Technical package

Supported living services for mental health

Promoting person-centred and rights-based approaches

World Health Organization

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QualityRights

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however, in all countries, whether low-, medium- or high-income, the collective response has been constrained by outdated legal and policy frameworks, and lack of resources.

The COVID-19 pandemic has further highlighted the inadequate and outdated nature of mental health systems and services worldwide.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 poor-quality care and violations of their human rights, which demands profound changes in mental health systems and service delivery.**
- **In many parts of the world examples exist of good practice, community-based mental health services that are person-centred, recovery-oriented and adhere to human rights standards.**
- **In many cases these good practice, community-based mental health services show lower costs of service provision than comparable mainstream services.**
- **Significant changes in the social sector are required to support access to education, employment, housing and social benefits for people with mental health conditions and psychosocial disabilities.**
- **It is essential to scale up networks of integrated, community-based mental health services to accomplish the changes required by the CRPD.**
- **The recommendations and concrete action steps in this guidance provide a clear roadmap for countries to achieve these aims.**

Introduction

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

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

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

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

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

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

Examples of good practice community mental health services

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

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

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

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

Significant social sector changes are also required

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

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

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

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

Scaling up mental health service networks

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

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

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

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

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

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

Key recommendations

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

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

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

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

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

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

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

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

QualityRights

What is the WHO QualityRights initiative?

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

1

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

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

2

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

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

3

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

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

4

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

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

5

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

- WHO guidance currently under development

For more information visit the WHO QualityRights website

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

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

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

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

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

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

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

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

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

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

Specifically, the technical packages:

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

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

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

How to use the documents

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

These documents are designed for:

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

A note on terminology

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

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

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

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

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

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

1.

Introduction

Supported living services promote independent living by offering accommodation or support to obtain and maintain accommodation. Sometimes support is offered for basic needs, such as food and clothing, and for varying lengths of time. Supported living services are intended for people who have no housing or are homeless, and who may also have complex, long-term mental health needs. People may require extra support to live independently, or need time away from their own home environment. For more detailed discussion on housing support please refer to Section 3 of *Guidance on community mental health services: Promoting person-centred and rights-based approaches.*

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

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

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

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

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

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

2.

Supported living services for mental health – description and analysis

2.1

Hand in Hand supported living

Georgia

Primary classification: Supported living services

Other classifications:

☐ Community mental health centre ☐ Community outreach ☐ Peer support

☐ Crisis service ☐ Hospital-based service ☐ Supported living service

Availability in different locations:

☑ Yes ☐ No

Evidence:

☐ Published literature ☑ Grey literature ☐ None

Financing:

☑ State health sector ☑ State social sector ☑ Health insurance

☐ Donor funding ☐ Out-of-pocket payment

Context

Georgia is an upper-middle income country with an economy that has grown by 4.8% on average between 2010 and 2019 *(1)*. The mental health system is still predominantly institution-based although some efforts have been made to implement a 5-year National Action Plan for the deinstitutionalization and development of community-based mental health services and support, published in 2015 *(2)*.

The most recent substantial reform in Georgia has been an amendment to the constitution and over 200 statutory laws to end guardianship and substituted decision-making for people with disabilities, including psychosocial disabilities. The legal changes require the appointment of a supporter for the person with psychosocial needs, if they require help to make decisions. This supporter can only be appointed with the consent of the person concerned; they can choose to refuse or request a change of supporter at any time. This legislative reform has yet to be fully implemented however, as many individuals have not been adequately informed about the right and professionals, including judges, have not been adequately trained to implement the reforms. Additionally, because supporters are not paid for their support, staff at various services tend to be appointed as supporters, despite not always having a meaningful connection with the people they are supposed to support.

The housing service provided by the NGO Hand in Hand has a mission to create better living conditions for people with disabilities including those with mental health, intellectual or cognitive disabilities and to support their inclusion and integration into society *(3)*. Importantly, the NGO provides independent community living options for people who have been institutionalized. The homes are part of a network of community-based services provided by Hand in Hand, which includes housing and supported living services, personal assistance, and training for families and individuals supporting people with mental health conditions and disabilities in the community.

The community homes are located in Georgia's capital Tbilisi and in the city of Gurjaani. In Tbilisi there are two psychiatric hospitals with more than 300 beds, a psychiatric ward within two general hospitals with about 60 beds, a day-care centre for people with mental health conditions and eight mobile teams providing community-based treatment services (29 mobile teams operate throughout Georgia). In Gurjaani, there are neither psychiatric hospitals nor psychiatric wards within general hospitals, however a psychiatrist provides services at the local primary health care centre. In addition, there is a relatively new mobile team composed of a psychiatrist and a nurse. All are state-funded services.

Description of the service

At launch, 10 years ago, the housing and supported living service operated by Hand in Hand provided one house with six beneficiaries. Today, 30 adults are supported to live in four different houses in Gurjaani and two houses in Tbilisi. All the houses operate in the same way. Hand in Hand will open one more home in Batumi, another city, once the COVID-19 pandemic has stabilized.

Each of the homes welcomes up to five adults who sleep in individual or double bedrooms. All residents have their own beds, as well as a designated space to store their own belongings. They can lock away and have access to these belongings whenever they want. Although the service receives funding from the state based on the number of people in the house (six people are allowed, according to the rules), Hand in Hand refuses to accept more than five people per home, because accepting more would compromise the person-centred approach, which regards each individual as an individual, and not just as a part of a group.

The State Fund of Care and Protection and Assistance of (Statutory) Victims of Human Trafficking is the agency responsible for keeping a register of those who wish to join the service, and makes the final decision concerning applications. Those wanting to move into Hand in Hand houses must complete a written application. This is a generic application form that is not specific to the Hand in Hand service. Applicants must outline the support that they would like to receive and their willingness to join the service. They may have support from any person they please to complete the application and the process is supervised by a state social worker. The application is assessed by a coordinator and manager at Hand in Hand. They consider the individual's personality, communication abilities, support needs and general compatibility with the other residents when making an admission decision.

Priority for the housing service is given to adults with mental health conditions and psychosocial disabilities who currently live in institutions, over those who do not. Applicants who are related to other Hand in Hand residents, for example children, are also given priority. The service also caters for adults raised in foster families who moved out after turning 18 years old and those who live at home but do not receive support from family or relatives. Exclusion criteria include individuals with severe cognitive disabilities, including dementia. Those with active forms of tuberculosis, syphilis, contagious skin conditions and other infectious diseases are excluded too. Due to a lack of finances and trained human resources, the housing service is not able to accept individuals with the highest support needs, such as those who require bathing, toileting, or feeding.

Should individuals decide to leave the housing service after moving in, they can either return to residential institutions, be transferred to community housing facilities which accommodate up to 24 other individuals or move into their own homes.

People living together are called a "family" *(4)*. They have chosen to live together through discussions with each potential housemate and the coordinator of the service, who has information about their desires, wishes and personalities. Most of the individuals have lived in institutions before moving in, so it is quite common for them to know potential housemates already. Individuals can visit the houses before choosing to move in, to meet other potential housemates with the residents' agreement. Housing residents are free to move out or to change house at any point if that is their wish. Families can be composed of people of different ages and sex. Parents and their children can live together regardless of ability or disability if this does not compromise the child's best interests, as assessed by a state social worker.

The environment is conducive to independent living: residents engage in daily activities of their choice, especially those that develop or maintain autonomy. Inclusion in the community is encouraged and supported. Residents, "prepare food, take care of the house and garden, buy household products, contact and interact with neighbours, participate in hobbies, [and] attend various cultural events."*(5)*

Each resident also participates actively in the creation, development and review of their own support plans. Hand in Hand assistants support individuals in the implementation of that plan using the MAPS or PATH method depending on the person's needs and wishes *(6)*, *(7)*. The MAPS tool contains general goals and wishes of the person, whereas the PATH tool provides concrete strategies and actions to be implemented to achieve identified goals. During a first stage of discussions, MAPS are more applicable and when concrete goals are identified, the PATHS tool tends to be used. These plans are developed by the individual together with an assistant, the coordinator and anybody else the resident invites to participate.

Each house is assigned a team comprising around 3.5 Hand in Hand assistants in total. The teams work in 24-hour shifts so that an assistant is present during the day and night. The level of support provided is flexible to meet and adapt to the evolving needs and wishes of each resident. For instance, when a person requires more care and support, intensive medical interventions or help with personal hygiene, an additional assistant may be involved. It is common for the level of support to decrease over time. For example, residents of the first house developed by Hand in Hand in 2011, have a much higher level of independence than residents of other houses.

The recruitment process for Hand in Hand staff consists of interviews, training and practice. There are no specific requirements in terms of educational or professional background, but applicants are required to pass a training course developed by Hand in Hand in collaboration with the Ministry of Health and Social Affairs. The training comprises six modules, addressing the following topics: forms and approaches of care in long-term care facilities; the benefits of individualized recovery-oriented care; managing conflicts and agitation; active support and support levels; sex and disability; and management of service which includes funding, administration, quality assurance, standards, monitoring. The modules which are taught over a period of six days (five hours per day) have a strong emphasis on the knowledge and skills necessary to ensure that services provided are based on the person's rights, and promote a dignified and independent life *(4)*.

Hand in Hand has recruited two service managers, a coordinator, 18 assistants, a director, a psychologist, a financial manager as well as a handyman. Service managers organize and manage the work and activities delivered by the staff working in each community home. The manager based in Tbilisi is currently responsible for two homes, and the one in Gurjaani is responsible for four. They develop yearly work plans and schedules for assistants and others; organize and monitor the inventory of households and make sure that residents' needs are being met; organize training and supervision of staff working directly with the beneficiaries; coordinate the reception and exit of service users; cooperate with state entities and the local communities; and are responsible for the leasing of the property with beneficiaries.

The coordinator, based at the NGO office in Tbilisi, maintains ongoing contact with residents via telephone or home visits. As with service managers, the coordinator tries to avoid interfering with the daily running of the houses. The coordinator's role is to store information about residents, including their social, health, and support needs, as well as personalities and interests safely; to consult assistants about individual residents and their case management when needed and; to support individuals in drafting, implementing and updating their person-centred support plans. In addition, coordinators are responsible for supporting individuals with their healthcare and other needs. For example, they may help to organize visits to the doctor, accompany people to appointments, support people with any treatment needs they may have and advocate for the individual's rights if they have been violated. Coordinators support people to build a circle of support and promote their social inclusion. Finally, they also contribute to the development of the service as a whole.

Assistants support individuals to achieve the outcomes set out in their personal plans. They can also be the designated supporters of some Hand in Hand residents but only if they have a bond with the individual. The choice of supporter is the individual's. In addition, assistants help individuals in the home with daily activities using the principles of Active Support *(8)*. These principles ensure that people receive the right range and level of support to be fully involved in their own lives and successful. For instance, assistants can support individuals in developing and maintaining their support network, with practical skills and work activities, and personal development in accordance with their plan. The support can be quite varied. It may involve facilitating appointments with psychologists, social workers, occupational therapists and other service providers. The assistant might help people to participate in sport or leisure activities, accompany people during outdoor activities, this facilitate relationships with co-residents, or assist with household chores, such as cleaning, laundry, and cooking. Assistants, importantly, also support people to defend their rights and in managing their personal affairs *(4)*. While residents choose what and when to eat, assistants pay attention to special dietary requirements. Their job also entails communicating changes in residents' health and wellbeing if something needs to be addressed collectively. They work together with the coordinator and other members of the individual's support network.

Managing the budget is the responsibility of the director, service managers and the financial manager. The funding, which is transferred to the organization by the state, is paid according to the number of beneficiaries and amounts to 30 Georgian lari or about US$ 9[b] per beneficiary per day. The houses do not have separate budgets. The service distributes the funds, paying for salaries, food, utilities and all other needs, to meet state standards and the needs of residents.

Core principles and values underlying the service

Respect for legal capacity

Instead of controlling or trying to "fix" people with mental health conditions and psychosocial disabilities, the service seeks cooperation with residents to develop the skills they need to get on with and participate in all areas of their lives. All decisions, from interactions with other residents and daily life, to care and treatment, are discussed and agreed. In this way, the will and preferences of the person are respected and residents use the services in a way that is agreeable to them.

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[b] Conversion as of March 2021.

To ensure the respect and promotion of legal capacity in the service, help is provided in accordance with the principles of Active Support *(9)*. Supported living staff are trained to ensure beneficiaries are empowered with the tools to make their own decisions and to live autonomous lives. This includes the opportunity to make choices and decisions regarding where, with whom, and how to live. All beneficiaries can decide what they want to eat and when, although residents will usually decide together, as in a family setting. If someone wants a different meal from others, that individual can prepare something else. Beneficiaries have access to all their documentation too. It is stored safely in the house where they live. Personal information is kept confidential.

Finally, residents' support networks are strengthened during their stay, and included in recovery journeys. For example, they indicate who they want included in the development of individual support plans: a friend, a relative, a priest, a neighbour, another assistant, the director, or anybody else they trust. The service ensures those named by the individual can participate. The person is always free to change their wishes anytime, regarding who is involved. However, the service will always take the time to reflect with the person on the reasons for this change. Moreover, families and friends also have access to training sessions, and are provided with information on how to best support individuals with mental health conditions and psychosocial, intellectual and cognitive disabilities as well as how to promote a dignified and independent life.

Non-coercive practices

Hand in Hand avoids the use of force and coercion. No action against the clients' will or agreement is undertaken in the Hand in Hand houses, including forced medication or treatment. In situations where a person's well-being has become negatively impacted, staff go to great lengths to find acceptable ways to support the person, sometimes together with a trusted member of their circle of support. In most cases this has been a successful approach for both the staff and resident, however in rare situations people have been hospitalized against their will.

Staff members are trained to know and identify triggers, sensitivities and reasons clients may exhibit challenging behaviour. As such they seek to manage and prevent an escalation. Staff members undergo systematic training in non-coercive measures and de-escalation techniques every two to three years. In a 2018 monitoring report, interviews with service residents in one community home revealed that there were no cases of violence against beneficiaries during the service delivery process *(10)*. If such a situation were to arise, the administration would discuss the specific situation, and report the incident in a file with the decisions undertaken.

Community inclusion

Hand in Hand services are geared towards promoting inclusion in the community. Ani Mgeladze, an intern in one of the Hand in Hand community homes, describes her experience of supporting Kristo, a resident. She said, "I visit Kristo every Monday, walk her to work, she's very eager to work [...] I help her socialize. I take her to Dadari (a Georgian toy company) *(11)*, where she works on wood, she polishes the wood, makes toys. [...] I try to back her in everything." *(12)*

Activities in the community are encouraged and range from attending sport events, the cinema, religious rituals, or going out to eat. One of the beneficiaries is a member of the Azadaki Garden integrated theatre and participates in plays *(10)*. Each year, beneficiaries together with assistants, can go on holiday to resort sites in Georgia for 10–14 days.

Half the residents of Hand in Hand have work because of the support provided to find and maintain employment *(12)*. During the last three years several beneficiaries from multiple homes have been employed by Babale and Kodala, social enterprises which manufacture toys and household items from wood and natural products. Individuals are also supported to find work in the community directly. One resident, Tamara Bitaeva, works as a janitor in a hospital. She said, "Everyone respects me a lot, and loves me. In the morning, when I get to work, everyone asks me, 'how are you Tamara?' [...] It's very good. I have monthly salary, every month, and I save it in the bank. I'm collecting money to buy a house, and I'm very happy." Another beneficiary is working with an NGO on a project to help implement Georgia's new legal capacity rules. He is a member of a peer-support group and will be on the Board of a new users' and survivors' organization in Georgia.

Finally, Hand in Hand supports individuals to build connections with the community through a communication strategy that has increased visibility at the local and national level. This has included TV stories as well as participation in media publications or articles published by other NGOs. Both staff and residents are included in all steps of the process; that includes drafting articles, conducting interviews, and appearing on talk shows. In addition, the NGO supports individuals in creating positive relationships with the surrounding community and it is common for residents to invite neighbours to visit and attend birthday parties and other social events. As such, there is general support and community acceptance of the Hand in Hand houses.

Participation

Beneficiaries are able to maintain contact with the residents from other houses. Residents at Hand in Hand houses can also participate in decision-making processes via feedback and complaints procedures built into the service. A 2018 monitoring report published by the government *(10)* indicates that the beneficiaries evaluated are aware and informed about how to use feedback and complaints procedures. They feel comfortable expressing their wishes, complaints or concerns freely to assistants or directly to members of the administration including the coordinator, director or managers. Beneficiaries' comments, wishes and opinions are reviewed by service staff in weekly meetings and improvements are made based on this feedback. Additionally, the telephone numbers of both the State Monitoring Unit and of the Ombudsman office are attached to the wall of each house, so residents can seek independent support when making complaints.

To date, neither individuals with mental health conditions and psychosocial disabilities nor former Hand in Hand residents have been hired as staff, volunteers or interns at the NGO. However, residents are regularly involved in discussions about the decisions regarding the service organization and development – usually once or twice a month or as often as needed. Consultations might also occur in online meetings.

Recovery Approach

The community homes at Hand in Hand work in accordance with the recovery approach. Individuals are empowered to regain control of their lives with the support they receive. The service helps them transition from institutions to the community and promotes independent living throughout. Each resident is an active participant in their own recovery by making daily choices about how to live and learning how to live collectively in a safe environment. The service also ensures that people develop and regularly update their own person-centred plans. Therefore, residents are encouraged to set goals that correspond to their own aspirations and wishes. Drafting these plans encourages individuals to think through and document their hopes, goals, what they want to avoid and achieve in life, as well as strategies to avoid fears and move closer to their dreams.

Individuals are supported to take up and develop any activity or skills that make their lives more meaningful and satisfying. Activities often help them find a role in society. For example, Rusudan Khardzeishvili, one resident *(12)* explains, “I wanted to have hens. Now I have hens and a vegetable garden and I take care of the family [other household residents]. I let the hens out in the morning, then I clean up, put some more grass, in the evening I put them inside and close the door.” The founder of the organization said, “[Residents] are much better than we are at identifying their role in the community.” This attitude empowers residents and helps them have a sense of personal responsibility, identity and meaning.

The housing service also promotes a recovery approach by promoting positive risk-taking. It focuses on peoples’ strengths, and by encouraging them to find an area, hobby or talent they are interested in. Hand in Hand’s founder *(3)* said, “I think we have to give people a chance to make their own mistakes, and learn from them. We all make mistakes, but only people with disabilities are treated differently, with their mistakes often being credited to their disability. Of course, we’re here [Hand in Hand] to assist them even when they make mistakes. We have to help them to acquire the necessary skills for independent living.”

Service evaluation

Hand in Hand conducted an informal survey in 2015 by collecting information from 15 Hand in Hand house residents ([Dateshidze A], [NGO - Hand in Hand], personal communication, [2020]). The survey questions asked who makes decisions on a number of daily life choices (examples included going for a walk, how they can spend their money and whether they should save it, what kind of haircut they can have, when they take a bath, or when they can eat). Responses show that individuals are the main decision makers. All respondents stated that they decided what clothes to wear, when they needed to clean their room and house, when they went to sleep or used their mobile phone. Similarly, everyone stated that they decided who could come to visit them and when they went to visit their families and friends.

As part of the Georgian government’s Programme for Social Rehabilitation and Child Care, Hand in Hand has been monitored and evaluated for compliance with service standards. The results from the 2018 evaluation report *(10)*, focusing on one Tbilisi house was positive, demonstrating that the house had an adequate standard of living with a hygienic, sanitary and comfortable environment. Individuals had access to a variety of services in the community, participated in entertaining and stimulating activities in the community and were able to develop key skills for independent living; these included organization, cleaning, cooking, hygiene, using household objects, going to shops, pharmacies and using money.

Both survey information collected by Hand in Hand, as well as government monitoring reports are valuable in building an understanding of the functioning and benefits of the service. Additionally, there is plenty of positive feedback from service users from different houses on the quality of the service provided and its impact on their lives. George Gviniashvili, one resident said, “My life is going really well. I like living here and I don’t want to go anywhere else. I want to stay because I’ve learned so many things here, and I have many friends and people around me.” *(12)*

Costs and cost comparisons

The Hand in Hand community has a yearly budget of about 300,000 Georgian lari(₾) (approximately US$ 90,361)[c] of which salaries represent about 60%. The average daily cost per resident of the home and support service in 2019 was ₾33 (approximately US$ 10)[c]. The comparative cost of psychiatric institutions was ₾29 (approximately US$ 9)[c], not including many additional administrative costs.

Overall, the state funds over 80% of Hand in Hand's expenses. The Ministry of Labour, Health and Social Affairs provides funds every month (based on ₾30, per person per day) according to how many persons are in service in the current month. In addition, the Open Society Foundation Georgia, as well as other donors, charities and Hand in Hand's small social enterprises provide the remaining 20%. Donations of furniture, home appliances, and books are also received. A famous Georgian writer and pianist even held a concert which enabled the NGO to purchase a house. Additionally, in Gurjaani, residents supplement their incomes by running small businesses in farming and producing honey and sweets. Some of the residents draw, knit, make jewellery, or other crafts. The NGO supports residents to sell their products and organize exhibitions or workshops if they wish to do so. Joint decisions are made on how the money earned will be used and distributed.

A co-financing system is also in place, whereby residents of the houses pay a symbolic monthly rent of ₾15 (about US$ 4.52) in Gurjaani, and ₾40 (about US$ 12) in Tbilisi. This creates a sense of responsibility and ownership and empowers beneficiaries to have higher standards and expectations of the service provided. Although there are no strict rules or obligations for co-payment *(12)*, it is based on an agreement which is signed by the beneficiary and service administration. Because individuals using the community homes are classed as individuals with disabilities, they are eligible for basic state health insurance as well as a monthly state disability pension amounting to ₾140-250 (approximately US$ 42-75 respectively) based on diagnosis. This quantity more than covers the co-payment amount. Some people also have access to other sources of funding from specific state programmes.

Challenges and solutions

Overcoming financial challenges

Securing the finance and other resources needed to start and continue the service was a major challenge due to insufficient state funding of the service compounded by high national inflation. The funding gap led to loss of qualified staff; indeed, it was difficult to maintain the quality of the service in the face of these financial and staffing problems.

Obtaining a house to locate the service and securing start-up funding from a donor were critical in getting the project off the ground therefore. Funding from the main donor was agreed for a number of years at a time and key to the stability of the service. Diverse sources of funding have been secured too, and there are ongoing efforts to maintain this. Funding now comes from the local municipality; the selling of handmade products, fruit and vegetables from the homes themselves and from charity fund-raising events.

Another way Hand in Hand secured funding was to progressively anchor itself in the mental health system of Georgia. It convinced a growing number of government officials and people working with individuals with mental health conditions and psychosocial disabilities of the importance of deinstitutionalization

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[c] Conversion as of March 2021.

and community-based mental healthcare services. In return it was recognized as one of the Ministry of Labour, Health and Social Affairs' financed social programmes in 2014. More recently, the government's support was illustrated by a substantial increase in government funding for Hand in Hand residents; in 2018 it increased from 16 GeL (US$ 4.82) to 30 GeL (US$ 9.03) per person per day *(12)*.

Overcoming stigma and building stakeholder commitment

A major challenge in Georgia was scepticism about the feasibility and cost-effectiveness of such a project around the country and within state agencies. Widespread and deeply rooted stigma around mental health conditions in the country contributed to the level of scepticism.

One solution employed by Hand in Hand was to identify allies in state agencies and NGOs. Finding those who shared the same values and wanted to support a new service working in this way was important. Additionally, working with decision-makers to inform them, change attitudes and revise regulations was vital too. Active advocacy work was carried out on the basis of a clear vision and strategy. The service actively promoted stories able to convey who benefited from the service and just how much people's lives had been transformed. This broke barriers.

Tackling staff retention

One of the major barriers was the difficulty in recruiting qualified people. Financial limitations meant staff were inadequately remunerated for their work. Assistants are paid just 500 GeL (approximately US$ 162), before 20% tax, whereas the average salary among the employed population in Georgia is about 1200 GeL.

As a solution, the service sought to recruit people with a generous nature, motivated by the idea of supporting people with mental health conditions and psychosocial disabilities to achieve independence and lead a dignified and meaningful life. Attention to the quality of care received by each person who came to the service was key to the success of the work.

The service worked with experienced international mentors too. This allowed the service to develop a core group of well-trained and professional staff. In turn, these staff have been able to develop training modules, so that there is good quality teaching in place for new recruits. Additionally, it established processes to enrol people to receive the service, train staff and commence delivery of the service.

Key considerations for different contexts

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

- maintaining the motivation and having a clear vision and strategy to get a service off the ground and sustain it;
- investing time and effort in staff, as well as the people using the service, is crucial to keeping high standards of care;
- advocating with state officials and the wider society alongside organizations that defend human rights is important;
- ensuring active advocacy work builds on a clear vision and strategy;
- evaluating functional outcomes, such as quality of life and levels of independent living;

- demonstrating results of the service. This provides good practice for governments and encourages them to change policies in a positive direction; and
- actively promoting the service, the stories of people who have benefited from the service.

Additional information and resources:

Website:
www.handinhand.ge

Videos:
Community For All, Georgia - Mental Health Initiative
https://vimeopro.com/gralfilm/include/video/336759271

Contact:
Amiran Dateshidze, Founder, Hand in Hand, Georgia,
Email: adateshidzw@yahoo.com
Maia Shishniashvili, Founder, Hand in Hand, Georgia,
Email: maia.shishnia@gmail.com

2.2

Home Again

Chennai, India

Primary classification: : Supported living services

Other classifications:

☐ Community mental health centre ☐ Community outreach ☐ Peer support

☐ Crisis service ☐ Hospital-based service ☐ Supported living service

Availability in different locations:

☑ Yes ☐ No

Evidence:

☑ Published literature ☑ Grey literature ☐ None

Financing:

☑ State health sector ☑ State social sector ☐ Health insurance

☑ Donor funding ☐ Out-of-pocket payment ☑ Other

Context

Home Again provides housing and supportive service options for people with mental health conditions and psychosocial disabilities in India. The service was created in 2015 by The Banyan, a non-profit organization that was founded to address the needs of people with severe mental health conditions and psychosocial disabilities living in homelessness or poverty *(13)*. The Banyan has now served a million people to date and has rural and urban operations in three states: Tamil Nadu, Kerala, and Maharashtra.

Firmly grounded in principles of social justice, inclusive development and equity, The Banyan offers three types of service for those who live on the margins. Firstly, crisis support and recovery services are offered to homeless women with mental health conditions and psychosocial disabilities, through Emergency Care and Recovery Centres (ECRCs). The ECRCs are located in Tamil Nadu's Chennai and Chengalpet districts. Another ECRC has opened in Guruvayur, Kerala.

Secondly, clinic-based well-being services are provided through NALAM, a community mental health programme. Here outpatient medical and social care are offered.

Finally, there are several long-term community-based services available through The Banyan's Inclusive Living options[d]. Home Again is one such service. Others include a Clustered Group Home (CGH) service, located at the Banyan Academy of Leadership in Mental Health (BALM) in Kovalam *(14)* (approximately 30 km from Chennai) and independent living or hostel Services. In 2017 The Banyan partnered with Ashadeep, a mental health organization to deliver Home Again in Assam state too. Ashadeep's programme accepts people who have been in long-term institutional care; with untraceable addresses; requiring long-term care who have been rejected by their families; or do not want to return home.

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[d] In Tamil Nadu: the service operates in two neighbourhoods in Chennai, in Kovandakurichi (near Trichy) and in several villages in Thiruporur block. In Kerala: it operates in Mallappuram, Kozhikode, Palakkad and Thrissur. In Maharashtra: it operates in In Navi Mumbai and Ratnagiri.

Home Again was inspired by the belief that social mixing and access to experiences are essential, not just for recovery from distress or trauma, but to live a good life. In line with this principle, the belief is that a family or home-like environment should be made available unconditionally. Importantly, services are provided in the absence of traditional views on whether individuals are, "fit for discharge" or require, "community readiness" assessments. Instead, what is valued at Home Again, is neurodiversity, social mixing and participation.

Description of the service

Home Again is a housing service for people with complex long-term mental health needs, who are living in poverty and can benefit from long-term support. In addition to housing, the service provides a range of support to enable individuals to experience life in regular neighbourhoods and participate socially, economically and politically where and when possible. Home Again was initiated in 2015.

Typically, people transition from institutionalized care within hospitals to independent or semi-independent living in the community. The broad aim of the service is to improve community inclusion, psychological health, quality of life and social mobility using housing and supportive services as the primary intervention. Therefore, using this service gives residents a choice, a sense of agency, work, leisure, varied forms of recreation and social interaction in the community *(15)*.

Home Again assists people to take up employment opportunities and government welfare entitlements, and participate in social groups, get-togethers, festivals and other recreational activities. It provides healthcare access support and case management (including assessments to determine the person's medical and psychosocial support needs, individual goal-setting and care plans). There is on-site personal assistance focused on supporting daily activities. Primary therapeutic approaches are used from Open Dialogue (for more information *see Mental health crisis services Promoting person-centred and rights-based approaches*), Behavioural Activation, including Problem-Solving Therapy, to other trauma-informed approaches *(16)*.

The philosophy that drives Home Again is that symbols of home, family and participation help to improve individuals' social and mental health. It says these symbols provide a unique form of comfort, meaning and hope, particularly to individuals in distress and deprived of ontological security. Stability derived from a house of one's own, according to Home Again, inspires a sense of independence and promotes a sense of engagement; individuals are more likely to seek newer experiences that are vital to growth and life.

The Banyan rents multiple houses in the community that service users may choose to live in. There are no exclusion criteria. However, state-run mental hospitals in Kerala do not allow the service to work with people with a history of extreme violence.

In 2019, 245 people were using the service in 50 houses. This number includes six homes (five for women and one for men), supported by Ashadeep in Assam. To support 60 people, four staff members – a programme manager, two case managers, and a nurse – are required, as well as 15-24 personal assistants, depending on the level of support required. The staff are distributed among several houses *(17)*.

Homes are rented, each with 4–5 people living together in affinity groups. They are located across several urban or rural neighbourhoods in the vicinity of essential services, such as shops, cultural hotspots and health care. Home Again accommodation typically has two bedrooms, a kitchen, a living room and two bathrooms. Accommodation must have adequate ventilation, sewage and plumbing. Cultural specificity and social appropriateness are essential when identifying houses, neighbourhoods and developing care plans. A mix of both independent houses and apartments, including those in gated communities, are available.

It is of paramount importance that each individual develops or builds on their own unique and collective identity, according to Home Again. For example, a resident may prefer to sleep on a mat on the floor – because it feels pleasurable and evokes memories of and nostalgia for the comforts of home. This option is more important than a bed that may be considered more comfortable and an essential right by others. If a simple meal made from rice, water, and chillies, or onions with buttermilk is preferred to what may be considered a wholesome meal, then that decision is respected. The individual's culture, expressed need and identity, is valued.

Entry into the service is offered to people who have lived for a year or more in any of The Banyan's facilities or certain state-run psychiatric hospitals (there are three in Kerala and one in Ratnagiri, Maharashtra) and who have no options for return to the community. Home Again is voluntary and based on choice. No one is forced to use the service. If offered the possibility of moving into a Home Again house the person can choose whether they wish to live in an urban or rural environment, and with whom. The Banyan does not set rigid house rules; rather people are encouraged to create their own routines and ways of living together, including boundaries and limits. So far, this has always happened organically, over a period of time. Conflicts sometimes arise however. When situations escalate, the case manager or personal assistant mediates and helps to negotiate the best way forward. Occasionally, residents express a desire to return to their original environment and support circle, even if it is within an institution. Service users' decisions are respected.

People using the service choose their own routines and determine their level of engagement within the homes. Mobility is not restricted. Visitors are welcome, and often neighbours visit. The space is a home that can be associated with leisure, fun, and spontaneity, even as it encourages people to build relationships, cooperate with housework, and manage and resolve conflicts. As in any other home, people who live there expect privacy *(15)*. No one identity is valued more or less than another; an individual in the service could experience severe disability in some areas but be a great cook and open to social mixing.

Each home is assigned personal assistants based on the support needs assessed by staff, using a technique called the Social Functioning Instrument. This covers 10 domains ranging from self-care and home management to cultural and spiritual pursuits. Some homes have no staff, while others have staff who visit for just a few hours a day. Some have sleep-in staff during the night only, while others may be staffed full-time; here the accommodation tends to have access to staff quarters and personal assistants work on a shift basis. As people become more comfortable in their spaces and routines, typically by about 18 months, the staffing level is decreased *(17)*.

Personal assistants are paid a salary and entitled to various work-related benefits. They are recruited from local communities and are motivated by their passion to support people in the recovery process. Personal assistants are predominantly from rural backgrounds, with no formal education in mental health.

The Banyan has encouraged people who have used, or are continuing to use, the Home Again service to become personal assistants themselves. The view is that lived experience lends itself to the process of caring and forming close relationships. By working as personal assistants, it is thought that individuals gain in confidence through financial independence and self-reliance. More importantly, the ability to care for another and better other peoples' lives improves self-image and self-perceptions, ultimately contributing to the recovery process.

The personal assistant must understand and help people identify experiences and goals they want for their lives; collaboratively assess support needs; help to learn or reconnect with skills and knowledge; and to offer opportunities and resources to the people they assist *(17)*. Personal assistants support individuals to care for themselves and help manage their own homes and social and economic transactions. They also work individually with each person using the service to plan their living experiences. They can help to connect people with employment opportunities and health services and to form social connections *(15)*.

Personal assistants undergo a week-long induction programme, drawn from a curriculum co-developed with the University of Pennsylvania, especially for this cadre. The programme, which prioritizes experienced-based learning, covers three areas: structure, process and protocols. Structure covers the intervention, who it is best suited to, and the values and ethos behind it. Process refers to the implementation of the service, for example how to identify a house, how to sensitize the clients to the idea of moving out of an institution, and how a household spends its day. Protocols are the guidelines that require implementation across all The Banyan's services, for example, guiding access to case records and the use or dissemination of information (including photos) from the service. On-the-job training is provided along with participation in weekly review meetings for guidance and supervision. These are an essential source of feedback for continued learning and growth.

The Banyan's Home Again staff communicate with beneficiaries primarily through personal assistants who follow up on collaboratively developed individualized care plans focused on values of respectful care, interdependence, exercising choice, and agency. Consent and confidentiality are continually emphasized. Any use of information for purposes other than service delivery, with an assigned clinical team, requires consent from the client. When people enrol into the service they fill out a consent form indicating how they want their information to be used. Any breaches to confidentiality by staff members is taken very seriously. If a person using the service feels that their trust has been broken they can opt for a different personal assistant to work with.

All people who use the service have direct access to senior mental health professionals and the Mental Health Commission, which evaluates The Banyan's services, by telephone. Case managers, who have a Master's in social work, make weekly visits too. Nurses visit homes weekly to check on the health issues of service users *(16)*.

Core principles and values underlying the service

Respect for Legal capacity

Access to Home Again is totally voluntary. It is one of several services provided by The Banyan that individuals can choose from; the service is offered to all individuals, regardless of their health status and ability to live independently. During their time in Home Again accommodation, people are free to do whatever they wish in terms of leisure, work or community interaction.

Most people using Home Again are supported to write an advance directive, which is revisited annually. In addition, staff are expected, and are constantly reminded, to understand the wishes of the people using the service; to discover the individual's preferences, hopes and dreams, explore experiences the individual may wish to recreate or reconnect with, and offer support towards these personal goals. The staff are therefore strongly oriented towards fulfilling the wishes of the person, rather than imposing their own ideas and routines. Through training, staff learn to question their own value systems and perspectives deeply, to understand how these might interfere with the service. It is Home Again policy that people using the service must be the primary agents of their own lives and the service is led by these individuals' preferences.

The organization and design of Home Again fosters the creation of support circles; these are not forced, but rather emerge organically and can involve housemates, staff and neighbours. These relationships also help to improve communication with people with high support needs and to understand their preferences.

Non-coercive practices

People using the service may leave and enter the home whenever they wish. Regular discussions are organised with service users and staff, are based on the Open Dialogue approach to ensure that any unintentional explicit or implicit coercion is addressed. The approaches highlight simple examples, such as the choice of television programme and who is in charge of the remote control in the house. Case managers are receiving training in Open Dialogue techniques.

In the rare event that a crisis requires referral to an inpatient service, the person is offered the opportunity to go to one of The Banyan's ECRS facilities. Seclusion and restraint are never used in these services.

Home Again policy stipulates that any person can choose whether to take prescribed medication; those who refuse medication are never forced or coerced into taking it. Rather, Open Dialogue strategies are used to explore and understand perspectives and the reasons for a person's choices. The person may blame the medication for their problems or experience side-effects which interfere significantly with their quality of life. In these cases, alternatives are explored and where appropriate, information on a safe form of medication reduction can be given. With the person's consent, a discussion with peers can be organized to talk about side-effects and ways to cope with them. Home Again recognizes that many people (including those on medication) can live with their symptoms with no significant disruption or distress in their lives.

If interpersonal conflicts arise in the house, collaborative conflict resolution is attempted with the reiteration of messages that set boundaries, using Open Dialogue strategies. Staff are trained in and expected to build supportive relationships of mutual trust with service users. They are also trained to create a safe space; actively listen; make clear that they are there to support; offer meaningful, reassuring responses; understand and validate the experiences and use articulated reasoning with service users; and finally, to repeat safe messages. Professional staff and peers with greater experience are always available for support, by telephone or in person, to help with this process.

Home Again has had an impact on coercive caste and gender-based practices. While choice of housing is usually based on affinity groups, different castes have lived together, and there has been a slow evolution to mixed class groups. Home Again also represents the rarer model of woman-led households, where women live independently without the support of men.

Community inclusion

The Home Again programme was initiated after The Banyan's service users requested a long-term care service that could also support people to reintegrate into society. This service aims to promote the inclusion of people with psychosocial disabilities into the "socio-economic fabric of the community through strong connections with stakeholders in areas of local governance, employment, entitlements, and social activity" *(15)*.

Home Again promotes various ways to connect with the community, from inviting neighbours to the house or paying visits to neighbours' houses, to adopting companion animals, establishing work placements in the community and helping individuals find and use the neighbourhood's key resources. It helps with enrolment into educational courses; shopping; access to leisure and recreational spaces and places of worship; banking access; voter rights and other entitlements; participating in civic engagement activities such as community meetings, and in creating self-help group meetings. Its staff help residents learn how to use transport and modern communications technology too *(18)*.

Relationships are fostered within the home as well as outside it. Whether relationships remain limited to day-to-day interactions with, say, the local shopkeeper, the milk delivery person or bank assistant, or become deeper, sustained friendships, depends very much on the neighbourhood setting. For example, rural neighbourhoods have a greater sense of cohesion and social exchange and therefore foster closer relationships than more diffuse, urban settings. That is why Home Again actively encourages people to plan or attend social get-togethers, and take part in regular social routines, such as evening sit-outs on the veranda, attending a church service or leading a namaz *(18)*. Sometimes the residents develop intimate relationships. There are no restrictions when consensual adults live together, neither is there a bias in favour of heteronormative relationships. Recently, a couple from the Home Again programme in Kerala, fell in love and married in 2020. Today they live independently in a rented house and run their own social enterprise.

Service users often begin to consider their own families more actively after they have moved into a Home Again house. In such instances, every effort is made to trace families and, depending on the situation and service user preference, they may return to live with their families *(18, 19)*.

Participation

The Banyan has a Mental Health Commission (MHC) that is led by people with lived experience. The commission evaluates and offers feedback on the Home Again service. Anyone is invited to participate in commission meetings. An external Human Rights (HR) committee, made up of people who use mental health services, disability activists, lawyers and carers of people with mental health conditions, is also available. The HR visits The Banyan's offices and facilities every month at a scheduled date and time. Home Again facilities are informed of these visits and anyone is free to speak to the committee. Alternatively, members of the committee can be contacted by telephone. People can offer feedback to either the MHC and HR on an anonymous basis. Both were set up by The Banyan and operate across all services, including Home Again sites.

Input from people who use the service is incorporated into an audit collated by the MHC and based on quarterly visits and interviews. Weekly visits are conducted by case managers who also record feedback; urgent issues are escalated immediately while others are raised for further discussion. In addition, a monthly focus group discussion with service users is held. Home Again's monthly Pulse meeting reviews the main activities, receives feedback from the MHC and HR committee, considers challenges and decides on next steps to improve services *(16)*.

People with lived experience, including those with a history of homelessness, represent a quarter of the staff, senior management team and the board. Both founders have received a mental health diagnosis, and a key member of the board has experienced both homelessness and mental health issues. The aim is to achieve a minimum of 50% representation over the next few years.

Many personal assistants have experienced distress too. They may have dropped out of higher education to mitigate against family poverty by working. Such experiences are a valuable source of lived experience that can improve their support for service users *(16)*. The service also works to link people with local peer networks in the community.

Recovery Approach

Home Again's services are tailored to the unique needs of the people using the service. Case management involves the use of detailed assessments to determine the person's medical and psychosocial support requirements and personalized care plans *(16)*. Personal assistants support service users in a dynamic, adaptive and responsive manner to cater to their personal needs. To protect the autonomy and independence of service users, Home Again has developed a standard code of practice. This ensures that service users are supported effectively, regardless of a staff member's personal ideological and philosophical orientation.

People at Home Again are supported to develop recovery plans as a way to consider and document their hopes, goals, struggles and successes, strategies for dealing with tense situations, and keeping well. Recovery plans are ongoing and evolving. Each month, an Open Dialogue-based session is facilitated where individual goals, experiences and needs are collaboratively assessed and follow-up actions are documented. Validating the narratives of service users is important, so these sessions recognize challenges faced by individuals, and collaboratively identify meaningful strategies to reach their goals.

Service evaluation

Home Again conducted a quasi-experimental, matched-control study of people using The Banyan's services for more than 12 months from 2014–2016. The survey included one urban community in Chennai and three rural communities south of Chennai. The experiences of 53 people who had chosen Home Again housing was evaluated and compared to 60 people who remained in The Banyan's institutional facilities – regarded as the care-as-usual group. Six-monthly outcome measures were collected on community functioning, disability, psychological health and quality of life *(15)*, using different questionnaires and scales, for 18 months *(16)*. Significant improvements were found for the parameter community functioning in the Home Again group, compared with the care-as-usual group, after six months and 18 months.

Many of the people using Home Again have reported positive experiences of using the service. A recent article in an Indian magazine, *The Week*, highlighted how two women who benefited from Home Again have since become role models for other women in the community *(17)*.

In addition, data was collected from the ethnographic observations of personal assistants and interviews carried out as part of earlier Home Again trials. Within this data, several Home Again residents commented on their experiences ([Rohatgi P], [The Banyan], unpublished data, [2015]).

One said, "Now I feel like how I did in my younger years, before I became ill, at home, going to school, coming back home, cooking[...]I feel very delighted[...]This is good, everyone will be happy, they will feel peaceful that they are at home."

Another said, "After a long while, it feels like home; the walls, the kitchen, the garden, the temple in the village, the smells, all this reminds me of the good times in my childhood with my parents."

Finally, one resident said, "The joy of shopping in the market amidst all the hustle and bustle, the walk in the fields, the process of cooking sambar for everyone and tasting it till it has the right taste and consistency, these are some small but important joys."

And a neighbour of a Home Again resident added: "We used to wonder what life would be like, when we had 'these people' as neighbours. I now drop my child when I go to work, and my lovely neighbour takes care of her and feeds her. I have found a great friend and support in her."

Costs and cost comparisons

Over the last twenty six years there has been a steady flow of funding from individual donors, who contribute on a regular basis. The service is funded mainly by The Hans Foundation, Rural India Supporting Trust, Azim Premji Philanthropic Initiative, TVS Group's Sundram Fasteners Limited, Bajaj Finserv, the Paul Hamlyn Foundation, and the HCL Foundation. In addition, a ₹15 Cr corpus has been built from through the Rural India Supporting Trust to generate a recurring interest for the service and to ensure the sustainability of essential resources.

The annual cost to run Home Again (based on 2019 data), is ₹9,060 (approximately US$ 124[e]) per person per month, inclusive of all welfare, staffing, capacity-building and administration. This compares with ₹29,245 (approximately US$ 402) per person, per month in government psychiatric facilities. On one site, three homes have been funded by the local village governments or panchayats. However, there is no cost for users of the service.

Challenges and solutions

Raising sufficient funds for a growing service

Sustaining and increasing funding has been a challenge especially as the costs of providing an ever-growing service (such as increased staffing, administration, rent, furnishings, health care, medicines, food and other expenses) rise.

One solution has been to seek funding partnerships with different levels of government and other organizations *(14)*. In Kerala, three houses were funded by the panchayat with more expected over the next three years. In Tamil Nadu, the government announced ₹1.38 Cr (approximately US$ 200,100[e]) for Home Again *(20)*.

In addition, the active use of available social benefits, disability allowances, housing schemes and the public health service helps to reduce the financial burden on each house. In Kerala, for example, the disability allowance, together with a 3% budget reservation for disability in panchayats, is expected to cover majority of the service user welfare costs.

Finally, a Supreme Court mandate to eliminate the institutionalization of persons with long-term mental health needs and move them into community care helped drive demand and improve funding *(17)*.

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[e] Conversion as of March 2021.

Tackling staff retention

A major challenge has been the high attrition rate of staff. Large numbers of the personal assistants have left due to the high pressures of the work and burnout; many clients having complex long-term requirements requiring high levels of support.

One solution was to broaden recruitment so that a wider range of people might be employed, including older women and people with lived experience. And since India is looking to enhance employment especially among women, The Banyan developed a diploma course in health and mental health care provision specifically for a new cadre of personal assistants who tend to be women, along with the University of Pennsylvania. It also encouraged strong engagement by people in the Home Again community. This resulted in many becoming personal assistants. One member of staff said, “While work can be challenging, particularly when a situation has to be de-escalated or when we face intractable problems, the satisfaction and meaning that we derive from our work, besides the financial independence, is incomparable.”

Engaging with the community in new areas

There have been challenges expanding the service into other geographical areas, where different cultures exist. Access to essential services and the availability of housing were also limiting factors, as well as finding stakeholders committed to the idea of social inclusion of people with mental illness.

Home Again used its strong ability to integrate individuals into the communities where they live to overcome these problems. Using the model of a home-like atmosphere and responsive personal assistants, service users began to occupy spaces in the community and social mixing occurred. The service impacted on local responses to mental health conditions and, in the process, reduced social distance and prejudice. Neighbourhoods where housing was initially difficult to secure now offered housing after seeing the benefits of the service.

Securing support for deinstitutionalization and community living

It was difficult initially, to obtain buy-in from both staff and residents to the feasibility of discharge from institutional care. Dialogue with residents, therefore, was critical in helping to persuade them that there were possible benefits of community living compared with staying in psychiatric hospitals.

Maintaining the values of the service

Despite active efforts at training, sometimes the desired ethos and values have not been observed or adhered to in every part of the service. There have also been difficulties in overcoming traditional paternalistic and controlling attitudes too.

Pragmatic forms of education and training new staff were used to overcome these problems. Capacity-building sessions with different stakeholders were also held across the service. Peer leaders, social workers and personal assistants familiar with the service and its ethos helped newly-recruited teams to understand the protocols that were developed. Senior managers also visited regularly to give advice and foster learning. Equally important were meetings and exchanges organized for user survivors and staff to share their field-level perspectives.

Together these responses helped new staff understand the need to respect the rights-based approach with the people that they serve, and therefore practice and implement the programme in the intended way. Spending time listening to people who had been working in the field for some time and those with lived experience helped them develop the right mindset to implement the programme.

Ensuring more peer leadership across different sites also contributed to a change in mindset. People with lived experience began to run Home Again projects in a number of places and took up posts as programme heads, peer advocates and personal assistants. Workshops and focus groups were held with people using the service so that the programme could be genuinely co-produced.

Key considerations for different contexts

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

- moving to user-led service audits, where service users are the researchers, to improve the quality of the service;
- using the ‘feedback loop’ approach to service development, so that feedback is collected periodically from residents, staff and personal assistants, and used to make modifications in the way the service is designed and delivered; and
- recognizing that one of most critical factors influencing transferability of Home Again relates to the wider mental health systems’ readiness to move to a values-based service.

Additional information and resources:

Website:
https://thebanyan.org/

Videos:
The Banyan Home again (Dec 2018)
https://www.youtube.com/watch?v=4iX7tSwa2Dc

Home Again (16th Jan 2017)
https://www.youtube.com/watch?v=FOyLSMHJjVg

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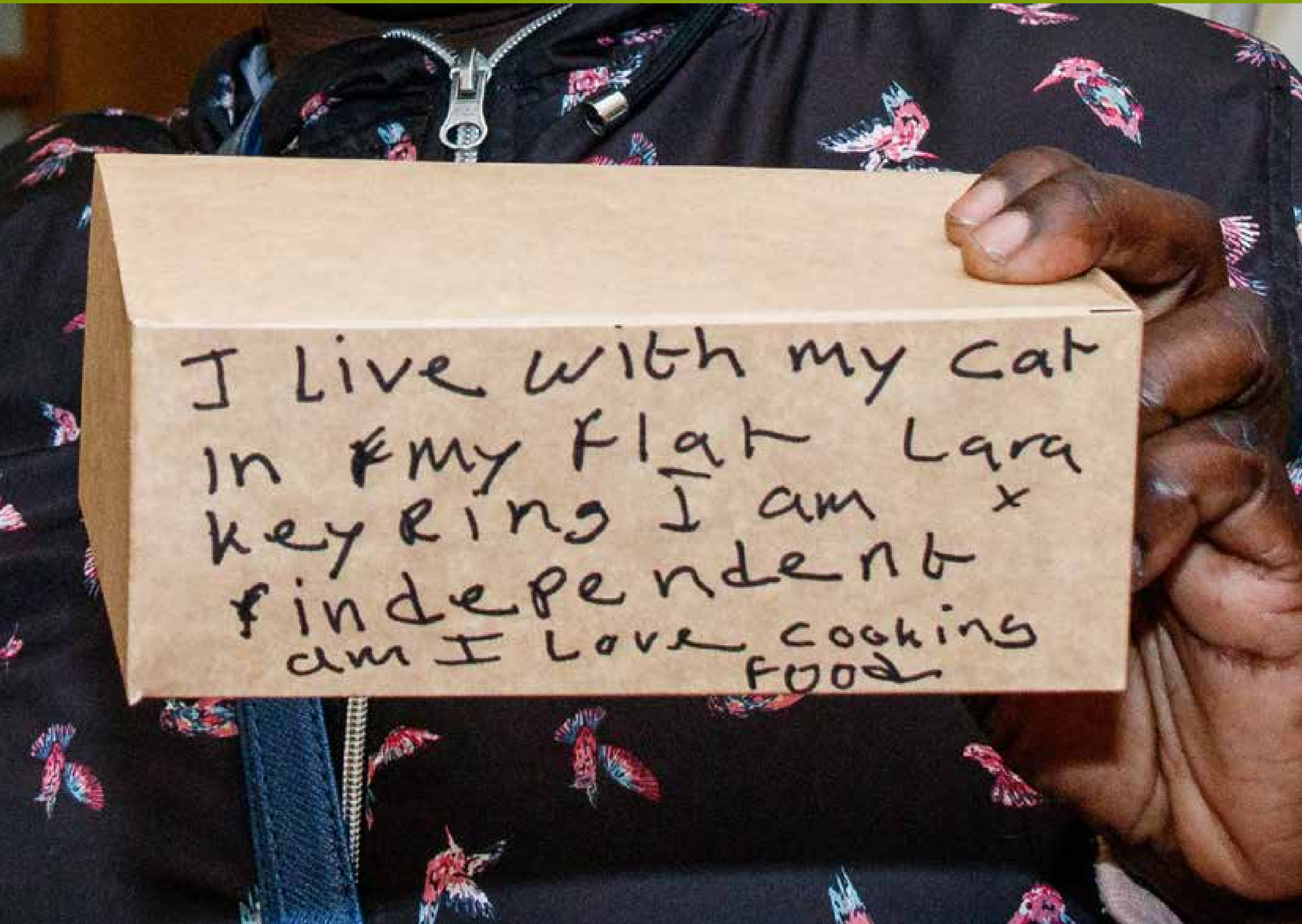
2.3

KeyRing Living Support Networks

United Kingdom of Great Britain and Northern Ireland



Primary classification: **Supported living service**

Other classifications:

☐ Community mental health centre ☑ Community outreach ☐ Peer support

☐ Crisis service ☐ Hospital-based service ☐ Supported living service

Availability in different locations:

☑ Yes ☐ No

Evidence:

☐ Published literature ☑ Grey literature ☐ None

Financing:

☐ State health sector ☑ State social sector ☐ Health insurance

☐ Donor funding ☑ Out-of-pocket payment

Context

The United Kingdom is a high-income country with a well-developed mental health system. In recent years, there have been concerns that the process of deinstitutionalization has come to an end. As in other European countries, there is evidence that growing numbers of people with mental health conditions and psychosocial disabilities have found themselves living in nursing homes and other inadequate forms of accommodation. Some have been detained in prisons and forensic facilities *(21)*. Some commentators have labelled the phenomenon, transinstitutionalization and even re-institutionalization *(22)*. In England, there is evidence of an increased focus on risk *(23)*; the country saw a 40% rise in detentions under its Mental Health Act between 2005–2016 *(24)*.

A 2017 report by the National Development Team for Inclusion (NDTi), a not-for-profit organization, raised concerns about a deterioration in the living situations of many people with disabilities. The NDTi said, "Although current health and social care policy and legislation emphasizes person-centred approaches and use of community-based options (e.g. the Care Act 2014), and discourages residential settings which are segregated from family and communities, this does not appear to be having a significant impact on current patterns" *(25)*.

Instead, said NDTi, concerns over costs have contributed to a move away from options that offered choice and control, towards more traditional forms of residential care. It highlighted alternative forms of supported living in the community that were possible and could result in a reduction in costs *(26)* citing KeyRing Living Supported Networks and Shared Lives (featured later in this section). A more recent study has confirmed its assertions on cost *(27)*.

Various countries have adapted the KeyRing model to fit their local environments including Pameijer in the Netherlands, Eteva in Finland, Brothers of Charity in Ireland and Australia's Housing Tasmania South West Region.

Description of the Service

KeyRing has been providing supported living services since 1990, with the mission to inspire people to build independent lives through networks of support, connection, flexible assistance and skills-building *(28, 29)*. KeyRing went from supporting about 900 people in 2007 to more than 2000 people in 2018 all over the country *(27, 30)*.

Networks of support consist of 10 or more ordinary homes located within walking distance of each other. KeyRing Members, people who face barriers to independent living, reside in all but one of those houses *(31)*. A Community Living Volunteer (CLV) lives in the remaining house paid for by KeyRing *(32)* and provides informal support to members with day-to-day life and activities, depending on their expressed needs *(33)*.

Each network ensures that KeyRing Members take control and responsibility over their lives by living in a place of their own, as well as contributing and being connected to their local community *(33)*. The premise behind KeyRing is that the more people are engaged and connected to a community, the more they see beyond the services and support, and the more independent they become *(28)*. The service also promotes an asset-based community development approach (ABCD) *(34)*, which means a focus on what each member can do to take more control of their daily tasks and activities.

The theory behind KeyRing can be summarized as follows:

- "**K**eep going": things don't always work or work the first time and people have barriers they must overcome. The service supports a person to overcome barriers at their own pace and follows the Member's lead;
- "**E**mpathy": Members' wishes and aspirations are of primary concern and the measure of success should be whether the service helps people achieve these wishes;
- "**Y**ou do it": the only way to empower people and make change sustainable is "doing with", using Members' skills and experience, not "doing for" ;
- "**R**espect": It is people's lives and aspirations, so they are the experts and should decide what happens;
- "**I**magination": supporting people to think of creative solutions to achieve their aims, working with other, like-minded people and organizations to help Members achieve the best they can;
- "**N**o fibs": honesty and transparency about what the service can and cannot provide and the reasons for this; and
- "**G**lobal": the approach might be universal, but how things pans out is individual. KeyRing is all about listening to and working alongside people in their local communities, so the people KeyRing supports gain greater independence, improve their wellbeing and are part of a network of contacts and friends *(27)*."

KeyRing has more than a hundred networks in about 50 local authority areas across England and Wales *(32)*. During 2017–2018, 2001 people received support from KeyRing, with a staff and volunteer team of 209 *(33)*. Their actions are described as "multilocal," which means they have local staff, volunteers and Members backed up by a smaller national team located in a central office in London *(35)*.

For each network, KeyRing works with a variety of different local people, from librarians to shopkeepers; after mapping out the resources available in the community. Guest speakers from the local area are often invited to speak to Members *(36)*. As people become more involved, they become less reliant on support services, and active citizens that offer their skills to the benefit of the local area.

CLVs dedicate at least 12 hours per week to supporting Members with issues such as dealing with bills and budgeting, getting into education, employment, or volunteering *(33)*.

Amy, a KeyRing Member stated, "If I get a letter that I don't understand, I can ring [the CLV] up and he'll come around and he'll explain it so I can understand it" *(37)*.

Lee Hart, a CLV said: "Members can call up and say, 'Can you come around and help with this?' Or I'll usually pop around generally once a week and check that everybody's alright" *(37)*. The CLV also promotes mutual support between network Members, as well as helping Members to build links with neighbours, community and local organizations. The CLVs can connect the Members through a local Community Hub, a local space where people can drop in for one-to-one support from a CLV, other volunteers, meet other Members or even members of the community if the rules of the Hub allow it. Through these hubs, members can socialize, plan events or get information and advice *(33)*.

KeyRing's Community Connections Volunteers *(38)*, give time to the network but do not take on the CLV roles. These volunteers may have a particular skill to share or want to take on a particular task, such as running a hub.

Support Managers supervise each CLV; these staff members are responsible for a cluster of networks. Support managers are responsible for taking referrals, assessing and allocating workers to Members, then giving ongoing support to the staff team to help them support Members to achieve their goals and ambitions *(29)*. Members can also contact the Support Manager directly *(33)*. There are other staff positions, such as Community Enablers, who work evenings and weekends to support Members who want to use their skills and talents, use and develop community connections. Enablers promote natural support relationships *(38)*.

Recruitment to work or volunteer with KeyRing is based on values rather than experience. Not all staff have experience of social care work, however they are recruited if they share the following values: equality, rights and respect, influence and inclusion, and change. As such, KeyRing said it looks for people who enable and empower; respond and review; improve and innovate; challenge the status quo and connect people *(38)*.

All staff and volunteers hired by KeyRing complete mandatory training as part of their induction, provided via Care Academy an online learning resource. Here they receive a comprehensive menu of courses relevant to health and social care *(39)*. All staff must complete at least four modules, which include Health & Safety, Lone Working, Safeguarding, and Supporting Equality and Diversity. Staff are also coached on developing KeyRing values, such as ABCD, empowerment, community organizing, and how to use the Outcome Star scheme *(40)* to help Members become more independent. Staff can then complete eight further modules which include Awareness of Mental Health, Dementia, and Learning Disabilities.

Once all 12 modules, and a probation period, are completed, staff are offered a Level 2 certificate in Care, and a Level 3 certificate in Learning Disability studies. Further training that supports specific needs or aids community development is also available. Courses in Mental Health, Domestic Violence, Substance Misuse, Welfare Benefits training, Epilepsy, British Sign Language are also on offer. Most support managers have completed a Level 5 diploma in Management too. KeyRing also offers staff access to Open Futures Learning content *(41)*, a video-based online teaching resource that strongly emphasizes independence, resilience and empowerment. Moreover, staff – including nurses, social workers, psychologists – bring experiences and learning prior to their time at KeyRing. KeyRing actively uses these skills to reinforce and develop what staff can do.

Initially, KeyRing provided an alternative to residential care for people with learning disabilities only *(42)*. Today, anyone who needs support to live independently can be welcomed into a network. That includes people with psychosocial disabilities and mental health conditions, drug and alcohol addictions, physical and sensory disability, autism and Asperger's and older people. While KeyRing does not like to label people, its website states that, "sometimes [they] do need to use labels to help people understand who KeyRing can support" *(28)*.

KeyRing accepts people who want to be part of a wider network and called upon for mutual support. This does not mean KeyRing Members must be skilled or confident in social settings. Rather, they understand that their support is part of something larger that they are happy to be involved with, even at difficult times.

Relationships between individuals within the Networks are the same as any social relationships and at times people do not get along. Often Members find social relationships difficult and need support to develop their skills and confidence. The CLV and staff therefore encourage the development of these skills. When people fall out or disagree, they are supported to resolve their issues. KeyRing does not expect everyone to be friends, but does expect them to be good neighbours.

While KeyRing has no specific exclusion criteria, people are asked to leave the network if they persistently do not engage, or their behaviour puts other Members, staff and volunteers at risk. If a network Member experiences a crisis, KeyRing will continue to provide support alongside other mental health services, which can include hospitalization. Occasionally people decide the Network does not suit them and they can be referred back to the local authority social work teams.

When someone becomes a KeyRing Member, staff will start by looking at every aspect of their lives to determine their immediate support requirements *(43)*. Subsequently, together, they co-produce a plan, which specifies a person's goals and short and long-term actions needed to achieve them. The plan often includes a personal budget *(32)*; this puts the individual in charge and fosters independent living *(44)*. To create the plan, the staff member uses the Outcome Stars Support Planning Tool, which looks at ten areas of the person's life and identifies where the person is on a scale of 1-10 (where stage one indicates being stuck, to Stage 10, being self-reliant *(40)*) . Other stages include accepting help, believing, and learning.

When they join, new Members are initially put in contact with other Members, Community Living Volunteers and Community Connections Volunteers in the network, to ensure that they feel connected and can participate in peer-support. Individualized support is offered by the professional support team from KeyRing, which also works to mobilize community resources where possible for its Members. If network Members need additional support over and above that required for day-to-day activities, they can also access one-to-one support with Community Enablers *(33)*.

Should they need to contact anyone urgently or when staff are not available *(32)*, KeyRing Members have access to trained advisers, 24 hours a day, seven days a week via Support, Management and Response Service (SMaRT), KeyRing's out-of-hours helpline. Helpline advisers[f] are trained in awareness of mental health, responding to suicidal callers and other skills.

Members can also access services designed to offer flexible timings and levels of support for each individual. For example, they may be helped to rehearse any journey required, provided with timely reminders and staff can accompany them to appointments if they wish it.

Members' housing can be rented from a local authority or housing association, owned by the resident or in shared ownership. Because networks are created around existing accommodation, residents do not always have to move to join a network. If they do move, KeyRing staff will make sure that the new Member is not giving up essential social and community ties *(32)*. KeyRing can support people to find housing in the network area, as well as support to keep it. Importantly, the property will always be in the Member's name and is not tied to their support from KeyRing *(28)*. People are supported for time-limited periods which are rarely longer than two years.

KeyRing is different from traditional support options. It focuses on building connections, building on people's strengths rather than deficits, and considers labels to be reductive. Danny McDowell, a former KeyRing Member and later a Board Trustee of the charity, *(34)* states, "They have time to listen. If they say they're going to do something they do it. I've been let down by others in the past, but they're not like other services. If KeyRing say they're going to help, they'll be here the next day and have it done. In other words, they practice what they preach. They're always there when I need them. I've got their emergency numbers; [...] I've got quite a lot of people I can pick up the phone to. If I phone someone and they can't make it, there'll be someone else who can make it. Although they don't work 24 hours, there's always someone on the end of the phone for me. [...] I've never come across a situation where I've asked them to help me with something and they couldn't do it."*(45)*

Core principles and values underlying the service

Respect for legal capacity

Legal capacity is an important aspect of KeyRing networks, both in design and practice. KeyRing's core mission is to promote Members' independent living and autonomy in the community. To achieve more independence, a focus is placed on, "doing with, using Members' skills and experience, not doing for, [as] the only way to empower people and make change sustainable" *(27)*. Staff are trained to start with what people can do and explore how they can increase independence in a way that empowers *(28)*. The service also emphasizes that Members are the experts and decide what happens; they choose where and with whom they live, and the housing contract is held in their name *(27)*. This creates a sense of responsibility and agency for the Members. The asset-based approach also creates an atmosphere of encouragement and positivity by focusing on people's strengths. Encouraging Members to grow their skills helps them to become more autonomous.

As Members arrive at KeyRing, they co-produce a support plan with the staff member, to ensure their wishes and aspirations are clearly written down and translated into the support they will receive at KeyRing. Support plans are revisited on a yearly basis, but Members can update more frequently if they wish.

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[f] NCHA Care and Support provides the helpline.

Members have flexible access to support by connecting with their CLV or any other peers in the network if they feel the need. They can also call the SMaRT helpline. KeyRing ensures that information about the network, service paperwork and support tools are available in an accessible format, which means that staff are well equipped to explain things clearly to Members *(45)*. For instance, an easy-to-read version of the co-production policy is available on the KeyRing website to ensure those who decide to join a KeyRing network are fully informed and can make independent decisions *(46)*. More generally, informed choices are always sought, by ensuring that network Members have access to information they can understand, can attend appointments and if they would like, have access to an advocate for support.

The existing support network a Member might already have, is also valued and included, if that person wishes. Residents do not have to move to join a network, since new networks can be created around existing accommodation. Thus members retain their social and family ties *(32)*.

The underlying belief that everyone has something to contribute in the community also means that peer support is valued and promoted, and staff and volunteers are considered as equal members of the community. This prevents power asymmetries from developing and acting as barriers, preventing Members from feeling comfortable enough to express their wishes, aspirations or complaints.

Non-coercive practices

Coercive practices, including seclusion and restraint, are never used within KeyRing services. If a manager feels that specific training on de-escalation is required, staff and volunteers can then receive it. Other training, such as working with challenging people and those who self-harm, are offered to employees through the Open Futures Learning platform. If a Member experiences a crisis, KeyRing can contact the local area's mental health or social work teams and together, decide on available services to which individuals could be referred. The appropriate support may or may not include hospitalization. If someone is taken to a hospital, KeyRing staff deal with the individual's housing and financial affairs, so that they have somewhere to return to. They also visit the Member and liaise with the mental health team and hospital to plan for discharge.

If someone is unwilling to take their medication, KeyRing organizes a multi-disciplinary discussion, including professionals, family members, care givers or others as appropriate and with the agreement of the member. The discussion promotes the understanding of benefits and risks of medication. KeyRing continues to support Members who choose not to take their medication although the member might be encouraged to speak with a Peer Volunteer taking the same one. If professionals believe it would be beneficial to continue with this treatment, KeyRing staff will persist in being clear about professional advice but will not judge a person for choosing not to. Additionally, the staff focus on other areas of the Member's life, perhaps identifying positive outcomes to goals they set out to achieve. The idea is that success in one area of their life can help "unstick" another area. While a Member's decision does not affect the support that is offered, if people become unwell it could potentially jeopardize their housing and ability to remain independent. If it is considered that a person is harming other network members or staff, KeyRing can also raise a Safeguarding alert with the local authority or police if appropriate.

Community inclusion

The use of the network means that Members live and are an integral part of the community. KeyRing's underlying philosophy is that the more people are connected to community life, the more they see beyond support services and the more they can be independent, active citizens. The range of support options available where they live encourages network Members to think further than their support worker. They may call a friend if they are worried about something or visit their local café if they feel lonely – and thus participate directly in community life.

Alongside the practical support that KeyRing is commissioned to provide, it also encourages other social and community connections, such as taking part in clubs, groups and sports locally, local community activities such as neighbourhood improvement projects, campaigning for local change, and raising money for charity *(45)*. People are also supported to find employment in the community. That is why Community Living Volunteers and Community Enablers are required to gain a thorough knowledge of community resources and activities, to better support connecting people. Formal support to maintain a tenancy or manage an independent life and mental health, is more successful as people connect, make friends and establish their own networks of support. It is this community development element of KeyRing's actions that is central to people's achievements.

Participation

KeyRing Members are involved in the running of the organization at all levels. First, peer support is at the core of the model. A Member explained, "Everybody helps each other; Members help each other and look out for each other. If one person's not well and they need a bit of shopping done, then they'll phone me - that's how the network works. It's a community I can rely on." *(45)*

Moreover, many network Members can evolve to volunteer or staff positions. For example, Anthony was a network Member for many years and is now the CLV in the Sandwell network. He uses his lived experience in the network to inform his work with current Members. Likewise, Dan took part in the Oldham Recovery Network and subsequently became a CLV and a paid support worker in another network. Daniel McDowell became a Board Trustee after having lived as a network Member.

Two positions on the Board of Trustees are reserved for people with lived experience who have used the services *(46)*. One such Member stated, "Being a KeyRing Member and in particular serving on the Board of Trustees has given me confidence in all aspects of my life, a sense of status; I've been a part of the day-to-day running of KeyRing." *(33)*

Board members with lived experience also receive additional training and meeting preparation so that they come to Board meetings informed and able to contribute on an equal footing with other Trustees.

KeyRing uses a co-production approach; everyone involved in a service works together to make it operational. Indeed, KeyRing, "wants Members to have a powerful voice at all levels of the organization" *(29)*. For example, KeyRing Members are regularly involved in delivering presentations and marketing the service to local authorities. They participate in staff and volunteer selection processes and have an equal say, with managers, on appointments. Members also have editorial control of the organization's quarterly newspaper. A working group, Working for Justice, which campaigns for people with learning disabilities who have experience with the justice system, also demonstrates how Members can be involved in running an organization. The working group has been directly involved in training prison officers in every prison in England on how to work with people with learning disabilities *(33)*.

In 2009 and 2013, Members have also participated in the running and decision-making for national KeyRing conferences, held at Warwick University with around 400 delegates. Members reportedly, made all key decisions concerning the conference and were fully involved in the practical aspects of running it *(33)*.

Finally, quality control also includes people with lived experience. Experts, with the relevant experience who check on KeyRing services, are called KeyCheckers *(46)*. There are also Member Satisfaction Surveys to ensure that Members' complaints and feedback are addressed.

Recovery approach

The recovery approach is central to all the actions carried out by KeyRing. Labelling, for example, is seen as limiting people's potential according to KeyRing. "Where others see labels such as learning disability, mental health issues, homelessness and addiction, we see skills and talents. We see people. We don't like labels. Labels can limit people's dreams. They don't tell you anything about what a person can achieve."*(28)*

KeyRing uses a holistic approach to the person and support, ensuring every aspect of Members' lives is considered when the person first enters a network. This is done through the Outcome Stars support plan. A CLINKS *(45)* report on KeyRing said, "The holistic, flexible and person-centred approach provided by KeyRing enables [its] clients to access long-term support around relationships, employment and finances, whilst helping them to feel part of their community and feel more in control of their future".

Another aspect of the service which reinforces the recovery approach is the emphasis on an asset-based approach which focuses on people's strengths, and what they can do. This generates more independence and recovery. Positive risk-taking, or letting people try and risk failure rather than 'doing for' them, is an integral part of recovery and seen as critical to building Members' skills and confidence. A Positive Risk Management Plan is also developed with network Members that includes identifying strategies to deal with difficult situations and wellbeing.

Service evaluation

Positive comments and feedback on the quality of services provided by KeyRing include Amy's. She stated, "[I] probably would have ended up in residential care if [I] didn't have [my CLV] Lee's support, and [my] life would have been a lot different to what it is now" *(37)*.

Other Member stories, published on KeyRing's website include one who said, "Being part of KeyRing and going to KeyRing events has given me new ideas, given me a sense of belonging, of not being alone. I've been able to meet, talk, pick up tips and tricks, and generally have a 'blast'." *(28)*

Likewise, stakeholders in the community also see the benefits of KeyRing networks. In an interview, one police officer stated: "KeyRing forms of a big part of the community. It is a vital link for us, because we have some hard-to-reach people in our community, and KeyRing provides that link for us to get to know the Members and them to get to know us." *(47)*

As well as qualitative data several reports over the years confirm these findings. The first independent evaluation of KeyRing was conducted by the Norah Fry Research Centre during 1998. It reported positively on the quality of the service and cost-effectiveness *(26)*. KeyRing was also evaluated by Paradigm, a Learning Disability Consultancy, in 2002. It concluded that Key Ring was, "considerably beyond most organisations in terms of focus and outcomes."

In 2006, the Department of Health published a report and case study on KeyRing Living Support Networks and concluded that the organization, "helps adults with support needs to achieve more than traditional forms of support" *(26)*. This research showed Members in three different networks were achieving good outcomes. Evidence was found that networks were enabling people with high levels of support to move gradually from paid care workers or family to living independently in the community.

Emerging Horizon *(48)* in 2015 conducted an evaluation of the Recovery Network over three years which included people recovering from substance misuse and addiction. Findings showed notable improvements across various areas of participants' lives, including health and psychological and wellbeing, retention of tenancy, attendance of mutual aid, engagement in meaningful activity, volunteering and ongoing abstinence.

A 2018 evaluation by the Housing Learning and Improvement Network (LIN), a knowledge hub and network of housing, health and social care professionals in England, Wales, and Scotland *(27)* said KeyRing networks could bring about financial savings based on how the service removed members' needs for other inputs. Assumptions, which were described as conservative, were based on an examination of client-level data from the four KeyRing networks. LIN concluded that, every year, KeyRing networks resulted in the following: 30% of Members avoided a psychiatric inpatient admission (lasting three weeks) or becoming homeless, a quarter no longer required weekly CPN visits nor weekly social worker/care coordinator visits, a fifth no longer required weekly drug/substance misuse worker visits and 10% no longer required weekly learning disability nurse visits.

Finally, according to a Governance International feature, edited by the KeyRing Communications Coordinator, 99.9% of KeyRing Members successfully sustain their own tenancy *(33)*.

Costs and cost comparisons

The service is funded from the Local Authority social care budget, allocated by Central Government. However, significant cuts in this funding since 2010 mean local authorities have looked to alternative sources to raise income; from business taxes and parking charges for example. KeyRing works with a number of partners and is open to commissioning from various sources *(49)*.

The cost for an individual using the service depends on where the network is located and the support a person requires. People are means tested and the assessment will be used to determine whether they are charged for all or some of the costs. Health insurance does not cover the service provided at KeyRing.

Housing LIN's 2018 independent evaluation conducted across four local authority areas – Halton, North East Lincolnshire, Oldham and Sandwell – estimated a Member receives support costs of £3,665 (approximately US$ 5,122[g]) per year (excluding housing or food) or £70 (approximately US$ 97[g]) per week *(27, 33)*.

For every £1 spent on KeyRing support, Housing LIN estimated a saving in overall support costs of £1.19 – almost a 120% return on the local authority's original investment *(33)*. It showed cashable savings (reduction in immediate support costs) of £187,168 (US$ 261,604[g]) per year using the KeyRing model. This is evidence that the KeyRing model costs less than traditional living services. According to the analysis, those savings came from moving people out of more costly residential environments, and from the reduction in overall support required by Members once they feel connected to the network. Furthermore, Housing LIN explained that the avoidance of crises – and that people are able to recover more quickly from them – generates wider financial benefits because it prevents future costs estimated to represent £278,347 (US$ 389,000[g]) per annum *(27)*.

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[g] Conversion as of March 2021.

The Department of Health, in its 2006 evaluation *(26)* stated that, "The costs of a network are, over time, more than offset by reductions in other forms of support as Members become more self-sufficient." *(26)*

Therefore, the cost-effectiveness of the model, including cashable savings as well as savings associated with prevention *(27)*, has encouraged local and national authorities to invest in developing more networks. KeyRing supports people to achieve more than could be done in more traditional settings.

Challenges and Solutions

Demonstrating the viability of the service

Persuading families, councils and social workers that people with disabilities could live independently in their own homes was a challenge. They assumed that everyone needed 24-hour support. Persuading local councils that the contribution of volunteers is as valuable as that of paid staff was also challenging.

To tackle these mindsets, the service began gathering an evidence base, demonstrating that the service could work. An independent researcher evaluated the service. Then, the service highlighted the success of its work to families and social workers who were sceptical, as well as the media. Importantly, the evaluation enabled the service to demonstrate that recruiting staff based on values and personality, rather than former health or social work experience, was practical and effective. The service was also able to use a law that requires local councils to help vulnerable adults remain in the community to make the case for providing the service. Strong and passionate leadership, with good communication skills was thus vital in changing mindsets.

Financial challenges

While the service used a grant to get the service off the ground, the reduction of government funding to local councils and short-term commissioning of services undermined new initiatives and partnerships such as this. In addition, the national reduction of social housing provision, with subsequent high rents has added to costs.

To tackle the problem, the service began to build strong relationships with housing providers, supporting people early (before they were housed) and negotiated difficult processes. It actively looked to reduce the organization's overhead costs through use of IT and reduction of bureaucracy. Active, and ongoing, engagement with commissioners and the commissioning process was vital. It allowed the service to learn of all new funding opportunities promptly. It worked with community partners on applications for grant funding too.

Key considerations for different contexts

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

- listening to the people the service is supporting, involving everyone in developing the organization and nurturing the organizational culture;
- finding ways of demonstrating impact and backing it up with financial evidence;
- encouraging mutual support;
- valuing volunteer and peer volunteer contribution equally;

- providing just enough professional input; and
- choosing areas where people would not need to travel significant distances to interact together and support each other.

Additional information and resources:

Website:
www.keyring.org

Videos:
KeyRing Network Model
https://vimeo.com/379267912

Contact:
Sarah Hatch, Communications Coordinator, Keyring Supported Living, United Kingdom,
Email: sarah.hatch@keyring.org

2.4

Shared Lives Scheme

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

Primary classification: **Supported living service**

Other classifications:

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

Availability in different locations:

☑ Yes ☐ No

Evidence:

☐ Published literature ☑ Grey literature ☐ None

Financing:

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

Context

Wales is one of the United Kingdom's four countries, along with England, Scotland and Northern Ireland. Wales' mental health strategy, called Together for Mental Health *(50)*, takes a rights-based approach. It explicitly promotes the recovery model as well as the empowerment and involvement of service users throughout the life course at an individual, operational and strategic level.

Shared Lives is a regulated form of social care delivered by Shared Lives carers trained and approved by a registered Shared Lives scheme *(51)*. Formerly known as Adult Placement, Shared Lives represents an alternative to care homes, home care and day centres. The service can also act as transitional care for those who have been in hospital or the foster care system for young people. Nearly 1000 people are supported by Shared Lives in Wales, and over 12 000 people are supported by Shared Lives in the UK *(52)*. The scheme in South East Wales, called South East Wales Shared Lives (SEW Shared Lives), initially worked mainly with adults with a learning disability but expanded to include adults with dementia and people with mental health conditions who have been discharged from hospital. More recently a Shared Lives for Mental Health Crisis service has been developed in collaboration with the Aneurin Bevan University Health Board (ABUHB), which serves the mental and physical health needs of Gwent, a county in South East Wales with 650 000 people. This crisis service, which is part of the wider SEW Shared Lives scheme, aims to change the way that services support people experiencing a crisis and their carers.

The main SEW scheme is the largest in Wales *(53)*, offering placements in five local authorities of Gwent (Blaenau Gwent, Caerphilly, Monmouthshire, Newport and Torfaen) and also Merthyr Tydful (this local authority is not included in the Shared Lives for Mental Health Crisis service area). The scheme includes some of the most deprived areas in Wales. SEW is delivered as a partnership between the six local authorities and ABUHB, with Caerphilly County Borough Council as the lead authority. The SEW scheme has thirteen Shared Lives workers, four adult placement coordinators, three managers, and a team of administrative staff.

In Wales, there are eight Shared Lives schemes covering 21 of the 22 local authorities. Many have been commended. The Shared Lives South West scheme received an "Outstanding" from the Care Quality Commission for example *(54)*. In the wider UK, Shared Lives operates in the majority of local authorities. Between 2017 and 2018, there was a 3% growth in the number of individuals and a 2% growth in the number of carers *(53)*.

Description of the service

The Shared Lives scheme is community-based, whereby an adult who needs support can move in with or regularly visit the home of an approved Shared Lives carer for a specified period of time. Individuals may have a mental health condition or psychosocial disability, may be experiencing a mental health crisis, have a diagnosis related to Autism spectrum disorder, or an alcohol or substance use condition. Service users may have been in foster care, have learning or physical disabilities, or are older people with a frailty or dementia. SEW Shared Lives approves and trains Shared Lives Carers, receives referrals, matches individuals with compatible Shared Lives Carers, and monitors the arrangements *(51, 55)*.

In this scheme, people who use this service can receive the following support *(56)*:

- somewhere to live in the long or short-term;
- somewhere to stay for short breaks or respite placements;
- somewhere to go for daytime or sessional support (not overnight);
- support to help prevent hospital admission;
- short-term support following hospital discharge; or
- intermediate or end-of-life care for adults who may require some adaptations to their living environment, sometimes to enable palliative care to be provided and who meet the eligibility criteria to receive social care support.

There is no background or specific experience required to become a Shared Lives carer *(57)*. The assessment process usually takes about three months and includes the following:

- an informal meeting to discuss background, lifestyle and experiences;
- checking references;
- a DBS check (Disclosure and Barring Service) for both individuals applying and other family members to ascertain any offending history; and
- a review by an independent panel (which includes social work managers, head managers and nurses). The applicant is invited to attend and participate in the panel.

If agreed by the panel, potential Shared Lives carers receive comprehensive support tailored to the types of arrangements they will provide. In addition to the core training provided to carers and their families, as part of the assessment process, those in the mental health crisis scheme attend Mental Health First Aid training. Training needs are regularly reviewed and the option for additional training and consultation from the crisis team and psychologists is available.

In general, Shared Lives Carers receive monthly one-on-one supervision from an allocated Shared Lives Worker. Meetings can be organized via phone, email or face to face, follow a formal agenda, and are recorded on individual case records so that they feed into the carer's annual review process *(57)*. Each year, the carer receives a copy of their carer review to which they can add their own comments, feedback and evaluation. Shared Lives carers in the SEW scheme can also choose to become members of Shared Lives Plus, a national charity that supports and develops Shared Lives schemes. Through this charity they have access to additional support including teleconferences with other Shared Lives carers, events, guidance on human rights, and on legal and administrative issues *(58)*.

Regular carers' meetings are held in different locations across South East Wales. These meetings give carers an opportunity to meet each other, offer and receive peer support and to discuss Shared Lives as part of a group. The discussions range from addressing general operational matters, such as training needs, updating legislation or policy in the organization, to guest speakers who talk about topics such as medication or Dialectical Behavioural Therapy (DBT). Discussions about specific individuals in the Shared Lives programme are not permitted during these meetings. Staff from the Shared Lives Scheme attend and facilitate the meetings *(59)*.

At the end of each Shared Lives arrangement, a shared lives worker will visit the carer to review the arrangement and discuss any matters that may have arisen, as well as how to address them in the future.

The SEW scheme, currently provides over 500 Shared Lives arrangements. There are more than 200 Shared Lives carer households providing arrangements for the scheme and more are continually recruited. Each carer household can support up to three individuals at a time, however it is unusual for a household to support more than two.

Shared Lives for Mental Health Crisis service

The Shared Lives for Mental Health Crisis service was launched after two years of planning in 2019. It provides support to individuals experiencing a mental health crisis and is an alternative to or helps facilitate early discharge from inpatient hospital settings. The service offers emergency placements with selected and trained families for people presenting to mental health crisis teams. Individuals are supported in these short-term arrangements (up to six weeks) by crisis team staff. They are assigned a link nurse within the crisis team who they meet on the first day of the placement and have contact with throughout.

To use the Shared Lives for Mental Health Crisis service, a referral is required from either the inpatient ward staff or mental health crisis team and may take place either after admission or following a crisis assessment. Health staff will discuss the likely needs of the individual in crisis and the Shared Lives team will look at the best match from their pool of available carers. This takes place within 24–48 hours and can be arranged on the same day.

Shared Lives and Crisis team staff facilitate an initial meeting. Here, the individual in crisis and the potential carer meet to discuss the individual's needs and what the carer can offer. The meeting can take place on the ward, but more often at the carer's home. Subsequently, if both parties are interested in going ahead, the arrangement can commence immediately. However, individuals can always opt to take some time to consider whether it is right for them. Once the arrangement has started, the individual, Shared Lives worker and crisis team staff will co-produce a personal plan. This sets out the actions required to meet the individual's well-being, care and support needs, and how the individual wishes will be supported to achieve their personal goals; it guides the carer to offer support in line with the needs and preferences of the individual. The plan is reviewed regularly with the individual to ensure it meets their day-to-day needs and chosen outcomes *(60)*. The plan is consistent with the care and treatment plan developed within mental health services.

The SEW Shared Lives workers visit carers on day one of the arrangement, jointly with the crisis team on day three and further visits are then organized at a frequency agreed with the carer and the individual. Each carer also has a dedicated scheme worker to talk through anything they think is important. Within the mental health crisis scheme individuals are supported on a one-to-one basis. Currently, this scheme operates in two areas of Gwent. However, following evaluation of this first stage, it is anticipated that an expansion to the other two areas where the crisis team operates, will go ahead.

Core principles and values underlying the service

Respect for Legal capacity

Choice, empowerment and autonomy are at the core of this service. As such, legal capacity is respected in the SEW Shared Lives scheme.

In relation to informed consent, individuals are given information about Shared Lives before they are referred to the service. They will have discussed the service with their care manager or lead health professional and will have consented to a referral being made.

It is essential that individuals using the service choose who they are going to live or stay with. This is why an arrangement only occurs if there is agreement from both the carer and the individual. There is emphasis on listening and acting upon service users' views *(60)*. The placement is arranged based on the service user and carers' personalities and lifestyles. One of the placement workers at Shared Lives *(61)* uses this example: "We would never think of asking a Liverpool fan to live with a Manchester United family" *(61)*.

Once an individual is referred to Shared Lives, the personal plan is co-produced with them. The way in which the individual's care and support will be provided is discussed and agreed with them and is regularly reviewed. Shared Lives workers ensure individuals understand the purpose and content of their personal plans before they receive services.

Individuals who would like support to make decisions are encouraged to include family members or other important people from their wider social network in the planning and decision-making process. Other professionals who know the individual well can also be included, for example community nurses, occupational therapists or psychologists. Individuals can also request support from an advocate if they or their representatives feel this would help them to maintain control of their care planning and service delivery.

Individuals are supported and encouraged to include their wishes for the future and what is important to them, when the personal plan is being created or reviewed. This may include broad wellbeing goals, specific personal wishes, or plans for a condition that could become worse or need end-of-life planning.

If a carer notices important changes in the individual's physical, mental or emotional health, they first talk to the person and request permission to consult a Shared Lives worker or health professional for guidance. Shared Lives workers are only consulted without the person's consent.

As regards the carer's job description, Shared Lives team is looking for people who, "have an interest in supporting people to [...] make their own choices and have new experiences"*(57)*.

A complaint mechanism is in place and service users are provided with a clear guide for making complaints. Individuals can also approach crisis team staff if they feel the need to.

Non-coercive practices

The use of coercion, force or restraint is prohibited by Shared Lives, and there are specific procedures in place to avoid their use.

Shared Lives staff and carers are trained in positive behaviour support theory and techniques, including de-escalation, being aware of and avoiding triggers and preventative measures. Training courses for carers on understanding trauma-informed practice are also in development. Collaborative risk assessments and management plans are in place for individuals who may need support to understand their behaviour and techniques to positively adjust their lives and address any safety-related issues during the arrangement. The service closely works with each individual to take into account what matters to them; each arrangement is highly personalized and designed to suit the individual. Overall, Shared Lives believes many of the triggers present in an inpatient environment, that may lead to agitation and subsequent restraint, will be absent in a Shared Lives setting.

Community inclusion

Community inclusion is at the core of Shared Lives values. All carers are considered self-employed and work from their own homes to provide long-term and respite placements, and if providing sessional support, carers regularly accompany individuals into the local community and introduce them to their wider social network. Everything happens, therefore, in the community; the relationship provides opportunities for people to engage in activities that support their recovery and receive care in a less stigmatized setting.

Individuals are assisted to be as physically, mentally and emotionally healthy as possible through the Shared Lives carers' support in line with their personal plan. In the community, this might include supporting an individual to access primary health services, attend appointments or annual health checks.

The service encourages individuals to be involved in their chosen activities, hobbies or interests and, where appropriate, access education, learning and development opportunities with help from their Shared Lives carer. Support could include help to find out about new opportunities, learning new transport routes, or being accompanied by a Shared Lives carer to attend new venues.

The service promotes individuals to have autonomy, make decisions and take control over day-to-day activities and events, including how their own care and support is provided. Shared Lives carers support individuals to be as independent as possible with finances, medication, and relationships.

The service supports individuals to maintain linguistic, cultural and religious beliefs. This includes matching an individual with a Shared Lives carer who, where possible, shares a common language, culture or religion, or instructing a Shared Lives carer to support the individual to maintain links with their cultural or religious community.

The service has a strong focus on supporting individuals to build positive relationships in the community. With support from Shared Lives carers, individuals frequently reconnect with their family members, old friends and develop new friendships and relationships. Shared Lives carers share their homes, family and community ties with individuals, providing opportunities for individuals to expand their social networks and develop new relationships.

The holistic approach at Shared Lives allows for individuals to rebuild aspects of their life that may have previously been harmed by challenges related to mental health issues, drug or alcohol use, or poor social circumstances.

Within the Mental Health Crisis Shared Lives Scheme, specifically, a third sector worker from the mental health charity Platform, based at the hospital and working alongside the ward and crisis team, also shares knowledge of networks within the community with the individual and Shared Lives carer. The Shared Lives carer then supports the individual to access the peer networks that they wish to, including projects from the mental health charity MIND and therapy groups. They also support individuals to access various activities within the wider community. This enables individuals to interact with other people and widen their social circles, if they want to. Activities include gardening, arts and crafts, choir, drama and music and many other social activities, community groups, volunteering positions, education and training opportunities.

The crisis team has recruited a peer mentor to link closely to individuals in the Shared Lives scheme. The idea of inviting people who have previously used Shared Lives to share their experiences with others is also being developed. One individual has already made a video story and presented on her experiences to a delegation of visiting health professionals from Czechia.

Participation

Shared Lives Plus, the national support organization, is a resource for Shared Lives carers and workers and helps to ensure that a lived experience perspective is factored into the wider service network.

Individuals with lived experience form part of the ABUHB's Mental Health Crisis Community of Practice and help to shape future services, including those provided by Shared Lives. For instance, an individual with lived experience attended the planning meetings in 2017–2018 to inform decision-making around the development of the Shared Lives for Mental Health Crisis service. More generally, people who use Shared Lives services nominate representatives to attend operational group and partnership boards. Here, they can give feedback which shapes operational and strategic policy matters.

Individuals using the service and their representatives are also consulted on a yearly basis via the service's annual quality assurance questionnaire. Here they can provide feedback on their carer and the staff at Shared Lives. Summary responses of those questionnaires are included in quality-of-care review reports.

Individuals who participate in the mental health crisis scheme have a Recovery Quality of Life (ReQoL) assessment at the beginning and end of their stay. They also complete a questionnaire examining their experience in the service. Qualitative and quantitative information gathered from individuals is used to plan changes to the service and ensure it is providing positive outcomes and experiences. The training offered, is in part provided by experts including psychologists and nurses.

Recovery Approach

All Shared Lives services operate in line with the recovery approach. According to Share Lives Plus *(62)*, "In Shared Lives, the goal is an ordinary family life, where everyone gets to contribute, have meaningful relationships and are able to be active, valued citizens."

Shared Lives promotes a holistic approach to care. The scheme's recently developed personal plan records in detail the individual's needs and personal goals, such as using the local bus or going to the shops *(60)*. Each service user has both a care and personal plan. Personal preferences are accommodated whenever possible.

Individuals at Shared Lives, including those within the mental health crisis service, are helped to develop and maintain skills such as preparing meals, shopping and budgeting, carrying out household tasks, expanding their social circle and community links, gaining confidence and increasing independence, accessing work or education, attending medical appointments, or having a holiday. Many testimonies, available on the Shared Lives blog, demonstrate the increase in autonomy felt by the individuals *(63)*. There are also videos that provide insight on individuals' and carers' experience with Shared Lives *(60)*.

A recent experience in the Shared Lives for Mental Health Crisis project involved a man who wanted to be able to cook meals for his son but had never developed cooking skills. His recurrent low mood meant he had struggled with motivation to learn the skills. During the Shared Lives arrangement, his carer taught him how to cook a series of simple meals that they practiced together. He was able to return home and cook for his son, which gave him a great sense of accomplishment and pride in his role as a father.

Service Evaluation

That some carers and users have been living together or visiting each other for decades highlights the quality of the matching process as well as the long-term impact of this service. An inspection of the South East Wales Shared Lives scheme, by the Care and Social Service Inspectorate for Wales in March 2018, was a scheduled, unannounced inspection. It looked at three areas in the SEW Shared Lives scheme: quality of life, quality of care, and quality of leadership and management. Information was gathered from visits to the main office and discussions with the staff and managers. Inspectors looked at personnel, carer and individual care files. They also looked at a sample of documents relating to the service, such as team meeting minutes and the independent panel's minutes *(60)*.

Overall, the results of this inspection were very positive:

- **Quality of Life.** The inspectors found that individuals are placed with carers who offer support that meets their needs. The rationale behind approving certain carers, by the independent panels, was judged to be clear. Care planning was found to be good and individual files demonstrated that people were appropriately matched, and their care was regularly reviewed. The inspection found that service users could feel confident that they were being supported by trained and supervised carers. The scheme was judged proactive in engaging service users to participate in decisions affecting them, for example through questionnaires and discussions with individuals, as part of the quality assurance review and service user meetings.
- **Quality of Staffing.** In its report, the inspectorate found that overall, people using the service were supported by a motivated and skilled team. Shared Lives workers and carers stated that, "they enjoyed working in the service." Others reported that, "training is really good" and that, "the manager is very supportive". Carers felt they could access support from the staff at any time. The scheme

exceeded its objectives to provide individual supervision for carers every six weeks, according to the inspectorate.

- **Quality of leadership and management.** The inspectorate said, “Overall, people using the service can be confident that effective structures and systems are in place to ensure the service is well run and that care is delivered to meet identified needs.” Both staff and carers felt they could raise any issues with the manager, it said. The inspection also confirmed that a comprehensive record of the meetings was being kept.

The Shared Lives approach beyond South East Wales and with other client groups has also been very successful. The Care Quality Commission (CQC) which regulates all Shared Lives Schemes in England, has consistently rated these services as providing the safest and highest-quality form of care *(6164)*. In 2019, the CQC rated 96% of all 150 Shared Lives schemes across England as, “Good” or, “Outstanding”, including the South East Wales scheme *(54, 65, 66)*.

A qualitative evaluation of Shared Lives placements was also conducted using the, “My Shared Life,” tool, posted on the Shared Lives Plus online platform. The tool measures outcomes for people who visit or live with a Shared Lives carer. It asks people about their wellbeing over months and years, with questions that were developed by people at Shared Lives Plus, to best reflect quality of life. Outcomes for this tool were extremely positive. The latest data from April 2019 showed that 97% of the people using Shared Lives felt they were part of the family most or all of the time, 89% felt involved with their community, 83% felt their physical health had improved while 88% said their emotional health had improved. Additionally, 86% reported that their carer’s support helped them have more choice in their daily lives and 89% reported that their carer’s support improved their social life *(67)*.

Since its creation in September 2019, the Shared Lives crisis scheme has supported 59 individuals in total. The average length of stay has been 15 nights; 24 people accessed the crisis service straight from the community while the others did so following a short hospital admission prior to early discharge into Shared Lives *(68)*.

Moreover, an evaluation compared the quality-of-life outcomes, measured using the ReQoL *(69)*, of 44 Shared Lives Mental Health Crisis users before admission and post-discharge with 15 control-group participants who were admitted to an acute psychiatric ward *(68)*. Preliminary results indicate that Shared Lives participants show significantly higher quality-of-life scores post discharge compared to levels at admission. In contrast, results from the matched control group were less reliable — reaching a lower level of significance over the same period. Data also shows that Patient Experience scores for Shared Lives participants, using the Patient Experience Questionnaire *(70)*, was very high; it averaged over nine on a 10-point scale with a range of 8–10 .

Additionally, people who used the Shared Lives Mental Health Crisis scheme experienced fewer admissions to acute inpatient units post-discharge than before they were admitted. It was estimated that for the first 32 people analysed, 374 bed days were saved during the scheme’s first year of operation. Furthermore, individuals had fewer contacts with accident and emergency departments and less onward referrals within mental health services, suggesting that Shared Lives is associated with a pattern of reduced service use over time. These early results suggest significant benefits for the Shared Lives group such as improved outcomes. This may result in the reduced use of services and, therefore, lower corresponding costs.

Finally, testimonies from the South East Wales Shared Lives blog or on video testimonies, are extremely positive *(61, 71-75)* as exemplified by the following extracts.

"You have welcomed me into your family with open arms, which not many people would feel comfortable doing, especially with the reputation that mental health patients have. You have made me feel like a normal human being for the first time in a long time and have given me the space to grow and develop, whilst also being there to support me and provide me with new experiences and conversations."

"My carers listened to me and I could do the ironing!" said an individual who found the act of ironing – something that would never be permitted on an in-patient ward – highly therapeutic and normalizing.

"I was welcomed as a family member, their parents come round, I'm mates with their nephew, I take the dog out for a walk. It's more of a home than a lodging."

Costs and cost comparisons

Individuals within the SEW Shared Lives scheme are financially assessed by their local authority and may be required to pay an assessed charge for their care and support; each local authority has a charging policy.

There is no financial cost or contribution for the Shared Lives for Mental Health Crisis scheme in South East Wales. Funding comes from the Welsh Government Transformation Fund, through the Health Board's Mental Health and Learning Disability Division. The full cost of the service for individuals experiencing a mental health crisis is met by ABUHB.

In 2020, Shared Lives carers in South East Wales received between £340 (approximately US$ 471[h]) and £588 (approximately US$ 822[h]) per week if someone moves in with them, depending on the level of support the individual requires; carers within the Mental Health Crisis scheme receive the highest rate to reflect the high level of support they provide. Carers who offer day support only are paid per block of time, usually four hours in a day.

Shared Lives is a relatively low-cost form of care and support; long-term Shared Lives arrangements are 43% cheaper than alternatives for people with learning disabilities, and 28% cheaper for people with mental health needs, saving an average of £26,000 (US$ 36,345[h]) and £8,000 (US$ 11,200[h]) per year respectively according to one evaluation *(76)*. Another report stated that entering a Shared Lives home, rather than residential care or an alternative, saved councils an annual average £13,000 per person *(77)*.

A week in the Shared Lives Mental Health Crisis scheme (including infrastructure costs and crisis team time) costs £672 (approximately US$ 939[h]) per week, compared with £3,213 (approximately US$ 4,490[h]) per week for inpatient hospital care (including direct and non-direct costs) in South East Wales ([Waites B], [Aneurin Bevan University Health Board], personal communication, [2020]). As the service is currently funded to offer 99 weeks of arrangements with Shared Lives carers, this will cost £66,528 (US$ 92,985[h]) to provide. Inpatient care for the same time period would cost £318,087 (US$ 444,583[h]). If it is assumed that the alternative would be hospital admission, the savings amount to £251,559 (US$ 351,621[h]) over a year.

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[h] Conversion as of March 2021.

Challenges and Solutions

Allaying concerns and anxieties amongst the mental health profession

A significant challenge was that professionals expressed concerns and anxiety about moving someone assessed as being too 'at risk' to remain in their home, out of a hospital and into a non-medical setting.

One method to help overcome these worries, was to ensure close senior management involvement and engagement so that the positive risk taking was highly visible. Importantly, decisions were supported by senior management not solely by individual clinicians or teams. The service also made the space for concerns and anxieties to be aired by holding three team development days; it shared case studies from the existing Shared Lives scheme; and most powerfully, enabled mental health staff to meet Shared Lives Carers and hear their experiences of supporting people in their own homes.

Managing funding challenges

Securing funding to get the initiative started was a challenge. Limited finances meant the service might have been introduced at the expense of other existing hard-pressed services.

Securing funds through the Welsh Government service transformation investment prevented other services from losing out. The SEW Shared Lives scheme specifically has received more funding to expand its services to short-term support, enabling people to recover their independence after ill-health. Ultimately, the Shared Lives for Mental Health Crisis scheme was funded based on this track record of successful practice and was fully funded by the Health Board using transformation funding.

Overcoming complexities when working with different partners

Establishing and working with different partners across health and social services, to make this service possible, was challenging. Considerable effort was put into getting the right people around the table in order to secure buy-in. The service held a series of meetings with key partners and local authorities. It also jointly delivered training to build the relationships and trust required to work in a truly collaborative way. Given the dramatic shift in thinking required, the service engaged a wide range of stakeholders — from those involved operationally with the service, to service users and carers. Importantly, it engaged stakeholders with seniority to ensure any departure from normal practice was approved every step of the way. The service worked hard to help certain stakeholders understand that the true value lies in the outcomes the service delivers, in terms of better experiences for individuals, and better outcomes over the longer term (for example reduced re-admission and other parameters). Ultimately, the process took two years from agreeing the direction to initial implementation.

Ongoing awareness-raising of the service as an alternative to "business as usual"

A factor that contributed to difficulties was maintaining recognition of the service as an alternative option to "business as usual", or traditional mental health services. Ensuring the regular presence of the Shared Lives teams in both the crisis team and in the weekly hospital ward round, helped to create an ongoing understanding and appreciation of the service.

Ensuring support to the carers and crisis team

Lack of adequate support for carers and the crisis team when issues arose during placements was a limiting factor. In response Shared Lives created a highly responsive carer support team with easy access to management; this team could find solutions and develop policies rapidly to respond to issues as they arose. In addition, it ensured that arrangements were appropriately goal-based so that they could be successful. It ensured that transitions out of placements were anticipated and planned from the outset.

Addressing issues efficiently was a priority. Therefore the service developed practical documents to help practitioners develop and improve their understanding of Shared Lives. These included an information-sharing protocol, operational guidance and specific policies on drug and alcohol use and also on boundaries and attachment to support good working practice in response to issues as they emerged. These were shaped by practitioners, carers, individuals and senior leaders, and ratified at senior levels of the organization.

Key considerations for different contexts

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

- having sufficient numbers of carers with the right knowledge and skills to meet demand is critical, as is having sufficient staff levels to meet the growing demand for the service;
- investing in systematic efforts to build the case for additional investment in staff;
- asking existing carers to spread the word;
- evaluating over the short, medium and long term, to demonstrate the value of the service;
- making sure there is resourced capacity to support evaluations of the project and presenting findings on a regular basis;
- gathering Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) and including pertinent data on service use (for example inpatient bed days, Accident and Emergency contacts, crisis team contacts);
- creating digital stories in which an individual and carer share their experiences; these help show the value of this service;
- maintaining a meticulous matching process to ensure the service remains tailored to the individual, as the quality of this form of social care depends on it;
- building quality care regulation capacity to guarantee an effective oversight system, inspected regularly by an independent body. This ensures relationships do not result in neglect, coercion, violence and abuse;
- ensuring the cultural context and degree of mental health stigma is taken in consideration. It may be less acceptable in some cultures to welcome someone into one's home in exchange for a salary; and
- testing the acceptability of this kind of service within a community because it relates to welcoming people into homes.

Additional information and resources:

Website:
https://www.caerphilly.gov.uk/sharedlives
https://abuhb.nhs.wales/about-us/public-engagement-consultation/transforming-adult-mental-health-services-in-gwent/

Videos:
Shelley Welton & Simon Burch's Story: Setting up the service
https://www.youtube.com/watch?v=8F55IboVbhg

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

Shared Lives for Mental Health Crisis
https://abuhb.nhs.wales/about-us/public-engagement-consultation/transforming-adult-mental-health-services-in-gwent/

Contact:
Benna Waites, Joint Head of Psychology, Counselling and Arts Therapies, Mental Health and Learning Disabilities, Aneurin Bevan University Health Board, United Kingdom,
Email: Benna.Waites@wales.nhs.uk

3.

Moving forward: from concept to good practice supported living services for mental health

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

Action steps for setting up or transforming supported living services for mental health:

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

Questions specific to setting up or transforming supported living services for mental health:

- Are you aiming to set up or to transform an existing supported living service?
- How will the service be structured: shared apartments, or housing, single rooms or double rooms?
- How will the service create a homely environment and atmosphere where personal space and the privacy of persons are respected?
- Will the service offer short-term or long-term supported living or both?
- What human resources will be required (such as peer support workers, occupational therapists, nurses, social workers, community or lay workers, and administrative staff)? What sorts of skills and training will be required for them to provide quality and evidence-based services in line with human rights?
- How will the residence be staffed? Will there be live-in staff or day and night shifts? Will there be on-call staff?
- Who are the beneficiaries of the service: will anyone be excluded? Will it be open to specific groups, such as people with specific needs and diagnoses, based on certain ages or gender, people living in poverty, people who have been institutionalized? How will the service be accessed?
- What will be the interrelationship between this and other services, support and resources in the community, including upward and downward referral systems?
- What support are you planning to provide within the service? Options may include:
    - assessments of support needs
    - interventions explicitly related to community inclusion
    - person-centred recovery planning
    - peer support
    - social and leisure activities
    - skills building (including self-care, managing money, cooking, domestic skills, time management, relationships, and parenting), and
    - other.
- What services are you planning to facilitate access to in the community?

Options may include:

- crisis services
- hospital-based services
- community mental health centres, and
- other.

- How will your service assess, provide for or refer people for any physical health conditions they may have?
- What strategies and training are you planning to put in place to realize legal capacity, non-coercive practices, participation, community inclusion and recovery orientation[i]?

Legal capacity

- How will the service ensure that mechanisms for supported decision-making are in place so that decisions are based on the will and preference of the person?
- How will the service approach informed consent by service users in relation to treatment decisions?
- What processes will the service put in place to systematically support people to develop advance plans?
- What kind of mechanisms will the service put in place to ensure that people can make a complaint if they need to?
- How will the service facilitate access to legal advice and representation by its users who may need this type of service (e.g. pro bono legal representation)?

Non-coercive practices

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

Participation

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

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

Community inclusion

- How will the service support people to find work and income generation opportunities, for example through a transitional employment programme, supported employment programme or through independent employment as appropriate?
- How will the service facilitate supported education and assistance in accessing community-based education opportunities and resources to continue education?
- How will the service facilitate access to social protection benefits?
- How will the service facilitate access to social and recreational programmes?

Recovery

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

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

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