



One-to-one peer support by and for people with lived experience

WHO QualityRights guidance module

QualityRights



World Health
Organization

Transforming services and promoting the rights of people with psychosocial,
intellectual and cognitive disabilities

One-to-one peer support by and for people with lived experience. WHO QualityRights guidance module

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The accompanying slides are available here <https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools>

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Foreword

Ensuring mental health and well-being has become a worldwide imperative and an important target of the Sustainable Development Goals.

But in all countries around the world, our response has been woefully insufficient, and we have made little progress to advance mental health as a fundamental human right.

One in ten people are affected by a mental health condition, up to 200 million people have an intellectual disability and an estimated 50 million people have dementia. Many persons with mental health conditions, or psychosocial, intellectual, or cognitive disabilities lack access to quality mental health services that respond to their needs and respect their rights and dignity.

Even today, people are locked up in institutions where they are isolated from society and marginalized in their communities. Many are subjected to physical, sexual, and emotional abuse and neglect in health services, prisons, and the community. They are also deprived of the right to make decisions for themselves, about their care and treatment, where they want to live, and their personal and financial affairs. They are often denied access to health care, education and employment opportunities, and are prevented from full inclusion and participation in community life. As a result, people with mental health conditions and intellectual disabilities die 10 to 20 years younger than the general population in low-, middle- and high-income countries alike.

The right to health is fundamental to the World Health Organization's (WHO's) mission and vision, and underpins our efforts to achieve universal health coverage (UHC). The foundation of UHC is strong health systems, based on primary care, that deliver evidence based, person-centred services that respect people's values and preferences.

Fourteen new WHO QualityRights training and guidance modules are now available to achieve this vision. They will enable countries to translate international human rights standards into practice by influencing policy and building the knowledge and skills to implement person-centered and recovery-based approaches. This is what is required to provide quality care and support and to promote mental health and well-being.

Our conviction is that everyone—whether a service provider or member of the community, needs to have the knowledge and skills to support someone who has a mental health condition, psychosocial, intellectual, or cognitive disability.

We hope that these QualityRights training and guidance modules will be used widely and that the approach they offer will become the norm rather than the exception in mental health and social services worldwide.



Dr Tedros Adhanom Ghebreyesus
Director-General
World Health Organization

Supporting statements

Dévoira Kestel, Director, Department of Mental Health and Substance Use, World Health Organization, Geneva

Around the world, there is increasing awareness of the importance of mental health and providing services and supports that are person-centred and promote a recovery oriented and human rights-based approach. This awareness comes alongside a recognition that mental health systems in high, middle and low-income countries are failing many individuals and communities due to limited access, poor quality services and human rights violations.

It is unacceptable that people using mental health services can be exposed to inhuman living conditions, harmful treatment practices, violence, neglect and abuse. There are many reports of services not responding to people's needs or failing to support them to live the independent lives in their community - instead their interactions with services often leaves them feeling hopeless and disempowered.

In the wider community context, people with mental health conditions, psychosocial, intellectual or cognitive disabilities are subjected to stigma, discrimination and extensive inequalities that permeate all aspects of their lives. They are denied opportunities to live where they choose, marry, have families, attend school, seek employment and enjoy leisure activities.

Adopting recovery and human rights approaches is essential if we are going to change this situation. A recovery approach ensures that services place people themselves at the centre of care. It focuses on supporting people to define what recovery looks like and means for them. This approach is about helping people to regain control of their identity and life, have hope for the future, and to live a life that has meaning for them, whether that be through work, relationships, community engagement, spirituality or some or all of these.

Recovery and human rights approaches are very much aligned. Both approaches promote key rights such as equality, non-discrimination, legal capacity, informed consent and community inclusion (all enshrined in the Convention on the Rights of Persons with Disabilities). However, the human rights approach imposes obligations on countries to promote these rights.

Through these training and guidance modules developed as part of the QualityRights initiative, the World Health Organization has taken decisive action to address these challenges and to support countries to meet their international human rights obligations. These tools enable several key actions to be realized around: promoting participation and community inclusion for people with lived experience; capacity building in order to end stigma and discrimination and promote rights and recovery; and strengthening peer support and civil society organisations to create mutually supportive relationships and empower people to advocate for a human rights and person-centred approach in mental health and social services.

I look forward to seeing these World Health Organization tools used in countries to provide a comprehensive response to the challenges faced by people with mental health conditions, psychosocial, intellectual or cognitive disabilities.

Dainius Puras, Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest attainable Standard of Physical and Mental Health.

QualityRights offers a new approach to mental health care which is rights-based and recovery-oriented.

This initiative of the World Health Organization is very timely. There is increasing understanding that mental health care policies and services worldwide need to change. Too often services for people with psychosocial disabilities and other mental health conditions are reliant on coercion, overmedicalization and institutionalization. This status quo is not acceptable, as it may continue to reinforce stigma and helplessness among both users and providers of mental health services.

All stakeholders – including policy-makers, mental health professionals and people using mental health services – need to be equipped with knowledge and skills in effective ways to manage change and to develop sustainable rights-based mental health services.

The QualityRights initiative, through specific well-designed modules, provides the necessary knowledge and skills, convincingly demonstrating that change is possible and that this change will lead to a win-win situation. Firstly, persons with disabilities and other mental health conditions, who may need mental health services, will be motivated to use services that empower them and respect their views. Secondly, providers of services will be competent and confident in applying measures that prevent coercion. As a result, power asymmetries will be reduced, and mutual trust and therapeutic alliance will be strengthened.

To abandon the legacy of outdated approaches in mental health care – based on power asymmetries, coercion and discrimination – may not be an easy direction to take. But there is growing understanding that the change towards rights-based and evidence-based mental health services is needed around the globe – in high-, middle- and low-income countries. WHO's QualityRights initiative and its training and guidance materials are extremely useful tools that will support and empower all stakeholders willing to go in this direction. I strongly recommend all countries to take QualityRights on board.

Catalina Devandas Aguilar, Special Rapporteur on the Rights of Persons with Disabilities

Persons with disabilities, particularly those with psychosocial and intellectual disabilities, often experience human rights violations in the context of mental health services. In most countries, mental health legislation allows involuntary hospitalization and treatment of persons with disabilities on grounds of their actual or perceived impairment, plus factors such as “medical necessity” and “dangerousness”. Seclusion and restraints are regularly used during emotional crisis and severe distress in many mental health services, but also as form of punishment. Women and girls with psychosocial and intellectual disabilities are regularly exposed to violence and harmful practices in mental health settings, including forced contraception, forced abortion and forced sterilization.

Against this background, the WHO QualityRights initiative can provide essential guidance on the implementation of mental health services and on community-based responses from a human rights perspective, offering a path towards ending institutionalization and involuntary hospitalization and treatment of persons with disabilities. This initiative calls for training health-care professionals to provide health care and psychosocial support to persons with disabilities in a way that is respectful of their rights. By promoting compliance with the CRPD and the 2030 Agenda frameworks, the WHO QualityRights modules bring us closer to realizing the rights of persons with disabilities.

Julian Eaton Director, Mental Health, CBM International

The increase in interest in mental health as a development priority offers the opportunity to close the huge gap in care and support, enabling people to realize their right to good health care where this has previously been lacking. Historically, mental health services have often been of very poor quality and have ignored the priorities and perspectives of people who were using them.

The WHO QualityRights programme has been instrumental in putting in place the means for measuring mental health services according to the standards of the Convention on the Rights of Persons with Disabilities. This often marks a paradigm shift from the way that services have historically worked. The new training and guidance modules are an excellent resource, facilitating better practice in supporting people with mental conditions and psychosocial disabilities, enabling their voices to be heard, and promoting healthier environments that foster recovery. There is a long way to go, but QualityRights is a crucial resource for service providers and users, guiding practical reform for services that value dignity and respect, wherever they may be in the world.

Charlene Sunkel, CEO, Global Mental Health Peer Network

The World Health Organization's QualityRights training and guidance package promotes a strong participatory approach. It recognizes and values the importance of the lived experience of people with psychosocial, intellectual or cognitive disabilities in promoting recovery, undertaking advocacy, conducting research and reducing stigma and discrimination. The QualityRights tools ensure compliance with human rights standards, implementing strategies to end coercive practices. They show how persons with lived experience can provide peer support and can also contribute to the development, design, implementation, monitoring and evaluation of mental health and social services. Lived experience is much more than just knowledge and skills. Expertise emanates from people's in-depth understanding of the social and human rights impact of living with a psychosocial, intellectual or cognitive disability and the adversities of being shunned, segregated and discriminated against. It emanates from having to struggle to navigate a mental health system that often fails to provide services or support that would be beneficial to the person as a unique individual and that speaks to their specific recovery needs.

The mental health system is not the only societal system that presents barriers through which the person must navigate; access to other life opportunities such as education, employment, housing and overall health and well-being can be equally challenging. The unique and in-depth perspectives of people with lived experience can be the catalyst for change and transformation of all societal systems in order to protect human rights, encourage inclusion in the community, improve quality of life, and promote empowerment – all of which can contribute towards improved mental health and well-being.

Kate Swaffer, Chair, CEO Dementia International Alliance

It has been an honour and pleasure for Dementia Alliance International (DAI) to work with the WHO QualityRights initiative and its collaborators on this very important project. Human rights have generally been ignored in practice for people with dementia. However, these modules introduce a new approach to mental health, and also to dementia which is a neurodegenerative condition that causes cognitive disabilities. In contrast to the current post-diagnostic pathway for dementia, which is a pathway focused only on deficits and leading only to disability and dependence, this new approach and these unique and enabling modules promote rights and encourage and support people with dementia to live more positively.

By promoting the need for clear access to rights, the modules are practical tools that can be used by everyone, regardless of who they are. The modules, which take key human rights principles and make them actionable in practice, are as applicable and effective for health professionals as they are for people with dementia and their family members. For example, highlighting the need and benefits of peer-to-peer support – which is a free service DAI has been offering people with dementia since 2013, even before it was officially launched – and focusing on the issue of legal capacity and its relevance in terms of Article 12 of the CRPD provide tangible ways to better inform professionals and families to ensure that the rights of people with dementia will no longer be denied. I personally have every confidence that these modules will support all people experiencing mental health problems and psychosocial, intellectual or cognitive disabilities to live with a better quality of life.

Ana Lucia Arellano, Chair, International Disability Alliance

The United Nations Convention on the Rights of Persons with Disabilities, or CRPD, is the groundbreaking human rights treaty that promotes the paradigm shift from considering persons with disabilities as objects of charity or medical treatment to fully recognizing them as subjects of rights. This paradigm shift is particularly significant for persons with intellectual, psychosocial and multiple disabilities, or for persons with more intense support needs. Article 12 of the CRPD is key in promoting this shift in that it recognizes that persons with disabilities can exercise full legal capacity. This is the core human right that establishes the foundation on which all the others can be exercised.

QualityRights is a superb tool for enabling professionals and health practitioners to better understand and embrace the CRPD. The tool creates a bridge between persons with psychosocial disabilities, users and survivors of psychiatry and mental health services and the health sector, respecting the principles and values of the CRPD. The QualityRights modules have been developed in close consultation with users and survivors of mental health services, linking their voices to messages conveyed to States Parties of the CRPD. The International Disability Alliance (IDA) and its member organizations offer congratulations for the work developed under the QualityRights initiative. We strongly encourage WHO to continue efforts to transform mental health laws, policies and systems until they are CRPD-compliant, echoing the strong voices that call out for “Nothing about us, without us!”

Connie Laurin-Bowie, Executive Director, Inclusion International

WHO QualityRights aims to empower individuals and Disabled Persons Organizations to know their human rights and to advocate for change to enable people to live independently in the community and receive appropriate supports. Inclusion International welcomes this initiative which seeks to promote rights that are often denied to people with intellectual disabilities – namely the right to access appropriate mental health services in the community, the right to choose, the right to have a family life, the right to live in the community, and the right to be active citizens. QualityRights is a valuable contribution to our collective efforts to shape and influence policies and practice which enable everyone to be included in their communities.

Alan Rosen, Professor, Illawarra Institute of Mental Health, University of Wollongong, and Brain & Mind Centre, University of Sydney, Australia.

Freedom is therapeutic. Facilitating human rights in our mental health services can bring healing. It can ensure that, whenever possible, the person who is living with a mental health condition: a) retains choice and control over the assistance and care provided and b) is offered good-quality clinical and home support, if needed, to live in the community without disruption and "on their own turf and terms".

Following a long history of human rights advocacy in psychiatry, these modules show how the right to adequate care and all human rights and fundamental freedoms can be met without contradiction. Coercion in care – such as restraints, seclusion, forced medications, locked inpatient units, being cooped up in restrictive spaces, and institutional warehousing – must be curtailed. The optimal attainment of liberty in care entails immense change. This includes the widespread systematizing of practical evidence-based alternatives to avoid coercion – i.e. open doors, open respite facilities, open and free access, open communities, open minds, open conversations between equals, supported community living, enhancement of individual and family communication, problem-solving skills and support, advance directives, training in soothing and de-escalation, supported decision-making, the recovery orientation of all services and peer workers, and the co-production of policy with all stakeholders.

The WHO QualityRights programme, based on the United Nations CRPD, has been transformed here into a highly practical set of modules. For our professions, these modules offer a trajectory and a horizon to work towards rather than a finite answer or deadline. As well as optimizing clinical and support services, our political, legal and social actions with service users and their families have to be combined with our own emancipation as professionals from institutional thinking and from being yoked to habitual practices in mental health care. Only then and together can we vastly improve the prospects for an empowered, purposeful, contributing life, with full citizenship and full rights, for persons living with severe, persistent or recurrent mental health problems.

Victor Limaza, Activist and facilitator of Justice for People with Disabilities, Documenta AC (Mexico)

Dignity and well-being are closely related concepts. Nowadays, those criteria by which we judge psychological suffering only in terms of neurochemical imbalances are being questioned, as is the view that certain manifestations of human diversity are pathologies that must be attacked to protect the person and society from supposed dangers, even though the interventions used may violate rights and cause irreversible damage. The interdisciplinary and holistic outlook in which subjective discomfort is addressed without undermining the dignity and ability of the person to make decisions, even in critical situations, should be the foundation on which the new mental health care models are constructed, respecting the principles of the CRPD. Understanding the experience of a person facing a critical state in their mental health is possible thanks to the bond generated through empathy, listening, open dialogue, accompaniment (especially among peers), support in decision-making, life in the community and the advance directives under strict safeguards. People with psychosocial disabilities are experts from experience and must be involved in developing the instruments that seek to lead to recovery. The QualityRights initiative of WHO is a good example of this paradigm shift providing tools and strategies for mental health care with the highest standards of respect for human rights. Undoubtedly, the full and equitable enjoyment of all human rights by every person promotes mental health.

Peter Yaro, Executive director, Basic Needs Ghana

The WHO package of training and guidance documents is a rich collection of material that aims to enhance work in mental health and rights-based inclusive development. The materials provide a significant step towards effective programming and mainstreaming of disabilities – especially psychosocial, intellectual and developmental disabilities – in interventions to address individuals' needs and rights as provided for in the CRPD. The QualityRights package marks a giant stride towards the longstanding recommendation that persons with lived experience be part and parcel of the conceptualization and implementation of interventions, together with the monitoring and evaluation of the project's achievements. With this guidance, the sustainability of initiatives can be assured and, for this reason, practitioners, service users, caregivers and all stakeholders are encouraged to utilize

the documents. In the approach presented here, there is no place for perpetrating violence and abuse on already vulnerable persons.

Michael Njenga, Chairperson of the Pan African Network of Persons with Psychosocial Disability, Executive Council Member, Africa Disability Forum and C.E.O. Users and Survivors of Psychiatry, Kenya

There is paradigm shift in the way we need to address mental health globally. The impetus for this shift has been created by the Convention on the Rights of Persons with Disabilities (CRPD) and by the adoption of the Sustainable Development Goals (SDGs) and the 2030 Agenda for Sustainable Development.

WHO's QualityRights tools and materials for training and guidance build on this key international human right as well as on international development instruments. The QualityRights initiative adopts a human rights-based approach to ensure that mental health services are provided within a human rights framework and are responsive to the needs of persons with psychosocial disabilities and mental health conditions. These materials also lay emphasis on the need to provide services as close as possible to where people live.

The QualityRights approach recognizes the importance of respecting each individual's inherent dignity and ensuring that all persons with psychosocial disabilities and mental health conditions have a voice, power and choice while accessing mental health services. This is an integral element in reforming mental health systems and services both globally and at local and national levels. It is essential, therefore, to make sure that these training tools and guidance materials are widely used so that they result in tangible outcomes at all levels for people with lived experience, their families, communities and entire societies.

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.
- 2** Improve the quality of care and human rights conditions in mental health and social services.
- 3** Create community-based and recovery-oriented services that respect and promote human rights.
- 4** Support the development of a civil society movement to conduct advocacy and influence policy-making.
- 5** Reform national policies and legislation in line with the Convention on the Rights of Persons with Disabilities and other international human rights standards.

For more information: http://www.who.int/mental_health/policy/quality_rights/en/

WHO QualityRights – Training and guidance tools

The following training and guidance modules and slide presentations available as part of the WHO QualityRights initiative, can be accessed at the following link: <https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools>

Service transformation tools

- The WHO QualityRights assessment toolkit
- Transforming services and promoting human rights

Training tools

Core modules

- Human rights
- Mental health, disability and human rights
- Recovery and the right to health
- Legal capacity and the right to decide
- Freedom from coercion, violence and abuse

Specialized modules

- Supported decision-making and advance planning
- Strategies to end seclusion and restraint
- Recovery practices for mental health and well-being

Evaluation tools

- Evaluation of the WHO QualityRights training on mental health, human rights and recovery: pre-training questionnaire
- Evaluation of the WHO QualityRights training on mental health, human rights and recovery: post-training questionnaire

Guidance tools

- One-to-one peer support by and for people with lived experience ←
- Peer support groups by and for people with lived experience
- Civil society organizations to promote human rights in mental health and related areas
- Advocacy for mental health, disability and human rights

Self-help tools

- Person-centred recovery planning for mental health and well-being – self-help tool

About this training and guidance

The QualityRights training and guidance modules have been developed to enhance knowledge, skills and understanding among key stakeholders on how to promote the rights of persons with psychosocial, intellectual or cognitive disabilities and improve the quality of services and supports being provided in mental health and related areas, in line with international human rights standards, and in particular the United Nations Convention on the Rights of Persons with Disabilities and the recovery approach.

Who is this training and guidance for?

- **People with psychosocial disabilities**
- **People with intellectual disabilities**
- **People with cognitive disabilities, including dementia**
- **People who are using or who have previously used mental health and social services**
- **Managers of general health, mental health and social services**
- **Mental health and other practitioners** (e.g. doctors, nurses, psychiatrists, psychiatric and geriatric nurses, neurologists, geriatricians, psychologists, occupational therapists, social workers, community support workers, personal assistants, peer supporters and volunteers)
- **Other staff working in or delivering mental health and social services, including community and home-based services** (e.g. attendants, cleaning, cooking, maintenance staff, administrators)
- **Nongovernmental organizations (NGOs), associations and faith-based organizations working in the areas of mental health, human rights or other relevant areas** (e.g. organizations of persons with disabilities (DPOs); organizations of users/survivors of psychiatry, advocacy organizations)
- **Families, support persons and other care partners**
- **Relevant ministries (Health, Social Affairs, Education, etc.) and policymakers**
- **Relevant government institutions and services** (e.g. the police, the judiciary, prison staff, bodies that monitor or inspect places of detention including mental and social services, law reform commissions, disability councils and national human rights institutions)
- **Other relevant organizations and stakeholders** (e.g. advocates, lawyers and legal aid organizations, academics, university students, community or spiritual leaders, and traditional healers if appropriate)

Who should deliver the training?

Training should be designed and delivered by a multidisciplinary team, including people with lived experience, members of disabled persons' organizations (DPOs), professionals working in mental health, disability and related fields, families and others.

If the training is about addressing the rights of people with psychosocial disabilities specifically, it is important to have representatives from that group as leaders for the training. Likewise, if the purpose is to build capacity on the rights of persons with intellectual or cognitive disabilities, the leaders of the training should also be from these groups.

In order to liven up discussions, different options can be considered. For instance, facilitators with specific knowledge of a particular part of the training can be brought in for specific aspects of the training. Another option may be to have a panel of trainers for specific parts of the training.

Ideally, facilitators should be familiar with the culture and context of the location where the training is taking place. It may be necessary to conduct train-the-trainer sessions in order to build up a pool of

people who are able to carry out the training within a particular culture or context. These train-the-trainer sessions should include persons with psychosocial, intellectual or cognitive disabilities. They should also include other relevant local stakeholders who contribute to improving the quality of mental health and social services and the human rights of people with psychosocial, intellectual or cognitive disabilities.

How should the training be delivered?

Ideally, all the QualityRights training modules should be delivered, starting with the five core foundational modules. This can be followed by more in-depth training using the specialized modules (see above).

The whole training can be conducted through multiple workshops taking place over the course of several months. Each separate training module does not necessarily have to be completed in one day. It can be divided into topics and can be conducted over the course of several days, as required.

Since the training materials are quite comprehensive and time and resources may be limited, it may be useful to adapt the training according to the existing knowledge and background of the group, as well as the desired outcomes of the training.

Thus, the way these training materials are used and delivered can be adapted according to the context and requirements.

- For example, if participants do not yet have any expertise in the areas of mental health, human rights and recovery, it would be important to conduct a 4–5-day workshop using the five core training modules. A 5 day sample agenda available at the following link: <https://qualityrights.org/wp-content/uploads/Sample-program-QR-training.pdf>
- If participants already have a basic understanding of the human rights of people with psychosocial, intellectual and cognitive disabilities but require more advanced knowledge about how specifically to promote the right to legal capacity in practice, then a workshop could be organized to focus on the module *Legal capacity and the right to decide* on day 1 and on the specialized module on *Supported decision-making and advance planning* (or selected parts of that module) on days 2, 3 and 4.

When adapting the training materials according to specific training requirements it is also important, prior to the training, to go through all the modules to be covered in order to get rid of unnecessary repetition.

- For example, if a training is planned, covering all the core modules, then it will not be necessary to cover topic 5 (zooming in on article 12) or topic 6 (zooming in on article 16) since these issues will be covered in much greater depth in the subsequent modules (module on *Legal capacity and the right to decide* and on *Freedom from coercion, violence and abuse* respectively).
- However if an introductory training is planned based solely on module 2, then it is essential to cover topics 5 and 6 of this module, since this will be the only exposure that the participants will receive on these issues and articles.

These are examples of the different and varied ways in which the training materials can be used. Other variations and permutations are also possible on the basis of the needs and requirements of the training in a particular context.

Preliminary note on language

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. Similarly, intellectual disability is referred to using different terms in different contexts including, for example, “learning disabilities” or “disorders of intellectual development” or “learning difficulties”.

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 terms “cognitive disability” and “intellectual disability” are designed to cover people who have received a diagnosis specifically related to their cognitive or intellectual function including, but not limited to, dementia and autism.

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 use of the term “disability” in this context does not imply that people have an impairment or a disorder.

We also use the terms “people who are using” or “who have previously used” mental health and social services to refer to people who do not necessarily identify as having a disability but who have a variety of experiences applicable to this training.

In addition, the use of the term “mental health and social services” in these modules refers to a wide range of services currently being provided by countries including, for example, community mental health centres, primary care clinics, outpatient services, psychiatric hospitals, psychiatric wards in general hospitals, rehabilitation centres, traditional healers, day care centres, homes for older people, and other “group” homes, as well as home-based services and services and supports offering alternatives to traditional mental health or social services, provided by a wide range of health and social care providers within public, private and nongovernmental sectors.

The terminology adopted in this document 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

The purpose of this module is to give guidance on how to provide and strengthen individualized peer support for people with psychosocial, intellectual or cognitive disabilities. The module focuses on the provision of one-to-one “in person” support rather than other forms such as social media and online peer-to-peer support. Individualized peer support is more established in the mental health field than it is for persons with intellectual or cognitive disabilities, and this is reflected in the paucity of real-life examples in this module related to these persons. However, this type of peer support is equally valuable for persons with intellectual or cognitive disabilities.

Peer support can be provided by different organizations. However, using independent peer-run organizations to deliver services can be extremely valuable as they can help people to connect to others outside structured one-to-one or group interactions. People have the possibility to form natural relationships with persons of their choice in their own environment, independent of any formal structures or settings.

This module should be used in conjunction with the other QualityRights training and guidance modules.

2. What is individualized peer support?

Individualized peer support in the context of this module is one-to-one support provided by a peer who has personal experience of issues and challenges similar to those of another peer who would like to benefit from this experience and support. Individualized peer support can be provided by people hired by mental health or social services, people working in an autonomous and independent peer support role or by people engaged in non-hierarchical and unpaid peer support. The aim is to support people on the issues they consider important for their recovery in a way that is free from assumptions and judgement. In doing so, the peer supporter becomes an empathetic listener, coach, advocate and partner.

Peer supporters, who are experts by experience, are able to relate to, connect with and support individuals who are going through challenges in a unique way because of their experience.

Peer support can be provided in a variety of settings – e.g. in people’s homes, in the premises of the peer-run organization, and in the full range of mental health and social services. Ideally, mental health or social services should contract independent organizations to arrange for peer supporters to work in the service in order to preserve the autonomy and independence of peer support activities. The service can facilitate access to individualized peer support for its users.

Peer support can be provided by volunteers or paid supporters. Depending on the organization or group, peer supporters may be referred to as peer specialists, peer leaders or recovery coaches, among other titles.

“The term ‘peer’ does not simply refer to someone who has had a particular experience. Peer-to-peer support is primarily about how people connect to and interact with one another in a mutual relationship.”.... “Based on wisdom gained from personal experience, people in peer roles advocate for growth and facilitate learning...” (1).

“[Peer support] may be social, emotional or practical support (or all of these) but importantly this support is mutually offered and reciprocal, allowing peers to benefit from the support whether they are giving or receiving it” (2).

Recent research examined peoples’ responses to the question “What constitutes a peer?” A significant majority expressed the view that a peer needs to have more than a shared experience of mental

distress in common. The peer also needs to have a shared view of what recovery means, a shared understanding of a diagnosis or experience, and a shared view of particular treatments. People also highlighted the importance of shared characteristics that are not directly related to mental health, such as gender, ethnicity, faith and age (3).

Peer support is central to the recovery approach. Through sharing experiences, listening empathetically and providing encouragement, peer supporters can support people with psychosocial, intellectual or cognitive disabilities to find their own meaning of recovery in order to live fulfilling and satisfying lives (4),(5).

The meaning of recovery can be different for each person. For many people recovery is about regaining control of their identity and life, having hope for their life, and living a life that has meaning for them, whether that be through work, relationships, community engagement or some or all of these. (For more information about recovery, see QualityRights training modules *Recovery and the right to health* and *Recovery practices for mental health and well being*).

Examples of peer support actions and practices include:

- Sharing experiences, strategies and stories of hope and recovery.
- Encouraging people to take responsibility for their own life and recovery.
- Encouraging people without doing things for them.
- Providing people with relevant information.
- Helping people to build social networks in the community.
- Supporting people to ensure that their human rights are respected.

3. Individualized peer support values

As peer support becomes more widespread in countries across the world, it is important that its development remains anchored in an intrinsic set of values including (6),(7):

Mutuality and equality: Peer support acknowledges that both parties can learn from each other within an equal, accepting and respectful relationship. With mutual peer support, power differentials are minimized and power is shared as equally as possible within the peer relationship. Peer supporters should not be in a position of reporting back to service providers about the people they are supporting as this is contrary to the values of mutuality and equality.

Self-determination and empowerment: Peer support is based on the principles of individual choice and autonomy, and peer supporters should create an environment in which the individual can take greater control of his or her own life. Empowerment is a process in which individuals gain confidence in their own capacity to make decisions and which can lead to enhanced personal strength and efficacy. Since the focus is on empowering people to make their own decisions, efforts are taken to avoid the development of a relationship of dependency between the peer supporter and person being supported.

Empathy: The ability to relate to another person through understanding their experience from their perspective is central to individualized peer support and leads to greater empathy in peer-to-peer relationships.

Recovery: Recovery is a unique and individual experience. A key value of individualized peer support is to help the person determine what is best for their own life and well-being. Peer support strives to be holistic and offers people an opportunity to explore multiple paths of recovery in order to select the one(s) that is right for them.

“Shortly after being discharged from hospital I was introduced to a... peer support worker. This peer worker was probably the single most important factor in my recovery. Working with him over many months I was able to slowly get some perspective on my life as well as design what might be my future. It was inspiring to hear his story of recovery and I felt that I could trust him more than any other mental health worker because of his own experience of mental illness” (8).

“Considering the situation of M... I always have put myself in his place, because he lived (in his home) generally without light, right? In the dark. And there was no running water. I have lived in a home like this, you know? It had no light, no running water. So ... once I was on the train, and I saw a guy selling a flashlight to put on the head, and I bought it from him... I brought the flashlight to M..., for him to put at his head and at least, have light inside his house, right?” (9).

Some models of peer support put a greater emphasis on mutuality, partnership and co-creation of knowledge, viewing the relationship between the peers as a two-way process (e.g. intentional peer support) while other models tend to function more as a service provision from one person to another.

4. Benefits of individualized peer support

(10)

The structural barriers and discrimination in society and services can leave those who seek help feeling marginalized, isolated, hopeless and frustrated. Individualized peer support can provide a safe and inclusive social environment, delivered by those with deep personal understanding, that fosters hope, participation and empowerment (11).

Peer support benefits both the people experiencing distress and facing difficult situations and the peer supporters themselves. For individuals, the key benefits afforded through the support of a peer include improved engagement with services and therapeutic relationships with providers, increased empowerment, personal growth, hope for recovery, and a reduction in inpatient admissions outside of their advanced crisis plans (12),(13),(14). Through transforming their own challenging experiences into a source of knowledge, peer supporters similarly experience benefits, improving their self-esteem and purpose, increasing their psychological and emotional well-being and enhancing their social inclusion, interpersonal skills and work capacity (15),(16),(17).

For services, achieving improved patient outcomes through strengthened therapeutic relationships, a decreased number of hospitalizations and a reduced length of stay has the supplementary benefit of decreasing health-care costs (18),(19).

Although it has been challenging to evaluate rigorously the effectiveness of peer support because of the nature and discrepancies of evaluating peer-support outcomes (20), there is widespread acknowledgement that the inclusion of people with lived experience in the delivery of mental health services is equally, if not more, effective than standard care (21). It is an important element in achieving recovery-oriented services (21), and has been observed by people using services, peer support workers and services as feasible, acceptable and beneficial to all stakeholders (22),(23).

The following box contains some examples describing the benefits of individualized peer support.

Raising awareness of the reality of living with dementia in the United Kingdom

Three peer support workers with cognitive disabilities share their experience and point out key benefits of peer support. To listen to their stories, access the following video: <https://youtu.be/yuZF1uiKTUA> (4:22) (accessed 9 April 2019).

Shery Mead - Intentional peer support: a personal retrospective (24)

"...When I was interning for school at a domestic violence programme, a woman comes to see me. She has been told that she is a courageous survivor by other workers but she probably should get into counselling. She gets sent to a community mental health programme. The next day she comes to see me and says that she has a serious mental illness. She no longer sees herself as a survivor but as sick.

What happened here? Why the sudden shift in explanation? Yesterday we were talking about what happened to her. We both knew the problem was abuse in the world. Today she is talking about what's wrong with her.

This troubles me. Over the next months, as we talk I gradually get the courage to bring it up. How did she go from talking about what had happened to her to talking about what is wrong with her?

Together we ponder this question. Our shared stories spark a modicum of self-reflection. We talk about what our lives have looked like since we were diagnosed and slowly we start to make some decisions about whether we want to stay there or not. We both acknowledge some comfort – feelings of safety, perhaps relief – from the fact of our diagnoses. Yet, somehow, our experiences begin to mean something different to us. Increasingly, we begin to challenge the idea that something is 'wrong' with us. Instead we consider that it is perhaps the events that happened to us that were wrong."

Individualized peer support initiated by a former service user at Instituto Centta specialized clinic in Madrid, Spain (25)

When Belen arrived at the clinic for treatment it was, in the words of her husband, "the last chance". After 25 years of fighting with eating disorders, their marriage was severely affected and they didn't know what to do any more. She wanted to live a better life but she could not believe that this was possible. After this last successful attempt, Belen recovered and started to transform her life at all levels. Something that happens with having an eating disorder is that those who suffer them can't really see a possibility of recovery – they do not believe that another life is possible.

Belen was very aware of this, so much that she knew that if only somebody who had gone through that terrible experience and recovered told others "I've been there, I know how it feels" they would be more willing to try. Belen talked to the clinic and she received their commitment to start the peer support unit. The unit has been supporting the treatment process of many persons with eating disorders (some of whom have joined the unit as supporters once recovered). Many have found in their individual chats with the supporters a time of trust and comfort. The families can also benefit, for instance by explaining why some parts of the treatment are more difficult for them and discussing how they can better support their family member.

Attending to diversity can also be beneficial to individualized peer support. For instance, peer support groups and programmes that reflect the needs of particular populations – such as young people,

minority ethnic communities or LGBTIQ – have shown success in promoting recovery, addressing stigma and discrimination, and improving access to mental health supports for groups that often face access barriers – both peer supporters and those in peer support relationships (26),(27),(28),(29) .

Attention to diversity: Black and minority ethnic (BME) communities in the United Kingdom (28)

(Key points from an interview with Jayasree Kalathil, a peer researcher in the United Kingdom responding to the question Why is it essential to think critically about race and diversity (and move beyond tokenism and rhetoric) in peer involvement efforts?)

Background:

- Mental health services are failing to meet the needs of people from BME communities.
- Many people from these communities are more likely to be “diagnosed with schizophrenia, involuntarily committed, sectioned under the Mental Health Act, put in seclusion, over-medicated, and given a Community Treatment Order, when compared to white British communities”.
- Discrimination, high rates of coercion, and stereotypes about black people (e.g. being “dangerous”) can undermine how mental health services respond to their needs and can make families and service users less likely to approach or remain in the services.

Peer involvement-specific barriers:

- Frameworks for peer involvement can assume that “collaborative work between those with personal experiences of using services and those who provide them will take place without challenges”.
- However, BME peers are often marginalized from or within peer involvement forums, thus limiting their input relating to service change and how services can become more equity-oriented.
- Studies have shown that many people from BME backgrounds feel that shared social positions (e.g. ethnic identity) and experiences (e.g. racial discrimination) with peers beyond mental health was important to them.

The T.D.M: Transitional Discharge Model (10:20) <https://youtu.be/OAwcyAZelfE> (accessed 9 April 2019).

Living it Forward (20:47) <https://youtu.be/Rg1PdLJzx5k> (accessed 12 April 2019).

5. Misconceptions about peer support

When a person thinks about the provision of peer support by and for people with psychosocial, intellectual or cognitive disabilities, there may be misunderstandings about the role of peer supporters. Common misconceptions about peer work are summarized in the chart below (6).

Misconception	Why this is a misconception
Peer support is vocational rehabilitation for persons working on their recovery	Choosing people to do peer support because the role will help them in their own recovery is a common mistake. This does not serve those receiving support and should not be the primary purpose of providing peer support.
Peer supporters are fragile and may relapse because of work stress and responsibilities (30)	Peer supporters show resilience, stability and a strong commitment to their own recovery. Peer supporters should be provided with the same benefits and discretion as other employees in managing their health issues. There is no evidence that work leads to relapses.
An effective peer supporter is anyone who has received mental health or related services	Effective peer supporters are skilled in using their experiences intentionally in support of others. Past experience of mental health or social services may be beneficial but not essential; interest in connecting with people, empathy, sharing one’s story and encouraging others to take responsibility are more important components.
Peer supporters should never discuss topics such as suicide or medications	Peer-to-peer conversations should not be limited only to light topics. Because of their own experiences, peer supporters are in an ideal position to discuss more complex and distressing aspects of experiencing distress, the benefits or negative effects of medication and other related issues. A peer supporter may also be the only person that someone wants to share these thoughts with.
Peer supporters will tell people to stop taking their medications or to ignore what their treatment providers want them to do as they often hold “anti-psychiatry” views and beliefs	People in peer roles have diverse backgrounds, views, beliefs and experiences about mental health or social services – some positive, others negative. Regardless of one’s own experience, peer support is about listening and supporting someone in the process of self-determination and not about imposing one’s own viewpoints or beliefs.
In the mental health service context, peer supporters have the same role as staff	Peer supporters’ primary role is to promote hope and belief in the possibility of recovery, empowerment, increased self-esteem, self-efficacy, self-management of difficulties, social inclusion and increased social networks. As such, they act as advocates for the person and should not have to work within traditional practice boundaries. For example, they should not diagnose people using services or prescribe/provide medication.

National Organization of Users and Survivors of Psychiatry (NOUSPR), Rwanda – The valuable role of peer supporters (31)

“Nothing is a greater incentive for being a part of our organization than to support people who are in distress and to provide care for peers through the Patient Experts Programme. Many NOUSPR members are content and proud of being a part of the organization to gather their ‘family’. Patient experts’ main duty is to be themselves and to provide a living example to their peers and their families that the future is bright. They have themselves experienced violence, trauma and neglect, but have recovered and are now self-reliant and supporting their peers to follow the same path. One of the ways of approaching peers is to tell their own personal stories of recovery: ‘Look at me. I, like this person, was shackled, beaten, electrocuted. But now I am here; I have come to support you...’”

6. From ethics to practice

Peer support can look very diverse on a daily basis because it is based on unique human relationships. Generally, peer supporters will provide support and advocacy, promote self-help and empowerment, and facilitate positive change through goal-setting, skills-building and identification of strengths (30). The primary responsibility of peer supporters is towards the person they are supporting, not to the service, organization or society. With this relationship being central, there are key objectives that peer supporters should aim to achieve in their daily work, including (32):

- Sharing experiences and knowledge without giving unsolicited advice.
- Advocating and supporting people to make their own decisions about recovery.
- Treating people with empathy, but not treating them as fragile.
- Valuing the peer role as a nonclinical position and, as such, avoiding pathologizing language.
- Supporting and staying connected to others in peer roles.
- Acting as change agents by sharing new ideas and helping others to be well informed.
- Acknowledging and being transparent about the power and privilege in peer roles and examining that on an ongoing basis.

The following table presents some adapted ethical and practice guidance for carrying out peer support based on a survey and focus groups involving 1000 peer supporters. The guidance sets very high standards for what needs to be practised and should be something that all countries strive to achieve (33):

ETHICAL GUIDANCE	PRACTICE GUIDANCE
<p>Peer support is voluntary</p> <p>The most basic value of peer support is that people freely choose to give or receive support. Nobody should be forced into a peer role or forced to receive peer support. The voluntary nature of peer support makes it easier to build trust and connections with others.</p>	<p>Practice: Support choice</p> <ol style="list-style-type: none"> 1. Peer supporters do not force or coerce others to participate in peer support services or any other service. 2. Peer supporters respect the rights of those they support to choose or cease peer support services or to change their peer supporter. For example, a woman may prefer to connect with a female peer supporter because of her personal experience. 3. Peer supporters also have the right to choose not to work with individuals with a particular background if the peer supporter’s personal approach or lack of expertise could interfere with the ability to provide effective support to these persons. In these situations, the peer supporter would refer the individuals to other peer supporters or other service providers. 4. Peer supporters advocate for choice when they observe coercion in any mental health or social service setting.
<p>Peer supporters are hopeful</p> <p>Belief that recovery is possible brings hope to those feeling hopeless. Hope is the catalyst of recovery for many people. Peer supporters demonstrate that recovery is real; they are the evidence that people can and do overcome the internal and external challenges that confront them.</p>	<p>Practice: Share hope</p> <ol style="list-style-type: none"> 1. Peer supporters tell stories of their personal recovery in relation to current struggles faced by those who are being supported. 2. Peer supporters act as ambassadors of recovery in all aspects of their work. 3. Peer supporters help others reframe life’s challenges as opportunities for personal growth.

<p>Peer supporters are open-minded and non-judgemental</p> <p>Being judged can be emotionally distressing and harmful. Peer supporters “meet people where they are at” in their recovery experience, even when the other person’s beliefs, attitudes or ways of approaching recovery are very different from their own. Being nonjudgemental means holding others in unconditional positive regard, with an open mind, a compassionate heart and full acceptance of each person as a unique individual. In relation to this, peer supporters acknowledge the importance of spiritual beliefs that people may have as part of their recovery.</p>	<p>Practice: Withhold judgement about others</p> <ol style="list-style-type: none"> 1. Peer supporters value diversity and the differences among people they are supporting as potential learning opportunities. 2. Peer supporters respect an individual’s right to choose the pathways to recovery that they believe will work best for them. 3. Peer supporters accept others as they are. 4. Peer supporters do not evaluate, judge or assess others.
<p>Peer supporters are empathetic</p> <p>Empathy is an emotional connection that is created by “putting yourself in the other person’s shoes”. Peer supporters do not assume they know exactly what the other person is feeling, even if they have experienced similar challenges.</p>	<p>Practice: Listen with emotional sensitivity</p> <ol style="list-style-type: none"> 1. Peer supporters practise effective listening skills that are non-judgemental. 2. Peer supporters understand that, even though others may share similar life experiences, the range of responses may vary considerably. 3. Peer supporters ask thoughtful questions and listen with sensitivity to be able to respond emotionally or spiritually to what the other person is feeling.
<p>Peer supporters are respectful</p> <p>Each person is valued and seen as having something important and unique to contribute to the world. Peer supporters treat people with kindness, warmth and dignity. Peer supporters accept and are open to differences, encouraging people to share the gifts, knowledge and strengths that come from human diversity. Peer supporters honour and make room for everyone’s ideas and opinions and believe every person is equally capable of contributing to the whole.</p>	<p>Practice: Be curious and embrace diversity</p> <ol style="list-style-type: none"> 1. Peer supporters embrace diversity (e.g. diverse social positions and ideas) as a means of personal growth for those they support and for themselves. 2. Peer supporters encourage others to explore how differences can contribute to their lives and the lives of those around them. 3. Peer supporters practise patience, kindness, warmth and dignity with everyone they interact with in their work. 4. Peer supporters see all people as worthy of all basic human rights. 5. Peer supporters embrace the full range of experiences, strengths and approaches to recovery for those they support and for themselves.

<p>Peer supporters facilitate change</p> <p>Some of the worst human rights violations are experienced by people with psychosocial, intellectual or cognitive disabilities. They are frequently seen as “objects of treatment” rather than human beings with the same fundamental rights to life, liberty and security as everyone else. People may be survivors of violence (including physical, sexual, emotional, spiritual and mental abuse or neglect). Those who are perceived as different by others may find themselves stereotyped, stigmatized and excluded by society. Internalized oppression is common among people who have been rejected by society. Peer supporters treat people as human beings and remain alert to any practice that is dehumanizing, demoralizing or degrading and will use their personal story and/or advocacy to be an agent for positive change.</p>	<p>Practice: Educate and advocate</p> <ol style="list-style-type: none"> 1. Peer supporters recognize and find appropriate ways to call attention to injustices. 2. Peer supporters strive to understand how injustices may affect people. 3. Peer supporters encourage, coach and inspire those they support to challenge and overcome injustices. 4. Peer supporters use language that is supportive, encouraging, inspiring, motivating and respectful. 5. Peer supporters help those they support to explore areas in need of change for themselves and for others. 6. Peer supporters recognize injustices that peers face in all contexts and act as advocates and facilitate change where appropriate. 7. Peer supporters educate others about their rights and the tools they have, such as advance directives and recovery plans.
<p>Peer supporters are honest and direct</p> <p>Clear and thoughtful communication is fundamental to effective peer support. Difficult issues are addressed with those who are directly involved. Privacy and confidentiality build trust. Honest communication enables people to move beyond the fear of creating conflictual situations or of hurting someone’s feelings to the ability to work together respectfully to resolve challenging issues with caring and compassion, including issues related to stigma, abuse, oppression, crisis or safety.</p>	<p>Practice: Address difficult issues with caring and compassion</p> <ol style="list-style-type: none"> 1. Peer supporters respect privacy and confidentiality. 2. Peer supporters engage, when desired by those they support, in open discussions about stigma, abuse, oppression, crisis or safety. 3. Peer supporters exercise compassion and caring in peer-support relationships. 4. Peer supporters do not make false promises and do not misrepresent themselves, others or circumstances. 5. Peer supporters strive to build peer relationships based on integrity, openness, respect and trust.

<p>Peer support is mutual and reciprocal In a peer support relationship, each person gives and receives in a fluid, constantly changing manner. This is very different from what most people experience in treatment programmes, where people are seen as needing help and staff are seen as providing that help. In peer support relationships, each person has things to teach and learn. This is true whether you are a paid or volunteer peer supporter.</p>	<p>Practice: Encourage peers to give and receive</p> <ol style="list-style-type: none"> 1. Peer supporters learn from those they support and those who are supported learn from peer supporters. 2. Peer supporters encourage peers to fulfil a fundamental human need -- to be able to give as well as receive. 3. Peer supporters facilitate respect; they honour a relationship with peers that evokes power-sharing and mutuality, wherever possible.
<p>Peer support is equally shared power By definition, peers are equal. Sharing power in a peer support relationship means equal opportunity for each person to express ideas and opinions, offer choices and contribute. Each person speaks and listens to what is said. Abuse of power is avoided when peer support is a true collaboration.</p>	<p>Practice: Embody equality</p> <ol style="list-style-type: none"> 1. Peer supporters use language that reflects a mutual relationship with those they support. 2. Peer supporters behave in ways that reflect respect and mutuality with those they support. 3. Peer supporters do not express or exercise power over those they support (e.g. control what they do, make decisions for them, etc.). 4. Peer supporters do not diagnose or offer medical services; they offer a complementary or alternative service.
<p>Peer recovery support is strengths-focused Each person has skills, gifts and talents they can use to better their own life. Peer support focuses on strengths. Peer supporters share their own experiences to encourage people to see the “silver lining” or the positive things they have gained through adversity. Through peer support, people get in touch with their strengths.</p>	<p>Practice: See what’s strong not what’s wrong</p> <ol style="list-style-type: none"> 1. Peer supporters encourage others to identify their strengths and use them to improve their lives. 2. Peer supporters focus on the strengths of those they support. 3. Peer supporters use their own experiences to demonstrate the use of one’s strengths, and to encourage and inspire those they support. 4. Peer supporters encourage others to explore dreams and goals meaningful to those they support. 5. Peer supporters operate from a strengths-based perspective and acknowledge the strengths, choices and decisions of peers as a foundation for recovery. 6. Peer supporters don’t fix or do for others what they can do for themselves.

<p>Peer support is transparent</p> <p>Peer support is the process of giving and receiving nonmedical assistance to achieve long-term recovery from mental distress. Peer supporters are experientially qualified to assist others in this process. Transparency refers to setting expectations with each person about what can or cannot be offered in a peer support relationship, and clarifying issues related to privacy and confidentiality. Peer supporters communicate with people in plain language so everyone can readily understand; they “put a face on recovery” by sharing personal recovery experiences to inspire hope and the belief that recovery is real.</p>	<p>Practice: Set clear expectations and use plain language</p> <ol style="list-style-type: none"> 1. Peer supporters clearly explain what can or cannot be expected of the peer support relationship. 2. Peer supporters use language that is clear, understandable and value- and judgement-free. 3. Peer supporters use language that is supportive and respectful. 4. Peer supporter roles are distinct from the roles of other health practitioners. 5. Peer supporters make only promises they believe they can keep and use accurate statements.
<p>Peer support is person-driven</p> <p>All people have a fundamental right to make decisions about all aspects of their lives. Peer supporters inform people about options, provide information about choices and respect their decisions. Peer supporters encourage people to move beyond their comfort zones, learn from their mistakes and move towards their chosen level of freedom and inclusion in the community of their choice.</p>	<p>Practice: Focus on the person, not the problems</p> <ol style="list-style-type: none"> 1. Peer supporters encourage those they support to make their own decisions. 2. Peer supporters help people they support to think through different options. 3. Peer supporters encourage people they support to try new things. 4. Peer supporters help others learn from mistakes. 5. Peer supporters encourage resilience. 6. Peer supporters encourage personal growth in others. 7. Peer supporters encourage and coach those they support to decide what they want in life and how to achieve it without judgement.

What Shery Mead learned from her experience as a peer supporter (24)

“The first thing you may notice is that you’re dying to ‘help’. Now, help is not necessarily a bad thing at all, but when you are out for your own satisfaction, help can turn into control... Help can become a double-edged sword if it’s used to be coercive, controlling, is fear-based or is just done to make the helper feel better about having done something.

[For example]... Someone you know seems to be really self-destructive, is always doing things that seem to take her away from what she seems to want. This friend says she wants to ‘get better’, to work on her recovery and so forth, but you see her doing things that get in the way, like having a second glass of wine, like not exercising, like sitting around reading all day when she could have been out looking for a job. [But]... we [could] take the time to learn a little more about our friend... What if that second glass of wine loosens her up enough to go to the interview she is dreading? What if not exercising but sitting around reading all day is exactly what she needs to do to get up the next day and go to the interview? And this is the lesson for us. Our assumptions about what others need is not always (if ever) accurate. Our assumptions are based on our perspective, our ‘worldview’. They are there because they belong to us and to our way of knowing, but try and impose them on someone else and you may find that you are not only not helpful, but losing a friend at the same time.

And so we talk about learning together versus helping... What’s different about learning rather than helping? Learning implies a curiosity, an inquisitiveness about the other, their way of knowing, their way of making sense of the world, whereas helping often implies that you already have the answers, that you know better, that you can come in and tell someone what to do, and if they do it, everything will work out the way it did for you when you were in their shoes. Well maybe and maybe not, but one thing is for certain: helping based on what’s worked for you can also be tremendously damaging.

The next principle to remember is to focus on the relationship rather than on the individual... When we pay attention to the relationship... we are paying attention to what is going on between us. In other words, we focus on the ‘space’ between us, what is happening right here, right now that can either move us forward or back... When I pay attention to what’s going on between us, it opens up a line of communication that supports honesty, safety, integrity, and ultimately changes the very direction I had wanted to go without you. In other words, when I pay attention to you and your changes, nothing I do factors into it, but when I put myself into the equation, I realize that yours and my interaction was just that, an interaction that might go anywhere. There is no predictability, just a seeming randomness. This randomness, this unpredictability is exactly what we are striving for in peer support, not the linear outcomes we’ve come to think of as success.

Finally, the third [principle]... is to not react out of fear but to try new ways of relating based on hope and possibility... When we’re afraid, we often just want things to go back to the way they were before, to settle down [and] to become more ‘stable’. Yet ‘stability’ may not be the goal here. Think of a time when things seemed really out of control for you, yet you had a sense of what you needed and wanted even if others around you said things as if they knew better. Chances are, things happened that were out of your control... This may have led you into dependence on someone else’s experience of the ‘problem’. In other words, you may have become reliant on someone else’s interpretation of your experience. This happens simply when someone says to you, ‘That doesn’t hurt, don’t cry over spilt milk, etc.’ and you wonder why you’re making a big deal out of something that others see as insignificant. Or the opposite, when what you’re doing doesn’t affect you at all and someone else is scared that you’re going to get hurt. And they continuously

say, 'Be careful'. Pretty soon you're terrified of something bad happening and you're reacting to their fear. This leads to complicated dynamics where one person's emotions drive the reaction of the other. This is too often what happens in mental health services when they tell us we are helpless. We have learned to be that way based on their fear.

*And so we go into doing peer support with a **focus on learning rather than helping**, with attention to the relationship rather than the individual, and on to creating opportunities for hope and possibility rather than fear, power and control.... it's... fun, rewarding, and simply about creating dynamics that promote health in all our relationships..."*

7. Language

How people in peer roles speak to and about others is important and can make a difference to how people feel about themselves and their recovery. Often, language used in mental health and social services reinforces power differentials, is not trauma-sensitive, makes people feel like their whole identity is tied to the mental health system and can pathologize normal responses to traumatic events. For example, terms like "service user", "consumer" and "client", as well as other terms to describe the person being supported, can be experienced as dehumanizing and may make someone feel powerless and unable to envision life beyond the system or service (1).

Language can also imply that a person has a permanent condition or disability, which can also be disempowering and undermine personal recovery. While this may be verbal, written language can be equally harmful. For instance, programmes that ask a person to provide evidence of a permanent condition or impairment to obtain disability benefits (implying that the person will always have a condition/impairment rather than promoting the idea that social benefits may be necessary for the person's situation to improve) can not only be stigmatizing but can act as a major barrier to engagement because the person does not identify with the language used by the programme (34).

Selecting appropriate language can be difficult and there is no agreed list of "good" and "bad" words or terms. What is important is to understand the values behind why certain words and phrases are chosen and to question the acceptance of certain language from a critical perspective.

Open and closed language (35)

Another important aspect of language to reflect on is whether the language used is open or closed. Closed language can force a viewpoint on a person that they may not agree with, with the result that their experiences are told through someone else's interpretation and judgement. Open language leaves room for a person to put their own meaning on their experiences and more accurately describes the person and their real situation.

Examples of closed versus open language:

Closed		Open
<i>Jeannie is schizophrenic (or has schizophrenia)</i>	versus	<i>Jeannie has been given a diagnosis of schizophrenia.</i>

The closed language is stigmatizing and disempowering because it defines Jeannie as her diagnosis and does not leave space for Jeannie to put her own meaning on her experiences. The open language states the fact that Jeannie was diagnosed with a particular condition, but also allows room for different interpretations of what that means to Jeannie.

Closed		Open
<i>George is noncompliant with his prescribed medications</i>	<i>versus</i>	<i>George doesn't want to take his prescribed medication.</i>

The use of “noncompliant” implies that George needs to be taking his medications and is doing something wrong, deviant or rebellious by not taking them. The open language states a fact which does not cast judgement on George, and also allows room for George to explain why if he chooses.

Closed		Open
<i>Luis is experiencing auditory hallucinations</i>	<i>versus</i>	<i>Luis is hearing voices.</i>

The closed language indicates that these voices are not real, but also that they are something bad that must be stopped. Luis may find nothing wrong with these voices, but the language paints them as something he should fear. The open language does not interpret the voices as either bad or good but states only that Luis is hearing them. This allows room for Luis to interpret his own reaction to his experience.

8. Competencies for peer supporters

People in peer roles will have different backgrounds, levels of training and skills. However, several core competencies for peer supporters have been identified. The list below summarizes some of these competencies in relation to their various roles (36):

Role 1: Peer supporters engage peers in collaborative and caring relationships

The competencies required for this role emphasize peer supporters’ ability to initiate and develop relationships with people. They include interpersonal skills, such as reaching out and being able to engage peers with careful attention, and knowledge about recovery and attitudes consistent with a recovery orientation.

Role 2: Peer supporters provide support

The competencies related to this role are critical for the peer supporter to be able to provide the support that people may want. The competencies include validating peers’ experiences and feelings, conveying hope to peers about recovery, making people aware of a range of ways of understanding difficulties and providing assistance to support peers in accomplishing tasks and goals.

Role 3: Peer supporters share lived experiences of recovery

The competencies required for this role are unique to peer support since most roles in mental health and social services do not emphasize the sharing of lived experiences. Peer supporters need to be skilful in telling their recovery stories and using their lived experiences as a way of inspiring and supporting someone going through recovery.

Role 4: Peer supporters personalize peer support

The competencies required for this role help peer supporters to tailor or individualize the support services provided to and with a peer. By personalizing peer support, the peer supporter operationalizes the idea that there are multiple pathways to recovery. This includes recognizing the uniqueness of each peer's process of recovery and respecting unique social positions, including the cultural and spiritual beliefs and practices of peers.

Role 5: Peer supporters support recovery planning

The competencies required for this role enable peer supporters to support others to take charge of their lives. Recovery often leads people to want to make changes in their lives. Recovery planning assists people to set and accomplish goals related to home, work, community and health.

Role 6: Peer supporters link to resources, services and supports

The competencies required for this role assist peer supporters to help other peers acquire the resources, services and supports they need to enhance their recovery. Peer supporters apply these competencies to assist other peers to link to resources or services both within mental health and social sectors and in the community. It is critical that peer supporters have knowledge of resources within their communities as well as online resources.

Role 7: Peer supporters provide information about skills related to health, wellness and recovery

The competencies required for this role relate to how peer supporters coach others or provide information about skills that enhance recovery. They recognize that peer supporters have knowledge, skills and experiences to offer others in recovery and that the recovery process often involves learning and growth. However, it is essential that the approaches match the preferences and needs of peers.

Role 8: Peer supporters help peers to manage crises

The competencies required for this role assist peer supporters to identify potential risks and to use procedures that reduce risks to peers and others. Peer supporters may have to manage situations in which there is intense distress and then work to ensure the safety and well-being of themselves and other peers. When meeting with peers, it is important to create a safe space and provide reassurance to those in distress.

Role 9: Peer supporters value communication

The competencies required for this role provide guidance on how peer supporters interact verbally and in writing with colleagues and others. They suggest language and processes to communicate and reflect the value of respect. This includes using person-centred, recovery-oriented language and active listening skills. This will enhance mutual understanding and create a shared language.

Role 10: Peer supporters value collaboration and teamwork

The competencies required for this role provide direction on how peer supporters can develop and maintain effective relationships with colleagues and others in order to enhance the peer support provided. The competencies involve not only interpersonal skills but also organizational skills in terms of engaging providers, and engaging efforts from mental health and social services, in order to meet the needs of peers. Where relevant, this also includes engaging peers' family members and other supports.

Role 11: Peer supporters promote leadership and advocacy

The competencies required for this role relate to actions that peer supporters use to provide leadership within mental health and social services in order to advance a recovery-oriented approach. They also guide peer supporters on how to advocate for the human rights of other peers.

Role 12: Peer supporters promote growth and development

The competencies required for this role show how peer supporters become more reflective and competent in their practice. They recommend specific actions that may serve to increase peer supporters' success and satisfaction in their current roles and contribute to career advancement. Creating a peer support structure and provision of supervision are important components of sustaining the peer role.

9. Job descriptions

A clear job description is needed to attract and hire peer supporters. The job description should accurately convey the expected tasks and functions that peer supporters are to undertake. This is not only for their own information but also to effectively communicate what peer roles are (and are not), especially if a new role is being introduced. Without a clear job description, other colleagues may not take peer supporters seriously, and they may be given tasks that are not consistent with peer roles and do not make good use of their skills. This can lead to an unproductive or adverse relationship between peer supporters and others.

A peer supporter's job description may include the core responsibilities and duties of the position as well as the preferred qualifications and competencies of an ideal candidate (37),(38).

Sample job description for peer supporters (39)

JOB DESCRIPTION

Job title: Peer Supporter

Directorate: Adult Directorate – Mental Health Programme

Reports to: Peer Support Specialist

Accountable to: Assistant Director

Initial base location: Outpatient Centre for Mental Health

Type of contract: Permanent

Hours: 25 hours per week

Purpose of the job

The Peer Supporter is employed with the objective that, having used mental health or social services, the Peer Supporter is able to draw on these experiences and be an advocate for peoples' needs and rights by providing opportunities for people receiving services to direct their own recovery process. Main purposes include:

- Supporting people on a one-to-one basis by offering recovery training and outreach to persons who use the Outpatient Center for Mental Health.
- Sharing personal recovery experiences and developing mutual peer-to-peer relationships.
- Supporting people to discover available service options both within the service and outside it.

Main responsibilities

The Peer Supporter will:

- Assist in the orientation process for people using the service in order to inspire hope and create connections.
- Support people in emotional distress by listening and being there, exhibiting a nonjudgemental approach with active listening and positive interactions.
- Support recovery education and wellness planning, and connect to self-help strategies with the goal of encouraging people to take an active self-directing role in their recovery process.
- Accompany people, when requested, to support access to, and utilization of, community resources.
- Improve the team's understanding of lived experience and educate staff about the recovery process and the damaging role that certain traditional practices can play in that process.
- Improve communication between people using the service and practitioners.

Qualifications and competencies

The successful candidate must be in a state of recovery and a self-identified current or former user of mental health or social services who can relate to others who are now using those services. The person must also:

- Be at least 18 years of age.
- Have lived experience of mental health services and/ or emotional distress.
- Be able to share their lived experience in a way that supports, empowers and brings hope.
- Be able to listen with empathy and to support people to discover their own solutions.
- Be able to work independently.
- Be able to assist in the development of a culture of recovery.
- Have a knowledge of community peer resources, and alternative resources, to support community integration.

10. Interviewing and hiring peer supporters

An important goal of the interview is to determine how well the potential peer supporter is able to describe the relevance of their lived experience to supporting others. It is not an interview about the nature of the personal diagnosis they have received, nor their treatment history or distress experienced. In some countries, inquiries about a disability are illegal and so the law of the country should be followed during this process. The candidate may wish to share this information, but they should not feel that they have to do so in order to be hired. However, it is crucial that candidates have experience of mental health services and/or mental and emotional distress and have worked through their recovery journey (40).

As the peer support role can be a new role within a community or country, there may be very few people with existing qualifications and experience in this area. In such situations, the interviewer will need to identify people on the basis of their potential rather than demonstrated experience.

It is also critical to involve a peer, or committee of peers, in the interview process. The interview questions can invite the peer support candidates to explain how their experience, skills and/or knowledge can assist others in their recovery.

Sample interview questions may include:

- What inspired you to apply for the peer supporter role?
- Can you tell me some ways in which you might use your strengths/skills and personal lived experience to support the people you would be working with?
- What have you learned through your own lived experience of mental distress and recovery that you think would be useful to your work here?
- How might your experience and skills support non-discrimination and equality in your work?
- Why do you think the support of peers is beneficial for people with psychosocial, intellectual or cognitive disabilities?
- If one of your peers feels resigned to their situation and without hope, how would you support them (41)?
- Do you have any previous experience of something similar to peer support?

The lack of applicants for the position may result in a temptation to move someone who is already on the staff to a peer role, to hire an applicant who is not a good fit for the post, or to lower the hiring standards for the position. However, peer supporters have a very important role in supporting others and it is critical to identify peer supporters who are right for the role and who will uphold the values of peer support such as respect, equality, mutuality, empathy and recovery (41).

Training and ongoing support is extremely helpful for all peer supporters and should be a prerequisite for newly-recruited peer supporters who have never before worked in a peer role. This does not mean that peer supporters who are new to the role will be less helpful or less successful than people with prior experience. It simply means that there will be different considerations for the interview, selection process and training requirements.

When introducing peer supporters within a service for the first time, it may be preferable to hire more than one peer, if resources allow. This will help to avoid peer drift phenomenon and isolation of the person working in a peer role.

Inclusion Europe: Project TOPSIDE – Training opportunities for peer supporters with intellectual disabilities in Europe (42)

TOPSIDE is an Inclusion Europe project aiming to develop peer support and peer training as new components in informal adult education for people with intellectual disabilities. Since access to formal or informal adult education and training can be limited for persons with intellectual disabilities, peer training and support focuses on helping to develop important skills in the areas of decision-making so that individuals can take control over their lives and perform their roles as active citizens.

Through the training curriculum, peer supporters learn how to improve their communication, how to support someone appropriately and how to empathize with others. Peer supporters learn to relate their own life experiences to peer support and use these examples and their own learning to support other persons. The training also looks at different values that the peer supporter could adopt: inclusion, person-centred thinking, good life, valued roles and citizenship in your own community.

Peers are able to support people who do not see these opportunities for themselves by opening their eyes to what is possible. The training has been designed in such a way that all skills outlined in the curriculum are anchored in reality and based on real-life situations. Skills that are progressively acquired and strengthened fall into three categories:

- Peer-to-peer skills covering communication, reaction and empathy in a face-to-face or group exchange.
- Inclusive values/skills covering inclusion, person-centred thinking, valued social roles and being a citizen in a community.
- Pragmatic skills covering experiences from different areas of life and the quality of life in relation to inclusion (e.g. home, rights, work, social life).

11. Conditions of work

Pay rates

Peer roles may be paid or unpaid. This can depend on the organizational structure and budget. For instance, a non-profit organization that depends primarily on volunteers to operate may have unpaid peer supporters, whereas a mental health or social service or an established peer supporter organization in the community may have paid peer supporters.

It can be difficult to change pay rates once they are established, so it is important to think through what the pay rate will be for peer supporters. The available pool of people with lived experience who are open and comfortable discussing their experiences with others, want to do peer work and are good at it may be small. Having the pay rate reflect this specialized position is therefore important. Setting a low pay rate, especially in comparison to the rest of paid staff, can convey a negative message that peer roles are trivial and less important (6).

It is also worth noting that, in some countries, paying peer supporters can potentially jeopardize any benefits that they may also be receiving, so it is important to make sure that pay rates are sufficient and do not lead to a loss of income for the peer supporter. Those who make the laws and policies of the country should also be mindful of this issue.

One issue to keep in mind is whether payment is likely to introduce a power imbalance in a one-to-one peer relationship in that, if one person is receiving payment and the other is not, it may be difficult for the relationship to be viewed as an equal one.

Mentoring and supervision (30),(6)

The provision of mentoring and supervision is one of the most important components in sustaining peer support roles. Peer roles may be met with resistance or confusion at first, so having the support of a supervisor who believes in peer support and in recovery-oriented care is important. Ideally, a supervisor for a peer supporter is someone who has worked in peer roles before. However, this may not always be possible. At the very least the supervisor should be trained or have experience in recovery-oriented practices (see the section on *Peer supporters in mental health and social services*) which will allow them to better understand the role of a peer supporter and the challenges that may arise when introducing peer roles, especially for the first time.

If this is not possible, another option is to reach out to local, regional, or national peer-to-peer organizations for supplementary training or supervision. This way, even if the peer supporter's direct supervisor has not worked in peer roles before, the peer supporter can still receive support from the peer community. Simple communication technology such as telephone calls or video calls can be used to provide support to peer supporters who are geographically isolated.

Regardless of previous experience in peer roles, any effective supervisor should be able to provide both task-oriented supervision (such as giving guidance on the day-to-day administrative tasks of the peer supporter) and process-oriented supervision (such as supporting the peer supporter in developing skills and expertise or offering suggestions for improvement).

Mr Chinmay Shah, Peer Support Volunteer, on being supported to move forward (43)

As part of the QualityRights project in Gujarat, India, peer support volunteers have been recruited and trained in each of the services. The role of the peer support volunteers is to provide support and advice to other people using services. This may involve, for instance, supporting people to develop and implement their recovery plans, informing them about their rights and ensuring that their rights are respected.

Mr Chinmay Shah, who is working as a peer support volunteer, has received mentoring from Mr Vinodh Macwana who is a staff attendant at the Hospital For Mental Health in Ahmedabad. This has helped him grow and develop his role as a peer support volunteer. He explains:

"I feel a sense of support when I meet Vinodh Bhai. He encourages us to get involved with the people using the service and motivates us to do things effectively without putting pressure on me. We meet him every morning before we start work and he always has a smile to share with us. He also encourages us to approach him whenever we feel the need. The mentoring process is helping us on a daily basis to develop our peer support skills. We improve our work by brainstorming and discussing issues with our mentor and we are aware that our suggestions are not only heard but are also implemented."

Performance reviews (6)

Once hired, peer supporters should be expected to fulfil their job requirements. However, flexibility and understanding in relation to taking leave of absence from work may be necessary as peers can experience challenges with their mental health and well-being and may, for instance, require short (or longer) breaks from the job. Regular performance reviews provide a good opportunity for both supervisors and peer supporters to discuss the job, any areas of concern, and what is going well. However, performance reviews should not be used to make changes that go against the core values of peer support.

12. Peer supporters in mental health and social services

It may be difficult to convince staff in mental health and social services that peer support is an essential part of the service. To be successfully integrated into the mental health or social service, peer support needs to be viewed as enriching service provision through the direct participation of people who have lived experience (44).

Peer supporters are there for people using the service in order to support them however and whenever they wish to be supported. This may mean “being there” and listening, supporting people to make their own decisions about what recovery is to them, or advocating on their behalf. There may be times when there are disagreements in approach, when the wishes and preferences of the people using the service differ from those of the mental health or social service. However, this does not mean that peer supporters and staff members are, by the very nature of their roles, at odds with each other.

There are many ways of contracting peer supporters in the service context. The optimal way to provide peer support is by contracting an independent peer-run organization which is external to the service but can work in close collaboration with the service. In this way, independence of the peer supporter from the service is maintained which helps to avoid conflicts of interest (45),(46).

Quote: Kevin Huckshorn, Director, Division of Substance and Mental Health, Delaware Health and Social Services (USA), on the power of peer support (47)

"In my humble opinion, the power of peer support, in hospital and community mental health settings, is more significant and valuable than any other evidence-based practice I have ever seen. I started, with guidance from Gayle Bluebird, to integrate peers into mental health work settings back in 1991. In every work arena since, peer support staff were the 'magic makers'.

The innate skills of peer support workers are legendary in my personal experience. And at this point I strongly believe that at least 50% of the mental health provider system needs to be peer support workers if we are to get to a system of care that is truly recovery-oriented, trauma-informed, compliant with the American Disability Act and is a system in which people with serious mental illness can find hope, courage and the energy to recover their lives in a way that works for them."

Creating a culture for peer support

The introduction of peer supporters in mental health and social services may require time to allow transition.

“Peer support works best when peer workers are based in settings that have a pre-existing commitment to the values and principles of recovery. Peer workers greatly enhance that commitment to recovery; however, the role should not be used to introduce recovery to settings that do not already have a commitment to the values of recovery” (48).

Taking time to introduce recovery-oriented care before integrating peer support roles into mental health and social services is crucial. Without a commitment to the principles of recovery, peer supporters are destined to fail. A key component of their work is to support other peers to understand what recovery means to them. If a mental health or social service does not adhere to recovery-oriented care, it will undermine the work of peer supporters from the very beginning.

Creating a culture for peer support is not about providing a one-time training session; rather, it is about an ongoing process of putting recovery principles into practice. Leadership buy-in, official recognition (e.g. peer support explicitly mentioned in the values of the organization/service), staff training, and effective mentoring and supervision are all important factors (49). Peer supporters need to feel safe and empowered themselves in order to support other persons effectively.

Similarly, providers of mental health or social services should not assume that introducing peer supporters is going to make magical changes to the system. A fundamental change in the power structure is necessary to adopt a truly recovery-oriented approach and to introduce peer support effectively.

Identifying management and other service staff who are peer support champions and who will take a leadership role with the transition and implementation of peer supporters will be particularly helpful. These staff members can advocate for the inclusion of peer supporters and address the concerns of other staff before, during and after the implementation process (6). As time goes by, peer support champions can also help to ensure that peer support remains a priority for the service (30).

As for any other staff, overall good working conditions within the service for peer supporters diminish the risk of burn-out and turnover.

Inform all staff and include them in discussions

All service staff need to be prepared in advance to overcome resistance within the service to hiring peer supporters. Staff may have concerns about the potential risk of relapse among peer supporters and whether they can handle the demands of the job. Staff may also question the competencies of peer supporters because some may not have diplomas or degrees. The addition of peer supporters may worry staff if they think peer supporters can eventually replace part or all of their work at a lower cost, or that peer supporters are unnecessary in limited-resource settings (30).

Consequently, it is extremely important to create an environment in which existing staff feel comfortable expressing their opinions. Taking the time to listen to any staff concerns and adequately addressing and responding to them can help foster a more welcoming environment for peer supporters. Explaining to staff the anticipated benefits of peer roles, confidentiality and ethics, and

how peer supporters will be integrated into the service, can help staff to be more prepared for this change.

Keeping the lines of communication open through regular meetings, even after peer supporters are hired, can help address sources of conflict or disagreement. Meetings should encourage openness and a participatory approach to problem-solving in order to alleviate any concerns and anxieties that may arise concerning the hiring of peer supporters and the respective roles of peer supporters and existing staff (6).

Policy awareness and training

An important step that should be taken to create a culture favouring peer support is to have the written policies, vision or value statements of the service that align with the vision of recovery (6). Engaging all staff in the process of drafting these policies and statements will also be very useful in getting everyone to fully understand and value peer support. This enables people to take ownership and to commit to the new directions that are being introduced. (Read more about the process of implementing a service change in the QualityRights module *Transforming services and promoting human rights*).

Complementing policy changes with training on human rights and recovery will create a positive environment and will facilitate the transition. Ideally, staff members should be offered the opportunity to visit services with a recovery-oriented approach in order to understand the core values of recovery and peer support. Speakers and events that discuss and focus on recovery-oriented care can be informative for staff and can also reinforce the fact that the service is committed to the recovery approach and to peer support.

Supporting peer supporters' role in mental health and social services (6),(30)

Establishing the role of peer supporters in the service is an important step in ensuring that they are able to do their jobs successfully, and other staff members will understand their role as well. While this may vary between different services, some points to consider are:

- **Team meetings:** Peer supporters should participate in meetings with other staff members. Just as the invitation to attend team meetings is important, so is the need to respect the values of peer support. For example, peer supporters should not be pressured to reveal private details that a peer has shared with them, or to attend meetings where individuals are discussed without being present. It is important to protect the unique role of the peer supporter.
- **Working hours:** Peer supporters may work full-time or part-time depending on their situation, as is the case for all other staff. Supporting people who are going through difficult experiences, working in an environment where peer support is new and constantly having to justify the peer roles, or being the only peer supporter working in the service can be emotionally and physically draining. Having a team of peer supporters can help because the peer supporters will be able to share knowledge and exchange experiences.
- **Specialized training:** In addition to basic-level peer support training, peer supporters can benefit from specialized training on human rights, policies and legislation. In addition, training on the context and needs of particular populations (e.g. the elderly), advanced

topics (e.g. smoking cessation) or suggestions for helpful exercises (e.g. body and breathing exercises) will help them to better support their peers and advance their skills and knowledge.

- **Continuing education:** Opportunities for continuing education should be made available to peer supporters. These educational opportunities may come in the form of online peer specialist courses or meetings and/or coursework with other peer supporters in the area. As the role of the peer supporter develops in countries, it is useful to think of offering professional development opportunities to advance their careers – e.g. as a peer support leader, peer support manager, peer support practitioner etc.

Good use and misuse of peer supporters (1)

The day-to-day work of peer supporters can vary and they should be flexible according to the different situations that may arise. Nevertheless, there are common traps that should be avoided as they are not consistent with the values of peer roles. For instance:

1. **Busy work:** A peer supporter has a unique set of skills and experiences and should not be used to complete routine tasks and busy work that no one else wants to do. Peer supporters are not an additional help for existing professionals.
2. **Mixed loyalties:** A peer supporter's commitment is first and foremost to the person being supported. A peer supporter should not have a particular agenda other than peer support. For example their role is *not* be about finding out information to provide to the rest of the team, completing treatment plans or monitoring compliance with medication.
3. **Power imbalance:** A peer supporter strives to minimize the power differential to create an equal relationship. The peer supporter should not be asked to do something that increases the power imbalance (e.g. being the one preparing coffee for the rest of the staff).

People may be unclear about the role of peers in certain situations. Below is a chart of some common topics that may arise while providing peer support and the differences in what makes it consistent or not consistent with peer roles.

Topic	Consistent with peer role	Not consistent with peer role
Medications	Supporting a peer to communicate concerns or views about medications; supporting a peer to gather information on medications.	Administering medications; reporting to staff members if peers are taking their medications or not; promoting adherence to treatment if the person has expressed reservations or concerns.
Treatment plans	Supporting a person to have their voice heard during the treatment planning process; facilitating completion of an advance directive and advocating for goals that are consistent with promoting recovery.	Writing a treatment plan; writing progress reports on treatment goals for other staff members.
Housing search	Assisting a peer with housing if they have asked for help; sharing one’s personal experience with a housing search.	Focusing only on housing search because it is in the treatment plan or because a staff member has told the peer supporter to focus on the housing search with a peer.
Answering phones	Occasionally helping out around the office; answering a peer-to-peer support line.	Routinely answering the telephone because no other staff member wants to; having to assess level of crises over the telephone and transfer to other staff.

Disagreements

Disagreements between peer supporters and service practices may occur when the roles of the peer supporter clash with the rules, regulations or practice of the service (e.g. when someone has been admitted to a service involuntarily). However, even in this situation, the peer supporter should be able to continue to advocate for the individual without fear of repercussions even if it conflicts with the approach taken by the service.

Peer drift (30)

Peer support is a unique role in a mental health or social service as it is rooted in shared experiences with other peers and peer supporters are part of the mental health team. Over time, peer supporters may demonstrate a shift in their attitude and actions towards a more clinical approach, perhaps due to internal or external pressures which may be conscious or unconscious. This is inconsistent with the role of a peer supporter.

This phenomenon has been called “peer drift” and includes “discomfort or defensiveness utilizing one’s recovery story and drifting toward a more distant hierarchal approach to service provision” (50). This drift may be gradual and hard to recognize personally, which is why having a supervisor and team committed to recovery and peer support can help, as can other peer supporters.

Peer drift can include a peer supporter telling peers what they should do instead of listening; focusing on people's diagnoses instead of their recovery; or being uncomfortable or ashamed of one's lived experience and recovery story. It is important to connect with other peer supporters and have peer support champions to talk with if peer supporters feel this way or others believe this may be happening.

Mentoring, supervision and peer support structures

When peer support is provided in the context of mentoring, supervision and peer support structures, the tendency towards peer drift can be addressed and minimized.

It can also be useful to create a peer support structure in which informal peer support meetings can be facilitated. This will give peer supporters from different services and from the community an opportunity to come together to debrief, share knowledge and experiences, discuss improvements and provide emotional support to each other.

In a safe and confidential space, peer supporters can have the opportunity to address and discuss how to counter potential challenging issues arising in their work. Some of these will be different from the challenges that arise for other staff members. In particular, issues related to boundaries may arise in the sense that peer supporters may be viewed more as friends than non-peer staff, since peer supporters disclose personal information and share intimate stories from their own lives (51). Other challenges that may arise in relation to peer support include power imbalances between peer supporters and other staff, stress for peer supporters, and maintaining the role of peer support (14).

In addition, it is important to promote a level of “**structural competence**” among staff. Structural competence is increasingly recognized as necessary to improve mental health and health equity (52),(53),(28),(54). It involves taking account of the ways in which structural and institutional factors (e.g. racism, socioeconomic marginalization, welfare policies) intersect to affect the risk for particular conditions (e.g. psychosis) and ultimately influence pathways to care, attitudes to treatment, availability of social support and outcomes (28).

In line with the principles of recovery and peer support, structural competence helps de-emphasize individuals' perceived problems or deficits and focuses on the unique contexts (e.g. discrimination, structural barriers to well-being) that influence individuals and their recovery.

Building capacity in this area can help bring attention to which groups are not engaging as peer supporters or peer support receivers; these are often groups that may experience multiple barriers to community participation or inclusion.

Below is a self-assessment checklist (55) on ensuring meaningful and equitable peer involvement.

Seven components of meaningful peer involvement – Self-assessment questions

TIMING

Have attempts been made to include peers *as early as possible* in planning a new initiative or programme?

- a. If not, how does the group plan to deal with potential power dynamics or tensions stemming from uneven or unequal involvement in early decisions that may have already significantly shaped a programme or initiative?

POWER

Do peers have the *power to make decisions and shape programmes*, or are they limited to advisory roles?

- a. If some staff members have the power to make concrete decisions about policy or programmes and others can only make comments or suggestions, how will any resulting power dynamics be addressed? What steps can be taken to ensure that peers feel they can make a meaningful contribution?
- b. In a project involving committees or working groups, are peers in a position similar to that of non-peers? For instance, are there peer chairs or co-chairs, or are peers limited to non-leadership roles?

COMPENSATION

Are peers financially compensated in a manner equal to non-peers?

- a. If some non-peers are compensated, but peer members are not, what steps can be taken to address the hierarchies that such a division might create?
- b. Have programme leaders fully thought through the implications of compensating non-peers but not peers?

NUMBERS

Is there a *critical mass* (or sufficient number) of peers involved to make a difference?

- a. If there is only one (or very few) peers involved in a majority non-peer group, can steps be taken to make those peers feel more supported?
- b. Have all possible steps been taken to ensure that peers (often, though not always, with less seniority than other non-peer group or project members) feel comfortable speaking out when in a minority?

WELLNESS

Have steps been taken to ensure that *peer wellness* is prioritized?

- a. In addition to more formal supports, has peer wellness been raised more informally (but explicitly) at the outset of a project or the start of new position? Have staff or other group members acknowledged potential stressors (micro-aggressions, or problems with other staff or members who might not be supportive of peer involvement) and affirmed the toll this can take? Is there a plan for addressing burn-out or frustration on the part of (minority) peers?
- b. If peers are expected to “advocate” within the project or group (often, though not always, from a minority position, or with less seniority), are the potential impacts of advocacy recognized? Are there concrete support plans? For example, what happens if a peer is put in a position in which she/he feels forced to “challenge” a more senior member or leader?

INVESTMENT

Has the programme or organization *invested in peer capacity-building* – e.g. paying peers to attend conferences and workshops and/or to learn new skills?

- a. If peers are involved in a project or committee in which they lack equivalent expertise to other members (e.g. a peer without evaluation experience on an evaluation committee), are efforts made to provide the peer with more background or additional training?

ORGANIZATIONAL OR PROJECT CULTURE

Have programme leaders or administrators taken explicit steps to ensure that peer perspectives are valued, and that resistance to peer involvement is systematically addressed?

- a. If a peer comes to another programme or project member or leader with concerns (about stigma, negative or dismissive attitudes or lack of investment), are these members or staff prepared to take steps to support the peer and/or challenge dismissive attitudes?
- b. Is there a process or protocol for expressing concerns or grievances? Have peers been assured that they will not be retaliated against or “punished” for raising concerns about other members or staff?
- c. If feasible, has programme or project-wide or in-house training on diversity or peer involvement been considered?

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The World Health Organization's QualityRights training and guidance modules focus on the knowledge and skills required to provide good quality mental health and social services and supports and to promote the rights of people with psychosocial, intellectual or cognitive disabilities.

Through exercises, presentations, case scenarios, extensive discussions and debates, the **QualityRights training modules** unpack some critical challenges that stakeholders are facing in countries everywhere. For instance:

- How do we respect people's will and preference, even in challenging situations?
- How do we ensure people's safety and at the same time respect each person's right to decide about their treatment, their life and their destiny?
- How do we end seclusion and restraint?
- How does a supported decision-making approach work if someone is unable to communicate their wishes?

The **QualityRights guidance modules** complement the training materials. The guidance modules on *Civil Society Organizations* and on *Advocacy* provide step-by-step guidance on how civil society movements in countries can take action to advocate for human rights-based approaches in the mental health and social sectors in order to achieve impactful and durable change. The guidance modules on *One-to-one peer support* and on *Peer support groups* provide concrete guidance on how to effectively set up and run these critical but often overlooked services.



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