

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



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

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

Key recommendations

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

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

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

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

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

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

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

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





What is the WHO QualityRights initiative?

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

-	
1	Build capacity to combat stigma and discrimination, and to promote human rights and recovery.
	<u>WHO QualityRights face to face training modules</u>
	 WHO QualityRights e-training on mental health and disability: Eliminating stigma and promoting human rights
2	Improve the quality of care and human rights conditions in mental health and social services.
	WHO QualityRights assessment toolkit
	 WHO QualityRights module on transforming services & promoting rights
	Create community-based and recovery-oriented services that respect and promote human rights.
5	WHO guidance and technical packages on community mental health
	 services: Promoting person-centred and rights-based approaches WHO QualityRights guidance module one-to-one peer support
	by and for people with lived experience
	WHO QualityRights guidance module on peer support groups
	 by and for people with lived experience WHO QualityRights person-centred recovery planning for mental health
	and well-being self-help tool
V	
Δ	Support the development of a civil society movement to conduct advocacy and influence policy-making.
	WHO QualityRights guidance module on advocacy for mental health, disability and human rights
	WHO QualityRights guidance module on civil society organizations to promote human rights in mental health and related areas
	7
5	Reform national policies and legislation in line with the Convention on the Rights of Persons with Disabilities and other international human rights standards.
	WHO guidance currently under development
×	

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

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

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

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

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

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

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

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

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



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

Specifically, the technical packages:

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

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

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

How to use the documents

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

These documents are designed for:

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

A note on terminology

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

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

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



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

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

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



Introduction

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.

The service networks described in this technical package were chosen based on good practices known to the World Health Organization. The selection process was based on five human rights and recovery criteria, namely: respect for legal capacity, ending coercive practices, participation, community inclusion, and the recovery approach. The services described in this technical package are not intended to be interpreted as best practice, but rather to illustrate what can be done and to demonstrate the wider potential of community-based mental health services that promote a person-centred, rights-based, recovery approach.

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



Comprehensive mental health service networks – description and analysis

2.1

East Lille community mental health service network

France



Context

France operates with a sectorized mental health system, with approximately 850 sectors offering adult mental health services within population catchment areas of about 70,000 people. The East Lille sector is located in the Hauts-de-France region and serves only adults in an area with 88,000 inhabitants and six suburban towns. The area suffers from relatively high unemployment (15.6%) compared to the national average (11.1%) (1), and has the shortest life expectancy in France. The area is also is known to have an "under-resourced" health system (1). The *Établissement Public de Santé Mentale* (EPSM) *Lille-Métropole*, in Armentières, 25 km west of Lille, provides administrative management of the service on a day-to-day basis, and is also responsible for nine additional sectors, and a child and adolescent service that serves all these sectors.

Since the 1970s, the mental health service in East Lille has undergone a series of major reforms and has promoted the concept of citizen psychiatry (*psychiatrie citoyenne*) which holds, as central elements, respect for the human rights of people who use mental health services and their empowerment.

The first key phase of these reforms took place from 1970–1995, which saw a wide-scale shift of resources from institutions to the community. In the 1970s, the service mainly consisted of six inpatient units, based in the asylum at Armentières. These hosted over 300 long-term residents, and 98% of the budget was dedicated to their full-time hospitalization. An overseeing body was created in 1977, the Medico-Psycho-Social Association (*Association Médico-Psycho-Sociale* (AMPS)), to facilitate deinstitutionalization. It brought together the mental health service management, professionals, elected officials from the six towns in East Lille, and other groups that were interested in developing services in the sector.

From the beginning, it was realized that reform could not only be about a reduction in the use of the asylum but would also require the inclusion of the wider community through educational work and a policy of integration. The next phase of reforms (1980–2010) involved the development of community-based mental health services alongside the integration of mental health into the health, social, and cultural services of the towns in the East Lille sector. There was also a movement towards the greater involvement of people with lived experience, family members, professional groups and elected officials, in the decisions of the mental health service.

The following phase, from 2005 to 2014, witnessed the development of a large intensive mobile care team. From 2011, the emphasis moved towards creating the conditions for health democracy, in which all the stakeholders in the field of mental health (especially people with lived experience) would come together to develop and implement policy in a spirit of dialogue and consultation. Finally, from 2014 onwards, the primary task was to bring a recovery philosophy to the centre of the service.

Since 2006, there have been important developments to sustain these achievements, including the replacement of AMPS in 2010 by a Local Mental Health Council (1), in line with changes in the rest of France (2). In East Lille, this local council is called the Intermunicipal Association for Health, Mental health and Citizenship (AISSMC), which is a forum where all the stakeholders from the six municipalities can meet, discuss and plan. It is chaired by the mayors of the municipalities and is co-led by the East Lille mental health service. As well as elected officials, managers and professionals, it involves people with lived experience, families and carers, residents, health and social services, general practitioners, social landlords, people from community centres, and people from the justice department. A general assembly is held every year.

The AISSMC activities are organized according to four primary themes:

- prevention meetings on mental health issues, promotion of physical activity, cancer screening, and coordination of complex situations;
- cultural actions promotion of cultural and anti-stigma actions that make use of a fund of contemporary art, mixing pieces of art from people with and without mental health conditions;
- housing issues allocation, maintenance and planning of housing for people with mental health conditions in the municipalities; and
- the local health contract a national system which aims to define and coordinate mental health actions in the territories along the main regionally defined issues, which benefits from strong participation of elected officials in the negotiations.

Description of the service

The network of mental health care provided by the East Lille sector has been built over 40 years of reorganization and reform. The commitment from the head of the sector and the team has demonstrated that a shift from inpatient care to diversified, community-based interventions for people with mental health issues and/or psychosocial, intellectual and cognitive disabilities is possible, with a similar budget and epidemiological profile to other mental health sectors in France. The reforms have been made possible by the involvement of the municipalities, other stakeholders, people with lived experience, and their carers. The Local Mental Health Council (AISSMC) is the basis for actions to promote rights and information on mental health in East Lille. Such councils now operate across France, with 230 currently constituted.

The concept of "citizen psychiatry" informs the entire East Lille mental health network, and is based on five pillars (3):

- 1. human rights are inalienable, and the presence of mental health conditions can never impede or prevent someone from accessing these rights and ensuring they are respected; justice and psychiatry, prison and hospital, seclusion and care must never be conflated;
- 2. society, and thus mental health services, need to adapt to people's needs, and not the other way around;
- 3. there is a need to close medical and social institutions that effectively exclude residents from their communities; and
- 4. there is a need to fight stigma and discrimination based on mental health conditions. This includes challenging stereotypes about dangerousness and lack of capacity.

On the basis of these values, the service in East Lille engages as a partner with other stakeholders, including people who use the service and their families, NGOs, elected officers in the municipalities, and others who are involved in the mental health field. Working in concert with these stakeholders, the various elements of the East Lille mental health system interrelate to form a coherent network.

Elements of the mental health service network

Local medico-psychological centres (Services Médico-Psychologiques de Proximité (SMPP))

SMPPs represent the first point of contact for people with the mental health system, and provide comprehensive care and support. They are based in two dedicated ambulatory services of the EPSM which are integrated into 12 other health-related facilities. A person is referred to the SMPP by their general practitioner (GP), and can consult a range of professionals there: nurses, psychiatrists, psychologists, psycho-motor therapists,^b social workers, peer-support workers, and an adapted sport coach.

On arrival at the SMPP, a nurse performs an initial assessment of the person's psychological and physical needs within 48 hours of the referral. This assessment is then discussed by a multi-disciplinary team that meets twice a week, and the team makes suggestions for care and plans future steps. The suggestions for care are always sent to the GP to ensure continuity of care and effective partnership. There are no waiting lists and all professionals working at the centre also have time allotted for home consultations. Consultations by the SMPP team can take place at a range of venues in the community, making it very accessible, including at a swimming pool and at a social and support centre for youths aged 16-25 (who may directly access services without being referred by a general practitioner).

Mobile team (Soins intensifs intégrés dans la cité (SIIC))

The mobile crisis and home-treatment team is the largest in France, in terms of the number of people cared for. It provides crisis response and intensive care at home for up to 15 people at a time. It is a multi-disciplinary team which includes a health executive, day and night nurses, psychologists, special educators, a psychiatrist, psychomotor therapist; and peer health mediator, available 24 hours per day, seven days a week. The average length of time that people are cared for is 12 days; most interventions are for a few days but some last for weeks. In 2018, a total of 253 people were cared for at home, and 640 crisis interventions took place at home, avoiding hospitalization. The ratio of equivalent full-time workers to people being cared for is 0.96 (nearly one professional per person) *(4)*. All workers in the service are sensitized to the recovery approach, the handling of crisis situations without coercion, and the human rights of service users.

Jérôme Bosch Clinic General Hospital

While the entire network is structured to prevent hospitalizations, when necessary, full time hospitalization can take place in the Jérôme Bosch Clinic which has 10 beds and is located next to Lille University Hospital. Its multidisciplinary team consists of a health executive, day and night nurses, a socio-cultural animator, a psychologist and Qualified Hospital Services Officers who are responsible for maintenance and hygiene. Processes are in place to avoid hospitalization, and especially forced admission. In 2018, there were 341 hospitalizations for a total of 222 people (some people had more than one episode of hospital care). At any time, an average of seven people are resident in the clinic, and the average length of stay is seven days ([Medical information service], [EPSM Lille Métropole], personal communication, [2020]).

b 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.

When a person enters the clinic, information is provided about their rights and obligations both verbally and in written format, and they can name a trusted person as a supporter. The organization and architecture of the clinic is set up to ensure that people can maintain their right to privacy. All rooms are single occupancy and every person in the service has a key to their room and a safe in which they can keep their personal belongings. People staying in the hospital are free to enter and leave their rooms as they wish.

The clinic relies on the close support network of the person using the service, in order to help with negotiation, safety and the avoidance of conflict. There is open visiting (5) and two rooms have a second bed for support people who can stay overnight at the clinic.

An important emphasis is placed on the availability of health professionals in the clinic: the ratio of fulltime workers to hospital beds is 3.1:1, with a minimum of three nurses during the day and two at night. There is also a nurse assistant, and a worker in the activity room who provides animations and artistic activities. On Sundays, external guests are invited, such as an artist or a sports coach, etc. Special needs workers (*éducateurs spécialisés*) are available daily to deal with social or administrative issues that a person using the service may encounter. Peer support workers who are employed by the EPSM come in each week to support people in hospital. These peer supporters have undertaken specific training to acquire a recognized national qualification.

Throughout their hospital stay, the objectives of care and support are defined with the person using the service. Within 24 hours of arriving at the hospital, there is a consultation with a general practitioner to assess any physical health needs. Most importantly, social workers and special needs workers are involved from the beginning to help address the individual's needs in terms of housing, protecting other human rights, and practical issues, such as caring for pets. An important aspect of the philosophy of the service is that hospitalization should never isolate a person from the rest of the outpatient system; all the ambulatory teams make visits to people who are in the hospital. The multi-disciplinary team meets daily to discuss care.

All health professionals in the sector receive specific training to prevent instances of conflict and violence. The service also employs the services of an external security firm for situations where there is a risk of violence. These security agents can be called by the hospital staff, but otherwise do not interfere in the care offered to individuals. Their role is to help to create a climate of non-violence by reassuring professionals and people using the service that they are safe.

In addition to general outpatient crisis plans, specific plans are also agreed upon to avoid any nonconsensual interventions. The service does not have a dedicated seclusion area and seclusion is never practiced. While the use of any form of restraint is rare, coercive interventions are not entirely prohibited and physical restraint is used, exceptionally, on a time-limited basis. The clinic monitors the use of restraint and records all such instances and the duration of each. Between 2011 and 2019 physical restraint was used with an average of 1.77 persons per year, but since 2017 only one person per year has been subject to the use of physical restraint ([Medical information service], [EPSM Lille Métropole], personal communication, [2020]). The service has an internal goal of reducing such instances to zero.

Chemical restraint is also rarely used and has recently received special attention. In 2019, nine cases of forced neuroleptic injection were reported. Each use of restraints is considered to be a major negative event in care and is subsequently investigated in order to ensure a continuous process of improving practices and reducing its use. Service users and their families are invited to participate in this.

The service places an emphasis on continuity of care as people transition out of the hospital. Families and trusted people are notified. An exit questionnaire is optionally completed by the service user, with support if needed (see Evaluation section below). A summary discharge letter is also given to the person who has used the service, with a copy for their GP.

Therapeutic host families

Staying with host families is another alternative to hospitalization. The goal of this service is to welcome a service user as a member of a family rather than being subject to a traditional patient/caregiver relationship. For this reason, the training of the host families does not focus on providing them with clinical caregiving skills; instead they receive training so that they understand how to support a person with a mental health condition or psychosocial disability within a recovery and human rights-based framework. They are also trained in preventing any form of mistreatment in the private homes, ways to help with agitation and crisis avoidance, and how to host a person as a family member.

This host family service was used by 42 people in 2018, with an average length of stay of 32 days (4). The families involved were able to offer seven places at a time. In 2019 the availability of places decreased to two families who were able to offer four places. The host families receiving training and financial support from the EPSM for their service. There is supervision throughout the hosting period, and separate feedback meetings with all involved stakeholders. Peer group meetings are organized between the host families once or twice a year to discuss the challenges that they face.

Intersectoral family and systemic therapy centre

The intersectoral family and network therapy centre (Don Jackson) is a specialized external consultation centre that delivers psychotherapeutic interventions for families and couples. Over 30 years, a total of 667 couples and 506 families have used these services. Although therapists from different backgrounds have worked at the centre, all have received additional training in the systemic approach to family and couples' therapy over a four-year period. This has created a common, multidisciplinary, holistic perspective from which to consider therapy and support.

Habicité

Habicité is an Assertive Community Treatment (ACT) *(6)* team that provides long term intensive input to 80 persons with mental health conditions. This team is comprised of nurses, social workers, peer supporters, psychologists and an executive with a 1:8 professional to service user ratio *(7)*. This service supports people in their personal recovery projects, allowing them to stay in their home and community. In addition, the service offers a range of communal housing; currently there are 13 apartments providing housing for 26 people. Access to this system has recently been democratized by including community representatives in the procedure, including elected representatives, experts with lived experience and social partners. Moreover, the service is now based on a "housing first" philosophy which means unconditional access to housing and unconditional support to make it work *(8)*.

Frontière\$

Frontière\$ is another element of the mental health service network, which is focused on increasing social inclusion and the general wellbeing of people using the service through physical, artistic, cultural, creative and professional activities. The team of *Frontière\$* comprises a nurse, a GP, an occupational

therapist, special needs educators, an artist, an adapted sports coach, a psychologist, psycho-motor educators, as well as five external people who organize the therapeutic activities and support people outside the service setting, through their connections with associations and other municipal bodies. Peer support workers currently at a training stage are also employed in the team and will continue to work with *Frontière\$* when they have completed their training.

One of its services is to organize inclusion activities in ordinary leisure environments, with individualized, sustained support for people experiencing a mental health crisis, through the Service for activities of inclusion and integrated care in the community (*Service d'activités d'insertion et de soins intégrés à la cite* (SAISIC)).

Further, its "*Sagacités*" system offers support to people who wish to attend activities with people outside the mental health service, also in an ordinary leisure and cultural environment. This support can either be very 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.

Lastly, this service offers support to facilitate access to and retention of employment through partnerships with local actors and stakeholders. An occupational therapist helps to define career and professional plans with service users, and a psychologist helps with motivation and evaluating vocational competencies.

Network coordination and connections between services

All mental health services in the East Lille network are connected and work together, which allows people to participate in one or more services: for example, people in *Habicité* can also be a part of Frontière\$. By 2018, a total of 3513 people were receiving care from the service network ([Medical information service], [EPSM Lille Métropole], unpublished data, [2018]), and 75% of the professionals employed by the mental health service in East Lille were working in mobile teams and other community-based roles. This intensive community-based support was sufficient to keep the number of inpatient beds to 10, with a current average daily bed occupancy of seven ([Medical information service], [EPSM Lille Métropole], personal communication, [2020]).

All East Lille mental health services work and operate as a network to create a coherent care pathway for each individual and are connected via an intranet network. All health professionals in the network have access to the information kept on the intranet about people using the service,^c ensuring continuity and making coordination between different elements of the service possible *(9)*. For example, in the SIIC, the intranet enables health professionals to rapidly identify the person's medical and psychosocial background, and to refer them to the doctor, nurse or psychologist that they know best. The same file is used for outpatient and inpatient care in order to prevent loss of information.

c In France, health information is subject to strict regulations regarding data access and storage. Information is stored on secure servers authorized to host health data and is accessible only to the healthcare team and to the person using the service, upon request. Access to medical files is under the strict control of an external institution, the *Commission d'accès aux documents administratifs*. As a general rule, people using the service can consult their file when they meet with professionals.
Core principles and values underlying the community-based mental health network

Respect for legal capacity

The service is committed to promoting respect for legal capacity by supporting initiatives and procedures that maximize independent and supported decision-making. However, the service does allow for involuntary admission and treatment.

Out of the 222 people hospitalized in East Lille from 2013–2019, compulsory hospitalizations averaged 86.4 persons per year (39%), which is an average of 101.6 persons per 100,000 inhabitants per year. This high rate corresponds to the extensive use of these measures in France generally – in 2018 there were 82,000 compulsory admissions in the country – a rate of 122.6 per 100,000 *(10)*. The mean length of stay in East Lille was 57 days, which is fairly close to the average for the Hauts-de-France region. The majority of these compulsory admissions are not organized by the staff from the East Lille sector, but by psychiatrists working in the general hospitals in Lille who see people in crisis who attend the Emergency departments of these hospitals. They arrange the admissions directly with the Jérôme Bosch clinic and effectively bypass the East Lille mobile crisis team (SIIC). The East Lille service does not have the authority to prevent this practice. However, once people are admitted to the clinic, plans are quickly made for discharge and the person's status is converted to voluntary as soon as this is legally permissible. The average length of stay is only seven days. One of the major obstacles is that French law requires, in some cases, that the person no longer presents with a mental health condition, before the measure can be lifted. One of the new objectives in 2020 is to achieve a rate of zero hospitalizations without consent that last for more than 72 hours.

To reinforce respect for legal capacity, the Users' Commission (La Commission des Usagers (CDU)) – a branch of EPSM Lille-Métropole in charge of relations between users and professionals – organizes three legal advice sessions per month, in which people have access to external and independent lawyers, as well as advice from representatives of users and families. Every involuntary hospitalization is subject to judicial review, as provided by law, on the 12th day. Each person using the service is assisted by a lawyer at no cost to themselves.

The East Lille network also uses advance planning as part of overall recovery plans, to discern and respect the will and preferences of individuals using services. These generic crisis plans are inspired by WRAP *(11)* and differ from the more specific plans used in the Jérôme Bosch clinic, which identify the triggers that might upset service users and list the interventions by professionals that they find helpful. These are used to anticipate and prevent conflict situations, and thus avoid coercive interventions. Advance plans are integrated using the online tool, Cariatides, to ensure that they are offered to the person in a user-friendly way and can be easily modified and followed-up throughout care. The target for the year 2018 was to ensure that every person going through the SIIC services is offered the opportunity to develop an advance plan. In 2018, around 300 people completed an advance plan, with a prioritization for those whose suicidal risk was high.

Alternatives to coercive practices

All the people working in the service receive training in de-escalation techniques, the recovery approach and in respecting patients' rights, which helps to avoid and manage conflict situations. While great efforts are made to care for people outside hospital, and a range of concrete alternatives to hospitalization are in place, forced admissions and forced treatment do sometimes occur. The rate of forced interventions is minimized in the Jérôme Bosch clinic through the use of crisis prevention plans. Even though these do not have legal status under French law, the service is fully committed to respecting a person's prevention plan. In all cases following a crisis, the person is invited to review the plan with staff so that it can be improved and made to work better in the future.

If a person refuses to take prescribed medication at the hospital, their wishes are respected. There is always a psychiatrist available to adjust the prescription as needed; they alone have the authority to make decisions regarding medication. If the providers think that a particular treatment would be beneficial, they negotiate (repeatedly, if needed) with the person who does not want to receive treatment, in order to reach informed consent. However, forced treatment still occurs at the clinic, even though every effort is made to avoid it.

Failure to respect consent, and in particular the use of physical or chemical restraint (through forced injection of medication) is considered a failure of care, and all such episodes are analyzed by the service afterwards. Any forced use of medication is carefully tracked by the service, and service users and their families participate in the analysis and evaluation of these events. In 2019, there were 11 uses of medication without consent (two of these involved long-acting medication; nine cases involved punctual use) ([Medical information service], [EPSM Lille Métropole], personal communication, [2020]). Seclusion is never used in the hospital or other East Lille services.

Community inclusion

Community inclusion is the cornerstone and underlying philosophy of the network. Initiatives such as Habicité, *Frontière\$*, the therapeutic host families, and the SMPP are examples of specialized support to promote community inclusion.

Several support groups are also offered to service users to promote community inclusion and citizenship. The topics of those groups are based on needs identified by people using the service, such as: how to use public transport, how to access activities, how to protect rights, and how to manage one's diet and "eat better, feel better" (particularly in relation to the effects of medication). These structured groups have a defined number of sessions and objectives and are led by various professionals. While they are subject to national regulations that require the presence of professionals, there are efforts to make these groups less "professional-dominated" with a greater emphasis on peer support and empowerment.

Therapeutic and social inclusion activities are also integrated into public and ordinary community activities, through the *Frontière\$* service through an initiative called "*hors-les-murs*", meaning outside of the facilities of the service. The East Lille sector has many partnerships with sports, cultural and social services to ensure participation of people with mental health conditions and psychosocial disabilities in ordinary community life. The aim is to use a person's wishes and motivations as a starting point, to support participation administratively so that he or she can take part in community activities, and if necessary, to assist in attending the activity, but withdrawing from this role as soon as feasible.

The East Lille service has established active links with many community-based services and organizations over the years, including with elected officials, social institutions, cultural institutions, user and family groups, and various health partners in the towns (GPs, pharmacists and private nurses etc.). It uses these links to help people using the service to re-establish their place in the community (1).

Participation

In 2008, two self-help groups (*Groupes d'Entraide Mutuelle*) were established, which marked the starting point of real participation of people with lived experience in the organization of the service. These groups were funded by the Ministry of Health and were independent of the East Lille sector. Their objective was to promote peer support in daily life, leisure and social activities. The groups then became partners of the sector, as local and national users' and carers' associations.

The creation of the Local Mental Health Council in 2010 (as discussed above) further emphasized participation of people with lived experience, along with their families and carers. In 2012, two peer support workers (*Médiateurs de Santé-pairs*) were hired as professionals in the mental health teams, which has now expanded to include five peer support workers. Also in 2012, a working group was created dedicated to the participation of people with lived experience – involving professionals, service user associations and peer support workers – which led to several innovations: a forum for people using the service in the form of a community workshop to discuss mental health and the organization of the service, communication tools, a suggestion form and a recovery charter drafted and signed by all stakeholders.

In 2015, people using the service elected four representatives who participate directly in the management meetings of the service, to work on suggestions and complaints, and to organize the users' forum. There are now six representatives who act as spokespersons for people using services in East Lille, who collect opinions and comments on the different network services through quarterly service user forums and suggestion boxes. They are also involved with investigating and reviewing the undesirable events forms that track use of coercive interventions, and participate in the sector's steering committee meetings, management meetings and working groups. These representatives receive training on human rights and the recovery approach and have monthly meetings with professionals from the sector, to discuss current topics and complaints to be addressed by the service. One of the spokespersons has received the WHO QualityRights training (4). Feedback is also systematically collected at the hospital through exit questionnaires at the time of discharge, and through satisfaction questionnaires (12) that are completed by people using the full range of services. Suggestion boxes are available at all services, where anonymous comments or complaints can be made. This development has been recognized with the "Users Rights" award of the Regional Health Agency and has benefited from two grants, which were used for the training of spokespersons and the development of communication tools.

In 2017, a training programme called "experts by experience" was developed, led by people with lived experience or members of service user and carer organizations. It provides training for professionals of the service on topics such as hearing voices, eating disorders, work and burn-out. These sessions happen every month and are aimed at informing the professionals about what is helpful (or not helpful) from the perspective of someone using the service (see next section).

At the institutional level of the EPSM, the Commission of Service Users monitors the way in which the rights of those using the service are being respected and represents service users' interests in the service decision-making bodies.

Recovery approach

The East Lille network has a steering group specifically on recovery and on promoting recovery-oriented tools in the sectors' services. Since 2014, all services have been guided explicitly by the recovery

approach. In the East Lille sector, all professionals are trained in the recovery approach through presentations and workshops by experts on recovery-based practices, including by persons with lived experience and external guests. The training takes place annually in groups of 20–30 people, to ensure that everyone in the service receives the training.

The East Lille mental health sector constantly explores new ways to support the recovery approach. For instance, one of the first tools used was called the Barometer, a recovery-based online platform. It aims to ensure that care not only concerns medication but focuses also on the person's general quality of life, their social network, their achievements and their strengths. The person, and if desired a support person, can then work together to craft specific objectives that contribute to the person's recovery, ensuring that progress is tracked consistently. This tool is used to encourage people to make advance plans and recovery plans which are formalized through their online medical file. The service further seeks to promote empowerment in many different ways; for example, training sessions for the professional staff are held by persons with lived experience every month. All these tools serve the same objective: to stay as close as possible to the needs that people identify for themselves, and, when needed, to help them articulate their own wishes and make their own decisions about care.

Service evaluation

The network of services in the East Lille sector keeps detailed audit figures for its activities, with annual objectives tracked monthly using well-defined and measurable indicators. An important achievement of this network is seen in the steadily decreasing rate of hospital admissions per year from 2002–2018 (from 497 to 341), despite a considerable increase in the number of people receiving care in the network (from 1677 to 3518 people). Furthermore, the length of stay at the in-patient unit decreased from 26 days to seven days over the same period ([Medical information service], [EPSM Lille Métropole], unpublished data, [2018]).

In 2018, 34 people out of 222 completed the exit questionnaire at the Jérôme Bosch Clinic. On a scale of 1 to 10, the mean satisfaction rating was 8.06 (SD = 1.94), and 79.4% said that they felt better, or much better, compared to how they felt at the time of admission ([Medical information service], [EPSM Lille Métropole], unpublished data, [2018]).

The local SMPP centres also track efficiency indicators which show that 80% of people have their initial assessment within 48 hours of contact. The quality of patient file completions showed between 80-100% success in 2018, which demonstrates accurate and reliable monitoring ([Medical information service], [EPSM Lille Métropole], unpublished data, [2018]).

In September 2018, an independent assessment team composed of eight members (including a psychiatrist, a quality director, a former hospital director, two lawyers, a psychologist, a family member and a service user), conducted the WHO QualityRights evaluation^d in all the services of the East Lille sector. It was found that three 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 *(4)*. The existing legal framework was found to be an important barrier to the full achievement of these two themes.

d These are the ratings for the five main themes, which are divided into 25 standards and 116 criteria. Full results and recommendations available on the QualityRights platform, see https://qualityRights.org/wp-content/uploads/QualityRights-59G21-report-2019.docx.

The East Lille sector has changed dramatically over a period of four decades. Efficiency outcomes demonstrate that the network is well-run, organized, and cost-effective. The number of new people being cared for in the sector has increased steadily over the last decades, paralleling a decrease in the number of hospitalizations and demonstrating a real capacity of the network to provide community-based alternatives for care. The costs of the service are no higher than elsewhere in France and are actually lower than the cost of mental health services in surrounding sectors.

The East Lille sector has been recognized by the French government and is being used as a model for further development of mental health policies in France. For example, the Roadmap for Mental Health and Psychiatry, published in 2018 (*Feuille de Route Santé Mentale et Psychiatrie*) (13) explicitly voices the government's objective to integrate people with lived experience in mental health care, to promote the recovery approach to services, and to facilitate the inclusion of people with mental health conditions and/or psychosocial, intellectual and cognitive disabilities in the community. In April 2019 an interministerial delegate was charged with its implementation and concurrently, the national budget for mental health was substantially increased (14). The East Lille sector was also mentioned positively in another recent parliamentary report (15). This national recognition demonstrates the East Lille approach is now becoming national policy.

Costs and cost comparisons

The service is entirely state-provided, and users of mental health services are completely covered by the national health care system.

The average cost per person using the service decreased steadily from 2013–2017, from \in 3,131 (approximately US\$ 3,684) in 2013 to \in 2,915 (approximately US\$ 3,430)^e in 2017 (4). These figures include costs associated with the whole care pathway, from the initial consultation to hospitalization. Overall in France, 61% of expenditure on mental health care is spent on hospitalization. However, in East Lille hospitalization represents only 28.5% of expenditure (4). The overall costs in East Lille are the lowest in the entire EPSM area.

Challenges and solutions

Challenging entrenched attitudes of stigma and discrimination

One of the obstacles encountered in establishing the network was that stigma attached to people with mental health conditions (amongst professionals as well as in the wider community) meant that coercive practices and poor standards of care were seen as acceptable. People with mental health conditions were not seen as people who had the same rights as other people. They were generally seen as lacking the capacity to make decisions for themselves.

To begin to address these pervasive attitudes, active engagement was necessary with the wider community about mental health and the rights of people who use services to overcome stigma, including bringing politicians and members of the community to visit psychiatric hospitals.

The East Lille sector further addressed this issue through development of the philosophy of "citizen psychiatry", which emphasizes the personal, social and cultural needs of people with mental health conditions and their entitlement to enjoy the same human rights as those of other citizens. Another

e Conversion rate as of March 2021.

aspect that has helped to change entrenched ideas is the broadening of the network's focus beyond health and widening of the scope of intervention to include social work, education and housing. The systematic involvement of service users and people with lived experience was also a critical aspect which helped slowly change perceptions and practices.

Working within the limits of an outdated national legislative framework

Another challenge faced by the East Lille network of services is that the presence of national legislation which allows for coercion continually serves to undermine the efforts of the mental health team to prevent it. Coercion is seen as the 'easy option' instead of something to be avoided at all costs. As a result, the network has encountered particular resistance to cultural change within mental health services themselves, in relation to coercive practices such as seclusion, restraint and forced treatment.

Fortunately, the sectorization of services in France allowed the local mental health service in East Lille to use its finances to fund alternatives to hospitalization. The East Lille network has found that creating a system where the voice of the person using the service is genuinely heard, acts to counterbalance the drive towards coercive interventions. Having staff trained by people with lived experience also helps them to understand fully the importance of a human rights and recovery agenda. Finally, taking time to explore in some detail any instance when coercion has happened, means that it is less likely to happen again.

Maintaining open communication among services

Being decentralized, the network also faces the ongoing daily challenge of maintaining a permanent dialogue among the services, in which the notions of recovery and human rights are central to all the different stakeholders. One important action to address this challenge involves the ongoing training of professionals and other stakeholders on recovery and rights-based approaches to mental health. Another key aspect has been the creation of the Local Health Councils (AISSMC). The community-wide consultation structure involves a wide group of stakeholders including people using the service, their families, staff of the mental health service, social services staff, elected representatives, artists, other citizens, GPs, the police, the justice department and education sector, in order to improve communication and create buy-in from all parties. A further innovation supporting cross-sector communication was the establishment of quarterly service user forums which collects opinions and comments from users of all the network services.

Key considerations for different contexts

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

- uworking with the aim of achieving zero coercion and zero hospitalizations in the service if possible, pushing the service to provide "unconditional care", characterized by availability and flexibility in working to the person's own agenda;
- systematically involving service users/people with lived experience in any new service development and in research and evaluation efforts;
- supporting people with lived experience to have a "professional" status in the service and helping them to develop the skills to represent others in a genuine way;



- avoiding a narrow clinical agenda and seeking instead to identify the full range of a person's personal, social and cultural needs (such as housing, education and employment, while working with other community stakeholders to respond to these issues;
- evaluating the service using the WHO Quality Rights assessment Tool Kit provides a very helpful way
 of evaluating the service, and is the most comprehensive evaluation tool made by and for all the
 actors involved;
- valuing the sense of pride that staff experience when they are able to provide care that is really responsive to the needs and demands of the people using the service; and
- considering evaluation outcomes on a "whole system" level, including levels of coercion, suicide figures, rates of people cared for outside of hospital and the costs of the service.

Additional information and 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

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2.2

Trieste community mental health service network



Context

Trieste is a city with a population of approximately 236,000 *(16)* and is the capital of the autonomous Friuli Venezia Giulia region in the north-east of Italy. A profound transformation of mental health services in Trieste began in the 1970s *(17)* with the closure of the old San Giovanni asylum, where 1200 people were being housed. Historically, the Italian reforms emerged within a social movement for the achievement of human rights across all Italian society. In Trieste, freedom and human rights became a central concern of mental health services, including the relocation of people from the institution to live in the community. The psychiatric institution was replaced by a network of community services which involved major changes in the allocation and spending of budgets *(17-21)*.

Today, the promotion of the citizenship of people with mental health conditions and psychosocial disabilities remains an essential feature and central tenet of the mental health service. In order to avoid fragmentation, all services are coordinated by the Department of Mental Health (DMH), which is responsible for the budgeting, planning and delivery of service *(22)*. In 2020, a newly established health care agency, the *Azienda Sanitaria Universitaria Giuliano Isontina*, became the legal entity responsible for Trieste and the neighbouring territory of Gorizia.^f While there is a common approach between both geographical areas the service description below focuses on Trieste as it developed up until the establishment of the wider organization in 2020.

Description of the mental health service network

Within the Trieste community mental health system, a "whole person, whole system, whole community" approach to mental health care has been developed, which places a major emphasis on working with the wider community to develop a fully integrated system of support with open doors and no restraint. People are supported as much as possible in their own homes and localities so that they are able to maintain links with their communities. There is an emphasis on human rights (including actions to promote social inclusion) and community participation, in order to avoid institutionalization and ensure people live their lives in their communities. This has been achieved through active engagement and collaboration with the health and welfare services, the juridical system, the cultural institutions, the regional and city authorities and other community organizations, in order to enhance the social capital of the city. The development of a broad partnership with peers, staff, trainees, volunteers, family members and social networks has also promoted a "whole life" approach. The Mental Health Department coordinates these partnerships, guided by key operational principles:

- · accepting responsibility for the mental health of the community
- active engagement and responsiveness (there are no waiting lists)
- high accessibility of the service
- continuity of care
- rapid responsiveness to crises in the community
- comprehensive care
- focus on teamwork and stakeholder participation (23).

f Gorizia is a city of 140,000, including the area of Monfalcone. The asylum in Gorizia was the site of the first reforms in Italy in 1961, led by Franco Basaglia who moved to Trieste in the 1970s.

Elements of the mental health service network

Community Mental Health Centres (CMHCs)

Community mental health centres (CMHCs) are the primary point of entry into the mental health services and system. There are four CMHCs in the territory of Trieste^g which form the heart of the service. Each serves a catchment area of 50,000 to 70,000 people. Each CMHC has a team of approximately 20-22 nurses and support workers, plus social workers, psychologists, rehabilitation specialists, and psychiatrists. Two members of staff are resident at night.

The teams at the centres are multi-disciplinary and work in a flexible and highly mobile way. Staff are involved in delivering care, providing support for the coordination of services and fostering recovery by connecting people to the different initiatives, services and opportunities in the community. Their overarching goal is not only to provide treatment and care in a human rights framework, but also to promote social integration and inclusion *(24)*.

Each CMHC contains six beds (the exception is Monfalcone which has eight beds). They are open 24 hours a day and accept all referrals. People who stay overnight are called "guests", rather than "patients" (24) and are encouraged to continue any involvement they may already have in ongoing activities in the community. They may host visitors as wished on an informal basis. The CMHCs also provide outreach activities for people requiring continuity of care and long-term support. Approximately 50% of the team's work takes place in the centres, and 50% in the community.

Between 08:00 and 20:00 the CMHCs operate a walk-in service. Anyone who enters or telephones a CMHC receives a swift response, usually within one to two hours. The staff members have a rota system, ensuring that a team member is always available. There is no waiting list.

A typical day involves a meeting at 08:00 in which the team organizes the structure of the day, with scheduled activities as well as any new priorities that may have emerged. Time is allocated to the guests staying in the service. Daily activities include outpatient visits, administration of medication, informal contacts/talks, group meetings, and the sharing of lunch and dinner together. There is a morning meeting with guests (for information, orientation, reassurance and possible self-disclosure). Staff members who are not involved in the internal activities of the CMHC perform scheduled visits to homes in order to provide support, or to accompany people to the CMHC for day care. Some people are accompanied to medical appointments, and others, for example, to carry out daily life activities, such as collecting their pension, visiting the bank, going to the police station, or attending their workplace etc. In the afternoon, there is a shift change and the new staff members may re-arrange activities if new priorities emerge during the day.

The primary aim is to create and maintain a therapeutic, but informal and friendly environment; the concepts of "doing with", and "being with", are the guiding principles for interactions between staff and guests. The intake assessment is problem-based, rather than diagnosis-based, and first-person narratives are used to understand people's life story and circumstances. If a person using the service, or their carer, considers a problem to be urgent, it is dealt with as a priority. Formalities are kept to a minimum. The first contact with a person is frequently made in the community, most often in their own home. In this case, a key worker is appointed promptly, and contact is made with the family and the

g There are a further two CMHCs in the territory of Gorizia (one in Gorizia and one in Monfalcone).



social network of the person. The team also works to mediate and to resolve any conflicts arising in the network, where possible, but the autonomy of the person is respected at all times.

The rapid response to crises in the community results in very few hospital admissions in Trieste. A person in crisis, if unable to receive support at home, is able to spend a brief time at the CMHC as a short-term guest. The offer of ongoing support and care, and an emphasis on discussion and joint decision-making, usually means that involuntary interventions are avoided. Long term follow-up and support is always available.

The CMHC centres and teams provide the following services (25):

- overnight hospitality and care
- day care
- an outpatient service
- home treatment via home visits
- crisis intervention at home, in the community, or at the CMHC
- individual and group therapy
- medication
- psychosocial support and work with social networks
- psychosocial rehabilitation
- support for group homes
- support in accessing education, cultural activities, vocational training and work placements
- social activities, self-help and leisure activities.

General hospital psychiatric services and unit (GHPU)

There is one general hospital mental health unit in Trieste (Servizio Psichiatrico di Diagnosi e Cura), which has six beds and provides a second point of entry to the mental health service. This unit covers the territory of both Trieste and Gorizia, a population of approximately 375,000. It is mainly used for emergencies at night. People usually stay for less than 24 hours and are referred to the CMHC in their own area as quickly as possible in order to transfer them to community-based care. The team based at the hospital includes two psychiatrists, one of whom is the Director of the unit, along with approximately 16 nurses. The team at the GHPU also provides a liaison service to the general hospital; most of their work is based in the emergency department.

Community inclusion support services and initiatives

The Trieste mental health service network has a comprehensive set of rehabilitation and residential support services working 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, to provide a comprehensive set of interventions aimed at making sure that people are able to live their lives in freedom and with a sense of dignity. The rehabilitation and residential support services interface and collaborate with social cooperatives in order to ensure access to supported housing, including the Trieste recovery house and other types of housing, which is implemented through the personalized health care budget. The aim of these programmes is to ensure full community inclusion and participation for people with mental health conditions and psychosocial disabilities.

Personalized health care budget

The personalized health care budget is designed mostly for people with complex needs as well as younger people thought to benefit most from a highly personalized programme. It addresses social factors and other challenges that might have a significant impact on people. A plan is developed, which includes a person's identified goals, and is discussed and agreed upon in collaboration with the person and sometimes his or her family. The latter are only involved with the individual's permission.

Finance for the personalized health care budget programme comes from mental health and sometimes welfare budgets. Several co-ops contribute to the planning and delivery of care. Typically, the areas covered are housing, education, training, employment and social relations *(26)*. The programme caters for approximately 160 people in Trieste every year. These "personal health budgets" (*budget individuali di salute*) support some of following programmes.

Supported accommodation

Supported accommodation is provided through several small residential flats, each of which caters for up to five people, or in people's own homes. These schemes provide accommodation for 42 people at any given time, and approximately 100 people every year. Staff provided by the social cooperatives give flexible support as needed, including on a full-time basis. They operate in collaboration with the CMHCs in order to guarantee continuity of care and treatment and to ensure independent living.

Trieste Recovery House opened in 2015 and is a residential project run through the health care budget programme as a collaboration between the Trieste Mental Health Department and a social cooperative. It has space for four to six people to stay, usually for a period of six months. It is open to people aged 18–35 who have had significant contact with the mental health service and who are interested in pursuing a recovery journey. Its essential operational principles are:

- 1. democracy, self-determination and emancipation ("nothing about me without me");
- 2. asset- and strength-based approaches;
- 3. a whole person, whole life approach;
- 4. acknowledgment of the expert by lived experience;
- 5. trialogical meetings;^h and
- 6. a shared learning environment (27).

Social enterprises (cooperatives)

The mental health service collaborates with a network of approximately 15 social cooperatives (28-32) in Trieste. Some cooperatives cater for the management of socio-health and educational services. They work closely with the staff from the CMHC teams and provide, for example, the previously mentioned supported accommodation. Other cooperatives carry out various activities (agricultural, industrial, commercial and service) and are mainly aimed at sustaining employment opportunities for people. In these social cooperatives at least 30% of the workers must be "disadvantaged people", who are treated as equals with the other workers (33, 34).

h Trialogues are meetings between people using services, their families and supporters and mental health professionals in which the goal is an open discussion of mental health problems, their consequences and ways forward (see: https://www.intervoiceonline.org/tag/trialogical-approach).

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These cooperatives offer job opportunities and educational/vocational training, employing approximately 800 people in Trieste. In 2018, there were 292 trainees receiving work-grants *(35)*. Over the years the work has covered a wide range of activities such as cleaning; building maintenance; transport; cafeteria work; catering; hotel and restaurant services; management of a beach resort; gardening; handicrafts; photo, video and radio production; computer services; serigraph printing; administrative services and personal services *(23)*.

An example is the Tritone Hotel in Trieste, which is a residence overlooking the sea – entirely managed by a social cooperative, mostly comprising users of services of the Trieste Mental Health Department. Other examples include Strawberry Fields Café (*II Posto delle Fragole*), a busy restaurant managed by users of mental health services. The cafes at the Opera House in Trieste, the public radio station, a historical bathhouse, and all museums and public gardens, employ at least one-third of their staff through contract with the social cooperatives of mental health service users (*30, 32, 36, 37*).

As well as the core services described above, Trieste also has several targeted programmes delivered in tandem with the other health district teams of the main health care agency, *Azienda Sanitaria Universitaria Giuliano Isontina*.

These include:

- a service for children and adolescents encompassing crisis care, through a day centre with therapeutic groups, psychoeducation, social activities and home visits;
- an early intervention service for psychosis in adolescents and young people;
- a service for young people with eating disorders;
- coordinated care for persons with physical, as well as psychosocial, disabilities;
- coordination of care for elderly persons in need of home assistance and in nursing homes (people with cognitive impairments and dementia);
- close support for family doctors in providing care to people experiencing mental distress or who have received a diagnosis of a mental health condition;
- improving care for persons with mental health and substance use conditions (coordinated through joint personalized care plans);
- work in prisons and with the Tribunal for persons who are on trial, or have been convicted; and
- work with families (a psychoeducational programme with 10 meetings/modules, self-help groups, and training course for a local carer association).

Other activities implemented through the Rehabilitation and Residential Support Services

Additional activities are organized across a number of locations through the Rehabilitation and Residential Support Services, with the aim of promoting social participation. Activities are run by volunteer associations, including organizations of peers and carers, and focus on defined areas such as wellbeing, physical health and sport, social participation, self-help and peer support, art expression and anti-stigma initiatives, gender programmes including culture, and work training and placement. Activities are organized in social spaces in the city and are in the style of clubs. Four of the organized activities/clubs, including a gym, are provided by the Department of Mental Health, with activities co-produced by the associations. Four other organized activities/clubs are run directly by the associations

themselves. Personalized health care budgets can be used to organize a very individualized programme of activities to suit the specific needs of a person.

Core principles and values underlying the service

Respect for legal capacity

From the very beginning of the reforms in the 1970s, the focus in Trieste has been on promoting autonomy, independence and a respect for the person's capacity to make their own decisions. This is reflected in the emphasis on the "rights of citizenship" *(23)*. There is an explicit commitment to a right to informed consent as well as other commitments in a Bill of Rights, introduced by the service in 1995. People working in the Department of Mental Health do not wear uniforms and work to minimize barriers and hierarchies between themselves and the people they provide care and support for. All services have an open-door policy, and people can go in and out without physical barriers such as locks, keys or codes.

Services in Trieste and Gorizia use the concept of "hospitality". This means that the person using the service is encouraged to stay in contact with their normal life as much as is possible while they are staying in the CMHC, and can also participate in the on-going daily activities of the centre, if they wish. CMHC staff, people who work in the cooperatives, volunteers, carers and peers are all present in the centre during the day, and anyone staying can socialize and interact as much as they wish. "Guests" who are in crisis in one of the CMHCs are made aware that they have a right to leave the service should they so desire, to go out to cafés or for a walk. Although there are no specific rules about this, guests are asked to let the staff know where they are going and what time they will return. The staff members negotiate with the person as to whether she or he is able to go on their trip unaccompanied or whether they require active support from staff or from a relative, a volunteer or a peer.

There is an emphasis on discussion regarding decisions about everything; the day-to-day care plan is adjusted according to personal needs, will and preferences. However, if guests who are experiencing a severe crisis wish to leave and abandon all forms of care, the staff negotiate and seek an agreed plan around safety. This can lead eventually to a legal decision to apply for involuntary treatment as last resort, after several attempts and offers of alternatives.

People using the service on a routine basis self-administer their own medication whenever possible. A number of people collect their medication at the centre and take it at home. They, along with carers or supporters, can attend discussion groups and training events related to the treatments used. The effects and side-effects of the various medications are carefully explained. Written information is also provided through leaflets. Thus, people are assisted to make informed decisions about medication and other interventions *(38)*.

Personalized care plans are developed with the active participation of the person and their network. Apart from clinical interventions, these are based on the individual circumstances of the person's life and can cover all relevant needs, from the person's living situation, including home repairs, maintenance, cleaning, or looking for more appropriate accommodation, to personal finances – such as the need for cash subsidies, use of the centre's safe, temporary daily money management, or support to maintain tenancies. The personalized care plan also covers aspects related to personal hygiene such as laundry, personal cleanliness and hairdressing, as well as purposeful activities, education, vocational training, work opportunities (such as simple tasks at the CMHC or job placements in a work cooperative or in an

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open market setting) and leisure, including workshops in drama, art, music and needlework, gym visits, day trips, holidays, parties, cinema and theatre trips *(24)*.

These plans also cover the best ways to avoid relapse, and the person's wishes in times of crisis, including where they would like to receive care. It is usually recommended that the person should keep in contact with the service, and phone immediately when in need (such as during a stressful event). These plans also include a negotiated account of the medication the person is going to take.

Formalized advance directives (*39*) are not routinely used. Furthermore, if a person is considered to have impaired decision-making capacity, the provisions of the Law 6/2004 covering legal agency apply, and a support administrator (or legal proxy: usually a trusted person, a relative or a friend) can be appointed by a tutelary judge. This does not equate to supported decision making as this person may take on a more of a guardianship role and make decisions for the person in a substituted manner.

Alternatives to coercive practices

The service aims to avoid all forms of institutionalization (such as psychiatric hospitalization, or incarceration in jail, forensic units and nursing homes for the elderly) and all types of coercive, compulsory interventions. However, involuntary treatment (*trattamento sanitario obbligatorio*) is sometimes used as prescribed by Italian law.

The vast majority of treatment, care and support is voluntary and average lengths of stay in either the CMHC or in the GHPU are short (an average of 13.8 days for the former; 1.7 days for the latter (40)). However, in the CMHCs, the "hospitality" extended to guests is informal and flexible, and sometimes lasts for weeks or months if needed until another solution or accommodation is possible. There is an explicit policy of "open door - no restraint" in both the CMHCs and the GHPU (16, 23, 41) and staff are trained in the use of dialogue, de-escalation strategies and the provision of personal support to guests under stress in order to avoid confrontation and the use of coercion. The various places in the CMHC: kitchen, garden, personal rooms are all used in de-escalation; seclusion has not been used since the psychiatric hospital was closed.

In 2019, the rate of involuntary treatment was 8.11 per 100,000 population in Trieste (42) compared to 15 per 100,000 in 2017 for Italy as a whole (43). Notably, Italy has the lowest rate of involuntary hospitalization of all countries surveyed in Europe (44). In situations where involuntary treatment is used according to the law, when all attempts to provide care with consent have failed, it must be requested by two psychiatrists and endorsed by the mayor, who is the highest authority in the town, responsible for public health. These compulsory admissions last initially for seven days. As a particularity of Trieste (and its region), these happen mainly in the CMHCs, where the "open door" principle continues to apply. Involuntary treatment may be extended by periods of seven days for several extensions but can also be withdrawn after few days (33) if consent to care is achieved.

When a person is receiving compulsory treatment, more staff are deployed in the CMHC, so that there are always two or three people available (mainly staff but also social cooperative support workers, peers, carers or volunteers) to meet the needs of a person in crisis. Close, personalized (one-to-one) care is therefore practiced. Family members may also be involved so that the person retains as much connection as possible to their daily life. The person may even continue to take trips into town if this is negotiated but, in the context of compulsory treatment, there is always someone to accompany the individual. The service aims to respond to the needs of the person, rather than acting in a "guarding" capacity.

In a limited number of cases, the police are involved to help and co-manage a situation, which is a legal requirement where immediate risk and a need for the protection of safety and health are considered to be at issue. Forensic hospitals were closed in Italy in 2015 *(41)*; however, Trieste had not sent anyone to these facilities for 40 years. After they were closed, "residential facilities for security measures" *(45)* replaced them. In the Friuli Venezia Giulia region, a decision was made to locate two secure beds in three locations (Trieste, Udine and Pordenone Provinces), rather than have a single unit. However, from 2015, only one person from Trieste has been hosted in such a facility.

Community inclusion

The service in Trieste has achieved a significant level of integration of mental health with other community-based services including housing, employment and education. The Department of Mental Health works closely with all health and welfare services and directly funds a wide series of independent partners in the not-for-profit sector, such as social enterprises, cooperatives and volunteer associations. Even when in crisis, people staying at the CMHC are actively encouraged to maintain their usual daily community activities. For people with complex needs, the personalized plans that come with a personal health care budget can be used creatively to help with autonomy and community inclusion.

Through a series of programmes developed in the community, people using the service are offered opportunities for engagement with a wide range of activities including sports, leisure, wellness, writing, films, museums and other cultural pursuits. Different educational and training courses are organized by associations and cultural agencies, in language, self-care, social identity and various aspects of community life. Through these various activities people are able to experience reciprocal relationships and new social roles. This is also achieved through job training and placement, and work in the social cooperatives.

Participation

The reforms in Trieste have always been concerned with the empowerment of people who are recipients of services, and users of the service are involved in planning, delivering and evaluating services (23). Group meetings of peers are actively encouraged and take place regularly in the CMHCs. Peer facilitators of these groups are paid for their work.

A designated office within the health care agency receives feedback and complaints from people using services, and people can also request to meet the Director of the Mental Health Service. There is also a Participatory Committee which represents the views of service users and carers along with their associations, and a social cooperatives' representative.

Recovery approach

The Trieste service network has sought to be responsive to the "whole life" needs of the person, rather than simply focusing on their diagnosis, and has sought to promote freedom, particularly from institutional residence or detention, as a therapeutic principle. A focus on personal autonomy, citizenship and human rights are basic elements of the "whole person, whole system, whole community" approach used in Trieste *(46)*.



The personalized care plans developed with people using the service incorporate explicit recovery goals *(26)* and allow people to explore their aspirations as a basis for an individual programme or a whole "life project". They can be assisted with money, work, training, education, living places, activities and relationships when necessary.

The Trieste mental health service network recovery approach is based on the following ideals.

- Holistic: services focus on values and principles rather than on diagnostic classifications and intervention techniques. Services attempt to respond to the "whole person" and their various needs, not simply their diagnostic label.
- Whole life/whole system-oriented: attention is directed towards contextual issues and the services seek to engage with the person's family and social network when appropriate. Much effort is spent on the promotion of social inclusion and cultural participation.
- Rights-based: attention is paid to citizenship, participation and civil rights (both legal and social), such as the right to socially meaningful work (*33*).

Over the past decade there has been a sustained effort to incorporate an overt philosophy of recovery into every aspect of the service. A Recovery Research Group produced a Recovery Charter in 2014 (47), which emerged from focus groups with people in all four CMHCs in Trieste and involved approximately 100 people, the majority of whom were people with lived experience (48).

Service evaluation

The changes in Trieste have been substantial since the reforms were initiated in the 1970s. From 1971 to 2018 (49) the number of beds was reduced from 1160 to 219 (40), while the number of people treated by the service has risen from 1160 to 4800 over the same period (35).ⁱ The suicide rate has also fallen from 25 per 100,000 population in the period 1971–1994, to 13 per 100,000 in 2015 (46). The number of people subjected to involuntary treatment each year dropped from 150 in 1971 to 18 in 2019 – a rate of 8.11 per 100,000 population (40). The number of people in forensic hospitals in Trieste has fallen from 15 in 1977 (49) to zero in 2006 (46) and onwards.

Several studies have evaluated the network of mental health services in Trieste and the transition from asylum to community-based care in the city. The first follow-up study after the reform law (conducted from 1983–1987) showed better outcomes for 20 patients with a diagnosis of schizophrenia in Trieste and Arezzo compared to 18 other Italian centres *(50)*. Further, a study of 27 "high priority users"ⁱ found that there was a high rate of social recovery at five-year follow up. A significant reduction of symptoms was also found, of about 20%, and a marked improvement of social functioning (score increased by 50%). Nine people secured competitive jobs, 12 achieved independent living, and a measure of unmet needs dropped from 75% to 25%. There was also a 70% reduction of days of admission, and only one person dropped out *(51)*.

Other studies over the years have also demonstrated important outcomes for the services in Trieste. A national survey carried out in 13 centres showed that the crisis care provided by the CMHCs open

i Excluding small accommodations.

j The people studied were selected by the team. Each had at least six of the following characteristics: high family burden, absence of a social network, isolation, frequent drop out from services, repeated failure of previous forms of treatment, episodes of involuntary treatment, imminent risk of serious social drift, imminent risk of committing crimes, use of illegal psychotropic substances.

24 hours a day, seven days per week, resulted in a faster crisis resolution, the prevention of future relapses, and better clinical and social outcomes at two-year follow-up (52-54). This also emphasized the importance of trusting therapeutic relationships, continuity and flexibility of care, and service comprehensiveness. A 50% reduction in emergency presentations at the General Hospital Casualty Department was also reported from 1984 to 2005 (24). Adherence to antipsychotic medication was 75% (55); this was ascribed to the comprehensive care approach with the development of good therapeutic relationships, social network involvement, and the attention to contextual factors associated with the "whole person, whole system, whole community" philosophy (38, 55).

Qualitative research has also been used to study the service network in Trieste, based on the analysis of recovery stories from a narrative point of view (56). An international research group pointed to the important interconnections between recovery, social inclusion and lived citizenship (57-61). High rates of service user satisfaction were reported in the early years of reform (62) and a survey carried out for a university dissertation pointed to satisfaction levels of 83% with the work of the CMHCs ([Zanello LE],[Università degli Studi di Trieste], unpublished observations, [2006]).

Costs and cost comparisons

The budget of the mental health service is heavily weighted towards community interventions (94%) and only a small proportion goes to the GHPU (6%). It is estimated that the annual cost of the service in Trieste in 2018 was approximately €80 per capita (23) (US\$ 94)^k which amounted to €16.7 million (approximately US\$ 19.6 million).j It is calculated that in 2019, the cost of the Mental Health Department amounted to 37% of the cost of the old psychiatric hospital (35). This represents about 4% of the overall health care budget in Trieste.

The service is paid for by the national health service which is publicly funded. A regional budget provided to the health care agency is then passed on to the Mental Health Department, based on historical expenditures. This is negotiated according to assigned and agreed objectives.

As in all of Italy, private care is available to people who have insurance or who can pay for this directly themselves. Care is also offered free of charge by private accredited providers and is reimbursed by the national health service. However, all private care in Trieste is "office-based" (consultation, psychotherapy, medication) and there are no private hospitals.

Challenges and solutions

Overcoming the legacy of institutionalization

Since the early 1970s, developments in the Trieste mental health service have been driven by a desire to overcome the legacy of institutionalization *(19)*. One of the obstacles to deinstitutionalization was the predominant view of "out of sight, out of mind" leading to the dominance of the psychiatric hospital, and associated power imbalances, human rights violations and social exclusion.

From the beginning, the political support of local and regional authorities and their policies was very important in the Trieste context. Other influential factors *(63)* in the Trieste approach included: the alliance of professionals, administrators, people using the service and their supporters and carers

k Conversion rate as of March 2021.

as well as multiple actors from outside the institution (volunteers, artists, active citizens, families, intellectuals, non-profit groups); the empowerment of service users in the service and the involvement of families (64). The development of a multi-professional team approach with task-sharing, and a stress on the importance of flexibility in terms of professional roles and inputs were also important factors influencing the professional workforce, along with investing in a comprehensive approach that serves to overcome resistance to change, and investing heavily in training, motivation, and professional development of staff (23).

Further, Trieste adopted a multisectoral approach with social care, addressing personal and daily life needs (e.g. housing, income, education, social inclusion etc) and social determinants of mental health. Some of the most important factors, however, involve working actively to prevent admissions to hospitals; adopting a person-centred approach integrating health and social care (*36*); and adopting a defined organizational model based on a network of services, which has as its main point of reference the services at the 24-hour Mental Health Centres, equipped with very few beds and managed by a single comprehensive team.

Since Trieste was designated as a WHO pilot centre for deinstitutionalization in 1973 (18), it has continued to innovate and develop, and has been hugely influential across the world (16, 65-68). It now has established links with countries and services in all continents and there are study visits by approximately 1000 people every year to the city (23). The Parliamentary Commission on the State of the Italian National Health System (69) and the Italian Fellowship of Mental Health Associations has since identified this as a model for the whole of Italy to adopt (41).

Changing institutional culture and power relations

The mental health system was built on a system of hierarchies. Working to overcome the institutional culture required challenging these hierarchies and the power relations that sustained them. Progress was made with persistent efforts to democratize the world of mental health by broadening discussions and decision-making processes to include all the stakeholders. Initially, daily assemblies were held in the psychiatric hospital in an effort to achieve this. Involving the families of people with mental health conditions and the wider community also helped to counteract the forces of social exclusion that had sustained the central position of the psychiatric hospital. Finally, developing ways for the voices of people using the service to be heard and acted upon created opportunities for people to take back their authority and independence for their own care.

Challenging the disease-centred ideology

The ideology associated with a disease-centred approach acted to silence the voice of the people using the service and meant that little attention was paid to their personal, social and cultural needs. The establishment of new forms of collective leadership and a whole new set of practices in the mental health system aimed at supporting people to lead a full life in the community was extremely important. Progress was also made through the development of associations and social cooperatives to nurture a new focus on the "whole person", rather than solely the biomedical model and a narrow disease-centred ideology.

Sustaining progress made

The Trieste mental health network faces a continual threat of slipping into new forms of institutionalization, or simply service "inertia". Further, there is an ever-present danger that paternalism, and even different forms of abusive behaviour, might emerge. Being aware of the problems and actively engaging with them helps avoid these risks.

Supporting staff through periods of change

Without the easy fallback of reliance on clinical models, the Trieste staff were pushed to use their own personal resources to relate to people using the service. This sometimes led to burnout and conflict because this was a new approach which was less structured and had more uncertainties. One of the solutions found was to create a culture of "sharing the burden", so that no staff member is left alone to carry all the worry and concern about a particular individual or family. Another organizational solution involved efforts to create a genuine democracy within the organization so that both people using the service and staff members feel that their voices are being heard and that their concerns are listened to.

Key considerations for different contexts

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

- nurturing critical thinking and reflection within the service as a vital ingredient of creating and sustaining the positive impact of your service;
- shifting from a clinical understanding of mental health conditions to a 'whole person-whole life' philosophy;
- investing heavily in staff training and development;
- creating opportunities for staff members, people using the service, their families and people from the wider community to meet and discuss the vision of the service; and
- recognizing that clinical outcomes (as measured by rating scales) are not as important as outcomes
 relating to the citizenship of the people using the services, such as the levels of coercion used by the
 services; and
- evaluating networks of services using an approach and measures that capture the overall working and outcomes of the network rather than just the individual services and interventions provided.

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.youtube.com/watch?v=5v0jki3GaBw&feature=youtu.be</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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Brazil community mental health service network a focus on Campinas



Context

Brazil is a federal republic, the world's fifth-largest country by area with 27 federative units and 5570 municipalities. It is the sixth most populous country in the world, with over 211 million people (70). It is an upper-middle-income country, but with high levels of social inequality (71). Universal healthcare is a constitutional right in Brazil provided under the country's Unified Health System (*Sistema Único de Saúde* (SUS)). Brazil's mental health network is provided under the SUS.

The mental health network in Brazil today is a reflection of the significant psychiatric reform that has taken place in Brazil since the late 1970s. Originating as a civil society movement, psychiatric reform took place through shifting from institutionalized care to care in the community and the development of a supporting legal framework, service regulations and rights-based mental health policy. Institutional structures and practices have been replaced by a community-based network of services through incremental resource reorientation (72, 73). 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%. By 2013, in contrast, nearly 80% of mental health budgeting was invested in community-based services while 20% was hospital expenses (74).

In 2017, though, psychiatric hospitals were again formally included in the mental health network (following a change in mental health policy in 2016) and federal government investment in the implementation of community-based services also decreased (75, 76). However, due to a level of autonomy at municipality and state level in the implementation of public policy and strong foundations in psychiatric reform from institutions, legal, financial and civil society, this shift did not automatically lead to a cessation in implementation of community-based services, nor the closure of psychiatric hospitals across municipalities (77).

All community-based mental health services in Brazil follow the main guiding principles of the mental health network in Brazil:

- promotion of equity;
- guarantee of open access to services;
- rights-driven, quality services offering comprehensive care based on a person-centred recovery plan and multi professional input;
- person-centred and needs-focused care and actions;
- respect for human rights;
- promotion of people's autonomy, social inclusion and participation, rights of citizenship and freedom;
- community-based approach with participation of people with lived experience;
- combating stigma and prejudice; and
- joint actions with other sectors, such as housing, work, education and culture, and the development of capacity building strategies (78).

The community-based mental health network is implemented throughout all regions in Brazil; how each element of the network is implemented and what people may experience though, varies. For the purpose of describing the network, a good practice example of a local (municipality level) network was selected to provide practical insight into its workings. The municipality of Campinas was selected for

the following reasons: it is a municipality with an entirely community-based mental health network, having closed the city's psychiatric hospital in 2017; it does not refer individuals to psychiatric hospitals outside of the municipality, for example, to regional hospitals; it has a comprehensive integrated network of services that work well together at the local level; and evaluation data is available.

Campinas – Profile

Campinas has a population of approximately 1.2 million people. In 2010, 30% of the population had monthly earnings less than half the national minimum wage. A total of 39% of the population had formal employment, with 72% aged between 15 to 64 years old *(79)*.

When the transformation of the Campinas mental health network began in 1990, there were 1200 psychiatric beds across five hospitals in Campinas. The first step in this process was the deinstitutionalization of the psychiatric hospital, *Sanatório Dr. Cândido Ferreira*. From the 2000s onwards, substitute services such as those described in this document began to be implemented and in parallel, a progressive and agreed closing of the psychiatric hospital beds and the deinstitutionalization of the people who lived there. In 2017 the *Sanatório Dr. Cândido Ferreira* psychiatric hospital was finally closed.

Description of the mental health service network in Brazil, with examples from Campinas

The services described below work together to provide continuous community mental health care and support that meets the needs of both the individual and the community. Mental health forums in Campinas provide an opportunity for community-based service professionals, the individuals who use the service and family members to come together to discuss and address common issues related to services and regional needs. The mental health network links with the general health network in addition to other relevant sectors and services (for example, employment, culture, sports) through the community-based mental health centres.

Elements of the mental health service network

Community-based mental health centres

Community-based mental health centres, known as *Centro de Atenção Psicosocial* (CAPS), are the cornerstone of the community-based mental health network in Brazil. CAPS provide continuous, tailored and comprehensive community-based mental health care to individuals with severe or persistent mental health conditions and/or psychosocial disabilities, including during challenging and crisis situations. CAPS have a rights-centred and people-centred approach. Their primary goals are providing psychosocial care, promotion of autonomy, addressing power imbalances and increased social participation. As a principle, CAPS do not refer users to psychiatric hospitals. CAPS are active both within the confines of the centre itself and in the community.

The number and type of CAPS in a region depends on the population and the unique needs of that region. CAPS services are classified according to catchment area and target population. CAPS I serve the adult population in catchment areas of over 15,000 people and CAPS II in areas of over 70,000. CAPS III services¹ cater for adults as well as children and adolescents in areas of over 150,000, and

I A more in-depth description of a CAPS III is provided separately in this guidance using the example of CAPS III Brasilândia in the technical package, *Community mental health centres: Promoting person-centred and rights-based approaches.*

are open 24 hours a day, seven days per week, providing overnight accommodation if needed. CAPSi serve children and adolescents, and CAPS ad provide support for problems and needs associated with substance use. Alternative configurations are also possible: for example, while CAPS I and CAPS II services mainly serve the adult population, they may also provide care and support to children and adolescents to ensure access to community-based support where a CAPSi is not available. Different types of CAPS can also be combined to meet the needs of the community. For example, In December 2017 new legislation established the creation of a new CAPS type: CAPS ad IV, focused on people with problems and needs associated with substance use in areas with over 500,000 people.

The staffing of each CAPS varies according to the type of CAPS, population needs, hours of operation and specific demands. Minimum staffing levels for each type of CAPS are prescribed by law as shown below; however, municipalities may fund staffing beyond these minimum levels. The staffing requirements refer to various staff categories. University level educated professionals include psychologists, social workers, occupational therapists, pedagogues, physical educators, speech therapists or other professionals as required for service users' needs. Mid-level professionals include nursing technicians and/or assistants, administrative technicians, educators and "artisans".

The minimum staffing levels for CAPS services are as follows.

CAPS I – a physician with training in mental health, a nurse, three university level educated professionals and four mid-level professionals.

CAPS II – a psychiatrist, a nurse with training in mental health, four university level educated professionals and six mid-level professionals.

CAPS III – two psychiatrists, a nurse with training in mental health, five university level educated professionals, eight mid-level professionals. For the night shift: three nursing technicians under the supervision of the nurse and a mid-level professional.

CAPS ad – a psychiatrist, a nurse with training in mental health, a clinical physician responsible for screening, evaluating and monitoring clinical complications, four university level educated professionals and six mid-level professionals.

CAPSi – a psychiatrist, neurologist or paediatrician with training in mental health, a nurse, four university level educated professionals and five mid-level professionals.

Among all of the CAPS modalities, CAPS III is considered a key strategic service to have in a mental health network. In operating 24 hours a day, seven days per week, and with the availability of a dorm facility, a network with a CAPS III can provide continuous care in the community to its users at all times but also to other CAPS in the network where a user would benefit from continuous (day and night) support. For smaller municipalities without a CAPS III, service users may be referred to a CAPS III in another city or region. CAPS III dorms are not considered nor used as traditional mental health beds. 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 (*78*). People can stay for up to 14 consecutive days during which the CAPS proactively support the user in addressing the factors that led them to require overnight support. The dorms aim to provide a similar environment to that of being at home. There are no rules or requirements in terms of using this service.

Operational principles

All CAPS services follow three guiding principles.

- Open door policies To access a CAPS a person can simply walk in without an appointment to have a first meeting about using the centre. A person may also be referred by another service, or can be visited at home. The CAPS physical structure aims to provide a welcoming and comfortable homely environment that helps people to feel at ease and encourages active participation and interaction (80). There is no involuntary admission or forced use of CAPS. No individual is refused access to the centre, including if they present in a crisis or challenging situation. A mental health diagnosis is not required to attend the centre.
- 2. Wide reaching community engagement For CAPS, being community-based is not limited to being a service that is available in the community, rather this principle requires full engagement with and understanding of the community, as well as the individuals who live there. CAPS team members talk to people in the community to understand the social dynamics and to map the common problems that most impact people's lives and mental health to gain a better understanding of possible mental health and psychosocial needs. At CAPS, team members identify and activate community resources and create partnerships with people and services to carry out mental health care initiatives. CAPS also engage with the community on mental health and psychosocial disability topics such as promotion of rights of individuals with psychosocial disabilities, and initiatives to reduce stigma and prejudice.
- 3. Deinstitutionalization As CAPS were designed to replace psychiatric hospitals and other institutionalization structures (81), all CAPS have capacity and responsibility to attend to complex, challenging and crisis situations, offering care and support with community-based practices. CAPS interpret this role as requiring more than acting as a physical alternative to traditional institutional services, but also deinstitutionalizing services, practices and attitudes. At an individual level, this can mean therapeutic support based on recognition of an individual's human rights, respect for different ways of life, practicing validation and empowerment of the user and respecting that the user has knowledge about themselves and their recovery process. At a service level, no doors in the centre are locked and the individuals who use the service can enter or leave any room in the centre at any time. Neither involuntary admission nor seclusion are used in a CAPS. The use of restraint goes against the core principles of the CAPS model.

Operational practices

While each CAPS can shape its practices to best meet the needs of service users and the wider community, there are important commonalities in operational practices across all CAPS services *(80)*.

Development of a person-centred recovery plan

A wide-ranging person-centred recovery plan for all service users (Projeto Terapêutico Singular (PTS)), is co-developed by the individual and a team member. It includes personal history, an individual's wants and needs, social relationships, current life context, challenges, strengths and goals. Individuals are encouraged to reflect about the future and take risks. There is also a focus on promoting an individual's rights and enjoying these rights. The plan also defines care strategies with shared responsibilities. Developing a PTS is seen as a strategy to empower people to take charge of their own recovery process. The PTS is reviewed and updated on an ongoing basis. All activities in a CAPS reflect the PTS of its users (82).

Empowerment actions

- CAPS seek to recognize and address power imbalances within the service (for example, team members recognize differences in power and seek to redistribute power in relationships).
- Staff create positive opportunities for dialogue, negotiation and exercising rights. For example, service users receive practical support for engaging with and participating in the community (such as making a purchase in the local market), support for managing finances and mediating conflicts.
- CAPS centres hold periodic assemblies with participation of the individuals who use the service, family
 members and staff. The assemblies provide opportunities to participate in discussions regarding
 daily life and activities of the CAPS, as well as debates on broader topics that affect CAPS users,
 such as poverty and stigma. In the assemblies, everyone participates on an equal basis and all are
 responsible for the discussions and decisions taken.
- Service users are encouraged to engage in management councils, mental health conferences and mental health service forums.

Needs-focused meetings between team members and CAPS users

- At a first welcoming meeting (Acolhimento), the aim is to create a welcoming and positive dynamic, and meet an individual's needs in that specific moment. The welcoming team member explains the service and together they begin the process of identifying whether the centre is the right service for that individual. Team members listen to understand the needs and wants of the individual, their personal history, their social and support network and general mental health. Information from the first meeting is recorded, and the service user has access to this information at any time. Standardized mental health screening tools or assessment tools are not used.
- All subsequent individual meetings (including therapeutic activities) maintain the same approach; team members actively listen to and recognize the individual's needs in that moment in time rather than focus on mental health diagnosis, personal history or past discussions.

Group activities

- CAPS services provide group activities both at the centre and in the community. Group activities provide opportunities to socialize and build relationships, and promote co-existence and a sense of belonging. Each CAPS defines which activities it will carry out depending on users' PTS and the resources available in the CAPS and in the community. Types of activities include self-care, art, theater, dance, social activities, cooking and gardening, amongst others.
- Some group activities are not limited to registered users of CAPS but may also have wider engagement and participation. These activities can provide broader opportunities to socialize, increase community participation and reduce stigma.

Home visits

• Individuals can be visited at home both for a first meeting about potentially using a CAPS or for further needs. This ensures that individuals who have difficulties reaching or accessing the centre can still access its support.

Family support

• CAPS services develop individual and collective care strategies for family members. The objective is to identify and meet the demands of family members in order to support their role and co-responsibility for care.

Providing a space to be and to participate

CAPS offer the possibility for users to spend the day and/or night (if a CAPS III) in the service. Users
can participate in activities that are happening and give their opinion on the service's practices and,
together with others, remodel them. They have a chance to be with other people and progressively
create new social relationships, a sense of belonging and a space to be and participate.

Crisis support

- Individuals in acute crisis are welcomed and supported, and there is no involuntary admission or forced use of the centre. An individual in crisis is never referred to another service where coercive practices could be used.
- In a CAPS, crises are understood as moments in a person's life and recovery during which the individual needs to be supported based on their stated wishes, needs and preferences. Support is based on the principles of Open Dialogue (for more information see Mental Health Crisis services: Promoting person-centred and rights-based approaches).
- Team members are available to listen to individuals, understand and mediate possible conflicts. Support can be provided at the service itself, at the individual's home or in community spaces.

Psychosocial rehabilitation

- Psychosocial rehabilitation is one of the most important aspects and activities of CAPS. These
 activities reflect the unique needs and life history of each individual and their PTS. Practices can
 include team members accompanying an individual as support in their daily activities, mediating
 relationships or conflicts with family members or their support network, or providing individual or
 group activities that contribute to an individual's recovery.
- A key focus of psychosocial rehabilitation is ensuring active citizenship. This may include, for example, accompanying an individual and providing support to navigate bureaucracies so that a person can have documentation and be formally recognized as a citizen; or to create opportunities so that a person can study or work, and in doing so, increasing that person's social participation.
- Psychosocial rehabilitation also involves creating and developing initiatives with community resources. Rehabilitation strategies are developed in the areas of housing, social life and work, creating opportunities to enable an individual's social participation and enhance autonomy.
- These actions also aim to build new social places of belonging for the individuals who access CAPS services, in that people can be increasingly recognized by society and have an active citizen role.

Network coordination and cohesion

- CAPS offer support to other mental health and general health services, including independent living facilities, primary health centres, emergency services and hospital services, and to other networks and institutions. The aim of this support is to promote collaboration in the co-management and coresponsibility of the various services and service networks to fulfil their role in each service user's PTS.
- As a strategic service in the mental health network, CAPS also develop and implement strategies to create links and partnerships with other services in the health, education, justice and social assistance network, as well as with community resources, with the aim of promoting and guaranteeing rights.



A typical day and night at a CAPS III - Campinas

In a CAPS III in Campinas, an average of 60 people (service users and team members) are at the service on any given day. The day at CAPS III is lively with diverse activities that promote well-being, self-care, social exchanges and the strengthening of relationships between the individuals who access the service, team members and the community. Generally the CAPS III has designated team members to ensure that the day at the CAPS flows, offering support in organizing meals for people coming to the service, listening and meeting the unexpected demands of the day, proposing activities and creating opportunities for social exchange. The individuals who use the CAPS come and go during the day. It is common for individuals to go to the CAPS during the day to watch a movie, talk, meet people, bake a cake, play games, read a newspaper together or water the plants for example.

In addition, CAPS III activities take place in the community. CAPS team members go to other community mental health services, such as the Núcleo de Atenção à Saúde da Família teams and independent living facilities, to provide support to Family Health Teams and to visit and provide support to independent living facility residents. Team Members also go out with CAPS III service users to accompany them in their activities, putting into practice the activities of psychosocial rehabilitation and actions in the community. For example, an individual and a team member might take public transport together to go somewhere (which involves planning the destination, separating the right amount of money to pay for the bus ticket, and selecting the right bus to take) or they may choose to take a walk around the neighbourhood (which involves leaving home, getting to know the neighbourhood, being around and relating to other people). Team members also support individuals to participate in other services, such as community-based "Coexistence Centres" and other city services such as cultural centres, and support activities to generate work and income.

At night, individuals are supported by professionals and activities are organized to meet the needs of people in the service at that time. A welcoming environment is created that enables people to experience a crisis in a safe, caring environment. The average duration of overnight stays in a CAPS III in Campinas is 6.7 days (in 2020).

While CAPS centres provide a key and strategic service in the community-based mental health network in Brazil, other services within the network play just as essential complimentary roles.

Community Based Health Centres

Community Based Health Centres (CBHC) (*Unidade Básica de Saúde*) are considered the first contact point for people to enter the Brazilian public health system (83). CBHCs provide basic community care across general practice, paediatrics, gynaecology, nursing and dentistry. Family Health Teams situated within the CBHC, provide an important link between the CBHC and the community. One of the key responsibilities of the Family Health Teams is to ensure every family in their catchment area is registered with their respective CBHC, to monitor each family's general health and living conditions and to provide health care. The Family Health Teams key practitioners are Community Health Workers (*Agentes Comunitários de Saúde*) who are basic level professionals with an understanding and knowledge of the community they work in, the people that live there, and the community's unique dynamics and challenges.

Community Based Health Centres – Campinas

There are 66 CBHCs in Campinas (approximately one for every 20,000 inhabitants). All CBHCs in Campinas are linked with and receive support from a CAPS service.

The typical staffing of a CBHC in Campinas varies, however minimum staffing includes: a coordinator, physicians (including specialists in paediatrics, gynaecology and obstetrics), nurses, a dentist, nursing assistants, dental assistants, and support staff. About a third of CBHCs have mental health professionals, including psychiatrists, psychologists and occupational therapists.

Small CBHCs in Campinas have between 16-20 individuals in professional roles, in addition to the support staff described above. Medium sized CBHCs are made up of approximately 47 professionals in addition to support staff, with large CBHCs having 84 professionals, plus support staff.

All CBHCs in Campinas have Family Health Teams and there are a further 146 Family Health Teams in Campinas. The minimum staffing of a Family Health Team includes: a physician, a nurse, two nursing technicians and community health agents. In addition, most Family Health Teams have other support professionals, including paediatricians, gynaecologists, nutritionists, psychologists, occupational therapists, physiotherapists, social workers, dentists and dental assistants.

Núcleo de Atenção à Saúde da Família (NASF) teams

NASF are multidisciplinary expert teams providing direct general support to Family Health Teams at the CBHCs. These teams are not mental health specific, but include mental health expertise. NASF teams typically comprise a social worker, psychologist, occupational therapist, nutritionist, physical education professional, pharmacist, physiotherapist and speech and language therapist, and usually a physician.

NASFs provide support by discussing clinical cases, doing shared consultations with the Family Health Teams and CBHC teams, collaborating in the development of PTS plans, and delivering prevention and health promotion activities. NASFs are also involved in capacity building for professionals in CBHCs in their specialist areas, and provide care and support to individuals with less severe or less complex mental health needs. When a NASF can successfully support CBHCs to meet these needs, it allows CAPS in the region to focus on providing care and support to individuals with more complex mental health needs. This can help to prevent excessive demand on a CAPS service. NASFs follow the same human rights principles as CAPS and link and engage with CAPS as needed. They do not practice or promote the use of seclusion, restraint or any other coercive practices.

NASFs are particularly important in municipalities with less than 15,000 inhabitants. These municipalities, which represent about 60% of Brazilian municipalities and account for approximately 12% of the total Brazilian population, are not large enough to qualified for a CAPS. Therefore within these municipalities, the actions of community-based health centres at primary health care level are the main care and support strategy for the mental health needs of the population they serve (73).

NASFs – Campinas

Campinas has a total of five NASFs. Their staffing levels reflect the unique needs and demands of the services they support and the communities they serve. All NASFs in Campinas typically include as a minimum: apsychiatrist, psychologist and occupational therapist, with additional professionals as needed.

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Street Outreach Teams

Street Outreach Teams (*Equipes de Consultório na Rua*) are part of the CBHC and are focused on the homeless population. They provide support, health care, protection against the risks to which this population is exposed (such as greater risk of urban violence, lack of financial income, absence of social support network, risks associated with drug use), and take actions to protect and promote the rights of this community. Teams provide mental health care to the homeless population in general but also to people with mental health conditions, psychosocial disabilities and problems associated with substance use. Street Outreach Teams map out the areas or regions frequented by individuals who may be able to benefit from their service, go directly to these areas to offer help and support, and provide referrals to health and social services.

Street Outreach Teams are in constant dialogue and develop partnerships with CBHCs, Family Health Teams and CAPS in order to best meet the needs of the population and individuals they serve *(78)*. The services share relevant information about the person and their recovery process, and identify actions or support required to meet the person's needs. Street Outreach Teams can also help to facilitate access to CAPS, including for individuals who use drugs. Teams consist of between four and seven members. Teams may include a nurse, psychologist, social worker, occupational therapist, doctor, social agent with lived experience, nursing assistant and dental health technician. Larger teams also include a physician. Street Outreach Teams do not refer or otherwise direct people to psychiatric hospitals or other services where coercion, restraint or seclusion may be used.

Street Outreach Teams – Campinas

There are two Street Outreach Teams in Campinas, who provided support to approximately 476 individuals per month in 2020. The typical staffing of a Street Outreach Team in Campinas includes:

- 1.75 medical professionals (equivalent to 70 hours, provided by 1 psychiatrist and 3 physicians)
- 2 nurses
- 1 occupational therapist
- 1 psychologist
- 1 social worker
- 3 harm reduction professionals
- 3 nursing technicians
- 1 administrative assistant
- 2 drivers
- 1 coordinator.

The Street Outreach Teams meet at the beginning of each working day to plan the day's activities. The teams provide an outreach service in areas of the city that have been mapped as places where people in vulnerable situations live, generally public squares. Each day, the Street Outreach Team travel to these designated areas, set up a tent from which they work and begin consultations (for example, nursing and social assistance assessments, referral to other services and social activities). In providing health care to the homeless population in Campinas, cultural activities such as music and capoeira (a dance-like martial art of Brazil) exist side-by-side with medical, nursing and mental health practices. Once assessed by the Street Outreach Team, a person can be referred to the primary care network

and/or to a CAPS where their mental health needs and/or any issues regarding substance use can be identified. The services then work closely together in an integrated manner to support and meet the needs of the individual.

The Street Outreach Teams in Campinas also work very closely with individuals who are homeless and pregnant. This includes identifying individuals who may need support, monitoring prenatal care and providing referrals to shelters and maternity hospitals. In 2020, Campinas Street Outreach Teams supported 100 women who were pregnant and homeless, allowing the baby to stay with the mother or extended family and avoiding the child being taken into care. The Street Outreach Team's relationship with the wider network, especially in terms of social assistance and public security, is crucial in the care of this population. Of the people supported each month by the street outreach service, an average of 20 individuals are accompanied to attend a CAPS for adults and 65 individuals are accompanied to attend the CAPS ad. Both CAPS and the Street Outreach Teams are responsible for the care of this population.

Independent living facilities

Independent living facilities (*Serviços Residenciais Terapêuticos* (SRT)) are houses located in the community designed for people with a history of long-term hospitalization (two years or more uninterrupted) who have been discharged from psychiatric hospitals or custody hospitals. For individuals who do not have a family or support network available, or there is no possibility to return to the family home, an SRT provides the individual with an independent accommodation option in the community. This service is part of the deinstitutionalization strategy of the Brazilian psychiatric reform process.

An SRT can accommodate up to ten residents, with houses exclusively for women, exclusively for men, and mixed houses (*81*). Each residence has five caregivers per work shift and one nursing technician. Residents of SRTs are also CAPS users. Using each individual's PTS, psychosocial rehabilitation is provided through a close partnership between the individual, the SRT and the CAPS, with the objective of promoting autonomy, social inclusion and guaranteeing rights. A person can live indefinitely in an SRT. They are seen as a person's home, rather than a health or social service and fall outside regulatory or inspection activities. As a principle, seclusion, coercion and restraint are not used in an SRT.

Independent living facilities – Campinas

Campinas has 20 SRTs with a total available capacity of 160 spaces. Currently SRTs in Campinas are housing 139 people.

The typical staffing of an SRT in Campinas includes a housing assistant, a monitor and a nursing technician, depending on the needs of the individuals in the SRT. Each house has its own unique configuration, also according to the needs of the people resident there.

In the day-to-day life of an SRT, residents may engage in various activities in the community – for leisure, religious observance, activities at the CAPS – or be at home pursuing their interests or having visitors. In each SRT there is a weekly discussion during which the residents decide on the menu for the week. The residents then go out to buy the necessary groceries, with the support of caregivers as needed. The residents also manage household chores; however, in the case of houses with people with more serious clinical conditions and with a greater need of support, there is a cleaning team.

The SRT houses are located in different neighbourhoods across Campinas. All SRTs are linked with a CAPS III and there is continuous dialogue and engagement between SRTs and CAPS services. A CAPS team member visits the SRT daily to check-in on the daily life at the residence, for example, to check if the shopping needs for the house are up to date, if anyone needs to make any personal purchases, and if all residents are well. The linking of SRTs with CAPS is particularly important as the same professionals who provide care at the CAPS are also involved in the psychosocial rehabilitation process in the community. This in turn, facilitates the overall development and oversight of the individual's care plan (PTS) at both a service and community level. However each SRT resident participates in the community's mental health services network according to their wishes and needs.

Going Back Home Programme

The Going Back Home Programme (*Programa De Volta Para Casa*) is a deinstitutionalization strategy that consists of a transfer of financial resources to people who have been discharged from long-term psychiatric hospitalization (two or more years uninterrupted) (*84*). The aim of the programme is to promote psychosocial rehabilitation by strengthening a person's contractual power by ensuring that the person has an income to be able to make choices, for example, about what to buy and where to go. The monthly amount paid at federal level was 412 Brazilian Real (R\$) (approximately US\$ 72)^m in 2020.

Going Back Home Programme – Campinas

In Campinas, a total of 139 individuals are currently recipients under the Going Back Home Programme, with a cost of R\$ 57,268 (approximately US\$ 10,070)^m per month.

Mental health beds in general hospitals

Mental health beds in general hospitals (*Leitos de saúde mental em Hospitais Gerais*) provide health care for people with mental health conditions, psychosocial disabilities, and problems and needs associated with substance use. Access to mental health beds in general hospitals is coordinated through a centralized bed management system. Admission is based on clinical criteria and hospitalizations must be of short duration (that is, until the clinical stability of the individual allows discharge). To access a bed, a mental health network service, such as a CAPS, must request the use of the bed; this ensures that only those people who have a specific need to use the bed will in fact use it, preventing the inappropriate use of hospital beds and avoiding unnecessary hospitalizations. CAPS may refer people to mental health beds at a general hospital, for example when an individual who uses that CAPS has co-morbidities, or difficulties or needs associated with their general health that requires secondary level care. Mental health beds in general hospitals can also act as a barrier to admissions to psychiatric hospitals in a region.

The mental health beds may be ring-fenced beds reserved by the hospital in the event an individual with mental health needs is admitted or they may be part of a mental health unit or ward. The number of mental health beds in a general hospital cannot exceed 15% of the total number of beds, up to a maximum of 25 beds. There is a minimum of four mental health beds in a general hospital.

m Conversion rate as of March 2021.

As part of the mental health network in Brazil, these beds follow the same principles as the previously listed services. However, at the time of writing no evaluation data was available on the use of coercive practices in these services. Anecdotal information suggests that coercive practices (namely the use of mechanical and chemical restraints) may be used and that this practice varies across hospitals. A further challenge is the effective integration of this service with other services in the network in order to guarantee the continuity of an individual's care across services.

Mental health beds in general hospitals - Campinas

There are 36 mental health beds in the two general hospitals in Campinas. One hospital, *Complexo Hospitalar Mayor Edvaldo Orsi*, has 20 mental health beds and the other, *Hospital das Clínicas da UNICAMP* has a total of 14 such beds. The mental health beds are located in a designated ward in both hospitals.

To illustrate the staffing levels in one of these wards, the staffing at the mental health ward of the general hospital *Complexo Hospitalar Mayor Edvaldo* Orsi includes:

- 1 psychiatrist (service coordinator with medical responsibilities)
- 1 medical supervisor
- 1 nurse supervisor
- 1 psychiatrist on call
- 1 nurse
- 5 nurse technicians
- 1 occupational therapist
- 1 psychologist
- 1 social worker.

In Campinas, hospitalization is generally used for support during a crisis situation, based on the severity of the crisis and the needs of an individual. An individual may also be referred to one of these beds to remove them from their current environment, or because of the existence of a clinical comorbidity that requires psychiatric care and other medical specialties. These beds may also be used for the purpose of diagnosis (more common in the care of CAPS ad service users) and protection purposes, especially in the vulnerable underage population. Mental health beds in a general hospital may also be considered when the CAPS and general hospital considers that an individual may benefit from it. For example, the hospital may provide a more appropriate environment for some individuals than the busy active environment of a CAPS, and also provide an alternative if there are no dorm vacancies within a CAPS III in the network.

If an individual is admitted to a mental health bed in a general hospital in Campinas, the hospital team and the team from the reference service of that person (for example, a CAPS) work to continue the PTS of that individual. They will discuss the user's recovery plan and any adjustments that may be needed during their time in hospital. Visits by professionals to the individual, for example, from CAPS, are common and encouraged during the hospitalization period.

Engagement between the services and team members is ongoing throughout the time an individual is using one of these beds. The general hospital team also goes to CAPS to attend meetings and to discuss shared strategies to better serve the individuals who access these services.

The care provided by a general hospital follows the same principles of the mental health network and CAPS. In a crisis situation, both verbal and medication approaches are used, but medication is used only with the consent of the individual. The network reported, however, that restraints may still be used in extreme circumstances and this is important to change.

Mental health beds in general hospitals are important in the Campinas network for their role not only in providing additional support to individuals experiencing a crisis situation, but also for their ability to link and work with all the municipal mental health services.

Emergency and urgent services

Urgent and emergency care services associated with the mental health network are part of the emergency services network of the general health system, including mobile emergency services, emergency care units (standalone emergency care-specific services) and hospital emergency rooms. As a general guideline, the urgent and emergency care services work together with CAPS when an individual with mental health needs presents at one of these services. On arrival, the emergency service contacts the relevant CAPS for that individual. Once contact is made, the CAPS has shared responsibility for the individual's care, including for example, discussing the individual's needs, following up emergency service actions, resuming the person's PTS in the community upon discharge from the emergency service, etc.

Other mental health network services

Reception Units (*Unidade de Acolhimento*) are community-based residential services, designed to provide support to CAPS centres in the health care of people with problems and needs associated with substance use who are in situations of social vulnerability and/or when a more intense presence and monitoring for a transitory period of time is required. This service is not described in more detail as substance use services were beyond the scope of this document.

Cross-network initiatives

A strength of the network in Brazil is not only that these services co-exist to meet the evolving needs of the community, but also in its cross-network initiatives that are transformative in terms of the individual and community. Such initiatives have been instrumental in widening the perception of and engagement with mental health and psychosocial disability at a community level.

Coexistence Centres

Coexistence Centres (Centro de Convivência (CECO)) are community-based centres open to all members of the community, and the participation of people with psychosocial disabilities, cognitive disabilities, older adults, and children and adolescents with social vulnerabilities is highly encouraged. The primary goal of CECOs is the mediation and promotion of opportunities for coexistance, promoting social inclusion and belonging. While CECOs are considered part of the national mental

health policy, they are currently only implemented in some regions of Brazil. CECOs are funded at state and municipality level.

Coexistence Centres – Campinas

There are five Coexistence Centres (CECOs) across Campinas each with a service capacity of between 120 and 300 people per month. The typical staffing at a CECO in Campinas includes: two professionals (psychologist, occupational therapist, group leader, physical educator or nurse), a monitor, cleaning assistant and coordinator.

The CECOs of Campinas were established as part of local public policy before CECOs were recognized at a national policy level, and are funded at a local level. CECOs are usually located in public parks or green areas and link health, sport, culture, education and the environment from a psychosocial rehabilitation, prevention and health promotion perspective.

CECO activities reflect two main themes – coexistence (group activities, public meetings, promoting understanding and tolerance of differences between people) and partnerships (with public institutions and civil society) that can contribute to the inclusion and autonomy of individuals accessing the CECO. For example, a literacy programme for young people and adults was developed by the CECO in partnership with the educational sector, in which both CAPS users and residents of SRTs may participate.

Each CECO has its own schedule of activities published monthly. Activities include literacy, guitar lessons, English, capoeira, zumba, painting and craft activities, garden activities, a cinema workshop and cooking, among others. All activities are free, open to the community and often rely on the active participation of volunteers.

CECOs also link directly to mental health services. For example, if a CAPS identifies that a CECO can enhance the PTS of an individual (in the sense that participating in some CECO activity could be beneficial to the person) a referral can be made. Likewise a CECO can also identify if someone who attends its activities could potentially benefit from a CAPS service and facilitate a referral.

Work and income generation services and initiatives

Work and income generation initiatives aim to guarantee the right to work and to provide training and qualifications for work. These initiatives promote social inclusion and autonomy, increasing power and improving people's living conditions. They are also a psychosocial rehabilitation strategy for strengthening the protagonism of individuals who access the mental health network. Some of the initiatives carried out in different regions include cooking, craft products, clothing production, agriculture, recycling, stamping, rendering of services, sales, among others. These initiatives are based on the solidarity economy perspective *(85)*.

Work and income generation services and initiatives – Campinas

Campinas has two services focused on the Solidarity Economy and the generation of work and income – Workshops House (*Casa das Oficinas*) and the Centre for Workshops and Work (*Núcleo das Oficinas e Trabalho*). Both of these services develop activities focused on guaranteeing the right to work, promoting autonomy, fostering social inclusion through work, and participation in social associations and cooperatives. They develop collective and participative training activities and
income and work generation activities, in a variety of areas. A further entity focuses on commercializing products, Workshops Warehouse (*Armazém das Oficinas*).

Casa das Oficinas is staffed by a coordinator, psychologist, occupational therapist, monitors, administrative assistant and cleaning assistant. It has seven work and income generation initiatives in the areas of cooking, stationary and sewing (Gira Mundo), handicrafts, printing, bread making and mosaics. Approximately 50 people per month access this service.

Nucleo de Oficinas e Trabalho is staffed by a coordinator and administrative assistants. Each of the work and income generation initiatives has a separate coordinator who may be an occupational therapist, psychologist, social worker or architect, and monitors. The organization has 12 work and income generation initiatives in the areas of: recycled paper, joinery, metalwork, mosaics, events, agricultural, culinary and restaurant, printing, flat stained glass, religious stained glass, sewing and hydraulic/ceramic tile. Approximately 300 people per month access this service.

To access one of these services, a person is referred by one of the municipality's mental health services, for example, a CAPS. After being informed of all the options for work and income generation projects and workshops, a person can then choose the initiative or activity in which they would like to participate. All participants are remunerated as a result of the production and sale of the products. The total sale value is divided among the participants according to the performance evaluation of each person. This monthly assessment is made by a group that includes the service coordinator, a monitor of the project or workshop and the individual, considering criteria such as attendance, punctuality, responsibility, initiative and creativity.

The network in Campinas reported the number of people who manage to participate in the formal job market is however, still very small. An alternative employment avenue has been developed with employment directly by *Serviço de Saude Dr. Cândido Ferreira*. As of September 2020, 34 people had gained employment through this initiative.

Cultural initiatives – Campinas

The mental health network in Campinas also has a number of collective and cross-network projects that include the participation of individuals who use mental health services, professionals and family members from different CAPS, SRTs, CECOs and beyond. Examples of initiatives include: *Rádio Maluco Beleza*, a radio programme that brings together individuals who use mental health services, family members, social projects, employees and people from the community. It is on air 24 hours a day with a variety of programmes that address different themes; *Jornal Candura*, a bimonthly publication covering news and events related to mental health services, addressing issues of social inclusion and citizenship; and *Coletivo de esportes*, a sports initiative responsible for InterCAPS, an event that brings together the CAPS of the city of Campinas and region in a football championship and celebration of the 18 May, the national day on which the civil society social movement celebrates and demands advances on psychiatric reform. *Coletivo de esportes* is also responsible for the Inclusion Cup, a weekly football championship among the CAPS in Campinas. This initiative promotes weekly meetings between employees, the individuals who use the service and family members through sports activities in mental health services and in community spaces.

Core principles and values underlying the service

Respect for legal capacity

Respect for the legal capacity of individuals who access mental health services is embedded in the principles of the community-based mental health network in Brazil. At a service level, this is reflected in person-led recovery plans, the absence of involuntary admission or treatment, proactive addressing of power imbalances and support of individuals to exercise and enjoy their legal capacity both within the service and in their communities. The Going Back Home Programme (*Volta Para Casa*) and SRTs support individuals with a history of institutionalization with a supported, person-led return to exercising their legal capacity in society.

Alternatives to coercive practices

The use of coercive practices is against the principles of the community-based mental health network in Brazil. Services instead emphasize the practice of negotiation and mediation in conflicting and challenging situations. In addressing power imbalances and recognizing an individual's own knowledge of their experiences, needs, wants, preferences, and person-led recovery plans, services develop a permanent dialogue and relationships of trust with service users, shifting service dynamics away from coercive practices. There were no reports of the use of coercive practices in NASF, CBHC, SRT or Street Outreach Teams in 2020. The occurrence of coercive practices in CAPS rare and considered an unacceptable practice by the service and its team members. The use of coercive practices (physical and chemical restraints) in general hospitals, however, was identified as being variable from hospital to hospital. This is an area that requires constant attention and efforts to change. Nevertheless, the network in Brazil illustrates the emphasis on and success of building relationships to prevent the use of coercive practices.

Community inclusion

At an individual level, a person is supported by the network to participate in their community according to their needs and preferences, guided by their person-centred recovery plan (PTS). Proportionate support is available, reflecting the needs of the individual, for examples through SRTs. The mental health network is active in the community, reflecting the collective nature of inclusion, and that it is through collective actions with people in the community that possibilities for social inclusion are created and in the process, the community and its relationships are transformed. Practices such as CAPS activities, CECOs and cultural initiatives that are open to the wider public promote community inclusion, diversity and reduced stigma. Partnerships between services and the practice of continuous care carried out between services increases people's access to and inclusion in the community across diverse areas including health, mental health, employment, sport and culture.

Participation

Strategies of collective dialogue, such as the CAPS assemblies, are actively used in the network. Users participate in the design and implementation of the service network, including network and service practices. This occurs daily through social exchanges within the services, in formal structures such as mental health forums, and also through the civil organization in the social movement for psychiatric reform.

Recovery approach

The community-based mental health network principles are consistent with the recovery approach, including promoting autonomy, social participation, community inclusion and equal rights. The use of individual person centred recovery plans (PTS) across services is consistent with the recovery approach, encouraging each individual to identify their own hopes, goals and aspirations and lead in their own recovery journey. The focus of each service and the structure of the network, in particular cross network initiatives, lend to a whole-person and holistic approach including essential recovery elements such as access to community participation, employment, education, culture and sports.

Service evaluation

Due to the size and complexity of the network in Brazil, the following is not a comprehensive description of all studies pertaining to the community-based mental health network in Brazil. This section includes evaluation data of the mental health network of different Brazilian municipalities and regions (divided into general network studies and CAPS-oriented studies). Studies are also presented from the case study municipality of Campinas. The evaluation data reviewed for the purpose of this document supports that the network can offer high quality services and support to the individual and community.

Community-based mental health network, Brazil

Several studies have evaluated the community-based mental health network in Brazil. 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) in relation to welcoming and humanizing attitudes, breaking with social isolation, establishing connections, improvement in clinical conditions, quality of life and support with mental health (86). It also reported improvement in self-confidence, emotional health, quality of sleep and the capacity to handle difficult situations. In comparing psychiatric hospitals and community-based mental health services and strategies that replaced psychiatric hospitals, community based mental health services were found to be more effective and efficient. A 2019 study demonstrated a correlation between increasing CAPS and primary health centre coverage with decreased psychiatric hospitalization rates (87). In a study of CAPS II linking with primary health care teams, quality of care increased in crisis situations in the community, preventing escalation and use of coercive practices such as police actions, use of physical force, involuntary conduct for emergencies and hospitalization (88). The role of the NASF has also been found to be effective in supporting mild and moderate mental health needs, preventing excess demand on specialist services such as CAPS, in municipalities who have clear policies and practices to support this practice (89, 90). The implementation 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 (91). Residential services such as the SRT have been found to support individuals who had experienced long term hospitalization to increase an individual's own sense of power and autonomy, to establish relationships and increase social participation (92, 93). Similar findings support the role of financial programmes such as Going Back Home to support individuals' return and life in the community after extensive periods of hospitalization (91, 94). However, studies have also identified that challenges exist in the networks, for example, the integration of services, the effectiveness of mental health actions provided by the network in supporting community based health centres (CBHCs) and capacity building of SRT caregivers to manage residents' complex demands and needs (90, 95). These studies highlight the scope for variance in the network in how well it can work together to meet the needs of the communities it serves and the importance of integration in a network infrastructure.

CAPS

Studies have identified high levels of satisfaction by both individuals who use CAPS and family members. When measuring level of satisfaction (on a scale of 1–5), a 2018 study reported a measure of 4.6. Questions relating to professional competence, needs-focused first meeting and care provided, and being treated with respect and dignity recorded the highest levels of satisfaction (96). CAPS were also found to favour the expansion of individuals' autonomy, co-responsibility in recovery, and protagonism (97, 98). Family members also reported satisfaction with the service, the quality of care and the support that they receive (99, 100).

In a prospective cohort study from 2010 with 1888 users of CAPS, the study found that CAPS practices were effective in supporting users in challenging and crisis situations *(101)*. After attending CAPS, 24% of users reported absence of crisis, 60% had crises less frequently and 70% reported less intensity. The longer the time attending the CAPS, the greater the time elapsed since the last psychiatric hospitalization. The implementation of CAPS has also been found to reduce the risk of suicide by 14% *(102)*. In a 2018 cross-sectional study, 917 CAPS users from four municipalities were interviewed. Results show that "in all cities, less than 10% of users had a psychiatric hospital admission after treatment at the CAPS was started" *(103)*.

Community-based mental health network, Campinas

Studies from Campinas have demonstrated the effectiveness of the network at both system and individual level. Long-term users of CAPS III in the city of Campinas showed a reduction in crisis occurrence, in medication use and number of psychiatric hospitalizations. Non-intensive CAPS users experienced reduced medication. Both individuals who used the service and family members reported high levels of confidence in the service at a time of crisis and in terms of psychosocial rehabilitation (104). Specific CAPS practices have also been positively received, in particular the availability and trust in the overnight accommodation facility of CAPS III and the allocation of a "reference practitioner" for all CAPS users (105, 106). In a cross-sectional study, 95% of CAPS users interviewed reported not having had any psychiatric hospitalization after starting to attend the CAPS; 73% reported seeking CAPS in a crisis situation and 0% reported seeking a psychiatric hospital. This study supports the premise of the community-based network in Campinas as a replacement to psychiatric hospitals (103). The positive integration between the mental health network and general health network was also identified as important, allowing the networks to share knowledge and experience, and allowing greater continuity of care (107).

Costs and cost comparisons

The mental health network is part of a wider health network of services and is delivered under the Unified Health System (SUS). This universal health system is financed at federal, state and municipal level, sustained through a public tax system. There is no direct cost for the population to access and use any service in the network.

Costs of the Campinas network

The annual health budget in Campinas in 2019 was approximately R\$ 1.2 billion (roughly US\$ 213 million).ⁿ The community-based mental health network was allocated 6.6% of this total budget, equivalent to R\$ 80 million (approximately US\$ 14 million). (This figure does not include the costs of mental health beds in the general hospitals, nor the wider CBHC non-mental health costs.)

This equates to a cost of approximately R\$ 67 (US\$ 12) per capita in Campinas per year (based on an approximate population of 1.2 million).

Challenges and solutions

Increasing poor health coverage

An early challenge in establishing the community-based mental health network in Campinas was the absence of a public health system to address coverage of general health, including mental health. The first steps toward overcoming this issue were taken in the 1980s when Brazil recognized and established health (and mental health) as a constitutional right with the implementation of its universal public health system (SUS) in 1988.

Challenging the predominance of the biomedical model and psychiatric hospitals

A major obstacle to establishing the community-based network in Campinas was the predominance of the biomedical model and psychiatric hospitals, leading to human rights violations, social exclusion and denial of power to people with mental health problems. The establishment of a human rights-based national mental health policy which focused on deinstitutionalization and freedom first principles and aimed at promoting continuous care at the community in all levels of health system began the process of deinstitutionalization.

Other approaches were sought at various levels and included: showcasing and promoting deinstitutionalization experiences including successes in closing psychiatric hospitals and developing community-based services; establishing a programme to continually evaluate progress towards reducing the size of psychiatric hospitals and expansion of community-based services; and further, a powerful lever of reform involved the redirecting of financing from psychiatric hospitals towards the development of community-based services using an incremental, phased approach. Finally, open dialogue and articulation of experiences from other countries helped to change mindsets and show possible paths forward.

Dissolving political resistance to deinstitutionalization

Another serious challenge faced by the network was the presence of local political resistance to deinstitutionalization and closure of psychiatric beds, at the municipality and community level. Other sectors and systems also held attitudes and practices that favoured institutionalization, including the legal system.

n Conversion as of March 2021.

A major aspect that helped overcome this barrier was the enacting of laws to guarantee the rights of people with mental health problems and establish service regulation norms to implement community-based mental health services.

Further, holding mental health conferences at national and municipal levels to encourage debates and democratize decision making amongst service users, family members and staff from the mental health network to discuss mental health policy and deinstitutionalization practices also helped address this political resistance. The network has been negotiated and debated by stakeholders at all levels of the mental health system, which created a level of buy-in and commitment. Finally, civil society movements remain active in pushing the progressiveness of the network forward.

Addressing poor workforce knowledge of human rights

Another ongoing challenge is the lack of knowledge and understanding of human rights in newly recruited professionals working in community-based mental health services. Engaging in continuous dialogue with all stakeholders including in different sectors, to address any concerns, and provide practical support to solve challenges at the local level has helped improve understanding of human rights in the mental health context. An additional effective solution has been the organizing of CAPS placements for people training in academic programmes and residency programmes that emphasize multidisciplinary approaches.

Key considerations for different contexts

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

- engaging continuously at all levels in the system, in particular with those who access mental health services, their families and civil society movements to identify the network services that are needed and wanted;
- embracing a whole person-centred approach to meet the entire range of needs of the individual (for example, mental, physical, employment, education, community participation);
- considering tiered services to meet the range of mental health needs in an appropriate setting (i.e. primary health centres through the support of NASFs able to meet low complexity needs, CAPS meeting high complexity needs); and
- establishing an overall coordinating body (CAPS and CBHC in the Brazilian context) that guide the mental health network in each area.

Additional Information and resources:

Website:

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_GIeJRWqOs8yWLDPQ/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>

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

Serviço de Saúde Dr. Candido Ferreira, Campinas, Brazil. Email: <u>contato@candido.org.br</u>



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

Action steps for setting up/transforming a network of services:

- Set up a group of different stakeholders whose expertise is crucial for setting up or transforming the network of services in your social, political and economic context. These stakeholders can include but are not limited to:
 - » policymakers and managers from health and social sectors, people with lived experience and their organizations, general health and mental health practitioners and associated organizations, legal experts, politicians, NGOs, OPDs, academic and research representatives and community gatekeepers such as local chiefs, traditional healers, leaders of faith-based organizations, carers and family members.
- Provide the opportunity for all stakeholders to thoroughly review and discuss the good practice services and networks outlined in all the technical packages to get an in-depth understanding of the respective services and networks. This is the opportunity to identify the values, principles and features you would like to see incorporated into your network given the social, political and economic context.
- Establish contact with the management/providers of the service(s) and networks that you are
 interested in to get information and advice on setting up/transforming a network in your context
 and to understand the nuances of their network. Ask specific questions about how the services and
 network operate keeping in mind the local context in which they would be developed. This can be done
 via a site visit to the good practice service/service network and/or video conference.
- Provide training and education on mental health, human rights and recovery to the groups who will be most relevant for setting up/transforming the network and individual services using WHO QualityRights face-to-face training materials (<u>https://www.who.int/publications/i/item/whoqualityrights-guidance-and-training-tools</u>) and e-training platform. Changing the attitudes and mindsets of key stakeholders is crucial to reduce potential resistance to change and to develop attitudes and practices in line with the human rights-based approach to mental health.
- Discuss and agree on the roles and responsibilities of the health and social sectors required to comprehensively address the support needs of people with mental health conditions and psychosocial disabilities that were identified in your stakeholder discussions, including but not limited to housing, employment, access to education and to adequate health services for overall health not just mental health.



Questions specific for setting up/transforming a network of services:

- What gaps have you identified in your network of services that need to be addressed (for example, in relation to the availability of crisis response services, community mental health centres, hospital-based services, community outreach services, peer support services and living support services, and in relation to how they operate in respecting rights and promoting recovery)?
- What existing community-based mental health services are you aiming to transform in your network of services (see services showcased in the other six technical packages)?
- What new community-based mental health services need to be created to fill any gaps in service provision (see for example, the services showcased in the other six technical packages)?
- Are there opportunities to build these service reforms into policies and strategies under development in the areas of mental health, general health, disability and other related areas?
- What treatments/interventions are you planning to provide through the network and within each category of service included in the network? For example:
 - » interventions explicitly related to community inclusion (see community inclusion section below)
 - » assessments of support needs and diagnosis if agreed by a person
 - » trauma informed therapy
 - » person-centred recovery planning
 - » psychotherapy, e.g. Cognitive Behavioural Therapy
 - » problem solving and behavioural activation/activity scheduling
 - » individual and group-based supportive counselling/therapy
 - » psychotropic and other medication (including prescribing medication, as well as support for withdrawing safely from medication)
 - » dialogue/meetings with families, friends and supporters (with the agreement of the person using the service)
 - » transitional support for people returning to their home and community
 - » crisis hotline phone-in
 - » peer support
 - » other.
- How will your service assess, provide for or refer people for any physical health conditions they may have?
- What additional human resources will be required (doctors including psychiatrists, general practitioners and others, psychologists, nurses, social workers, peer support workers, occupational therapists, outreach workers, community/lay workers, administrative staff, etc.) and what new skills and training will be required for them to provide quality and evidence-based service in line with human rights?

- What will be the interrelationship between all the services and supports within the network and with other services and resources in the community, including upward and downward referral systems?
- · What will be the overall coordinating mechanism for the network of services?
- What mechanism or forums will be required to support the operation of the network, in particular integration of services and consistency of principles and values across services in the network?
- What strategies and training will be put in place to realize legal capacity, non-coercive practices, participation, community inclusion and recovery orientation?^o

Legal capacity

- How will you ensure that mechanisms for supported decision making are in place in each service in the network to make sure that decisions are made based on the will and preference of the person?
- How will you ensure a consistent human rights-oriented approach to informed consent by service users in relation to treatment decisions across all services in your network?
- How will all network services ensure that people are:
 - » able to make informed decisions and choices about different options for their treatment and care; and
 - » provided with all critical information relating to medication and other treatment including on their efficacy and on any potential side effects?
- How will you ensure network services have processes in place to systematically support people to develop advance plans?
- How will you ensure network services have processes in place to respect each individual's advance plan?
- What kind of mechanisms will network services put in place to ensure that people can make a complaint if they need to?
- How will network services facilitate access to legal advice and legal representation by its users in need of this type of service, e.g. pro bono legal representation?

Non-coercive practices

- How will you ensure the systematic training of all staff on non-coercive responses and deescalation of tense and conflictual situations throughout the service network?
- Will the service network support people to write individualized plans to explore and respond to sensitivities and signs of distress?
- How will you create a "saying yes" and "can do" culture in which every effort is made to say "yes" rather than "no" in response to a request from people who are using the service, throughout the service network?

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



- How will the service network incorporate comfort rooms and response teams that operate in alignment with human rights principles?
- How will the service network incorporate human rights and recovery-oriented communitybased responses to individuals experiencing crisis or challenging situations?

Participation

- How will people with lived experience be an integral part of the team within services and the service network as staff, volunteers or consultants?
- How will people with lived experience be represented in the high-level decision-making in the different services and also at the network level?
- How will feedback be systematically collected from service users and integrated into the services of the network?
- How will the services in the network link people using the service to peer networks in the community?

Community inclusion

- How will the service network support people to find work and income generation, for example through a transitional employment programme, supported employment programme or through independent employment as appropriate?
- How will the service network facilitate access to housing services?
- How will the service network facilitate supported education and assistance in accessing community-based education opportunities and resources to continue education?
- How will the service network facilitate access to social protection benefits?
- How will the service network facilitate access to social, cultural and recreational programmes, initiatives and events?
- How will the service network support deinstitutionalization and the return of individuals back to the community, including people who have been long term residents of institutions?

Recovery

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

- Will the service network provide training and support activities regarding the human rightsbased approach in mental health to other stakeholders and in the community?
 - » Will the service network provide training and support to organizations in the community, including civil society groups?
 - » Will it provide training and support to staff of other health and social services, including non-specialized health services?
- Awareness-raising and advocacy
 - » Will the service network undertake awareness-raising on mental health and human rights, including with families, schools, employers, local organizations and other community settings?
 - » Will the service network undertake advocacy actions on mental health and human rights for the rights of people with mental health conditions and psychosocial disabilities and create positive opportunities for individuals to engage in the community with the ultimate aim of creating a community whereby individuals can live autonomously? This includes actions to reduce stigma around mental health and creating positive opportunities for community engagement.
- What actions will the service network undertake to understand the social dynamics of the local community and to map the frequent problems that most impact people's lives and mental health (for example, police violence, threats related to drug trafficking, economic hardship)?



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

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