Creating peer support groups in mental health and related areas

WHO QualityRights training to act, unite and empower for mental health

(P I L O T V E R S I O N)

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What is the WHO QualityRights initiative?

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

1   Build capacity to understand and promote human rights, recovery and independent living in the community.

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

3   Improve the quality of care and human rights conditions in inpatient, outpatient and community based mental health and related services.

4   Develop a civil society movement to conduct advocacy and influence policy-making to promote human rights.

5   Reform national policies and legislation in line with best practice, the CRPD and other international human rights standards.

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

WHO QualityRights - Guidance and training tools

The following guidance and training tools are available as part of the WHO QualityRights initiative:

Service assessment and improvement tools

- **The WHO QualityRights Assessment Tool Kit**
- **Implementing improvement plans for service change**

Training tools

Core modules
- **Understanding human rights**
- **Promoting human rights in mental health**
- **Improving mental health and related service environments and promoting community inclusion**
- **Realising recovery and the right to health in mental health and related services**
- **Protecting the right to legal capacity in mental health and related services**
- **Creating mental health and related services free from coercion, violence and abuse**

Advanced modules
- **Realising supported decision making and advance planning**
- **Strategies to end the use of seclusion, restraint and other coercive practices**
- **Promoting recovery in mental health and related services**
- **Promoting recovery in mental health and related services: handbook for personal use and teaching**

Guidance tools

- **Providing individualized peer support in mental health and related areas**
- **Creating peer support groups in mental health and related areas** ←
- **Setting up and operating a civil society organization in mental health and related areas**
- **Advocacy actions to promote human rights in mental health and related areas**
- **Putting in place policy and procedures for mental health and related services (in preparation)**
- **Developing national and state-level policy and legislation in mental health and related areas (in preparation)**
- **Guidance on CRPD compliant community-based services and supports in mental health and related areas (in preparation)**

About this guidance

This document has been developed to support countries to develop and strengthen peer support groups in mental health and related areas. It addresses the provision of peer support groups in the context of health services and the wider community.

Who is this 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 related services**
- **Managers of general health, mental health and related services**
- **Mental health and other practitioners** (e.g. doctors, nurses, psychiatrists, psychiatric nurses, neurologists, geriatricians, psychologists, occupational therapists, social workers, peers supporters and volunteers)
- **Other staff working in or delivering mental health and related services** (e.g. attendants, cleaning, cooking, maintenance staff)
- **Non-Governmental Organizations (NGOs), associations and faith-based organizations working in the area of mental health, human rights or other relevant areas** (e.g. Organizations of Persons with Disabilities (DPOs); Organization of users/survivors of psychiatry, Advocacy Organizations)
- **Families, care partners and others support people**
- **Ministry of Health policymakers**
- **Other government institutions and services** (e.g. the police, the judiciary, prison staff, law reform commissions, disability councils and national human rights institutions)
- **Other relevant organizations and stakeholders** (e.g. advocates, lawyers and legal aid organizations)

Preliminary note on language

We acknowledge that language and terminology reflects the evolving conceptualisation of disability and that different terms will be used by different people across contexts over time. People must be able to decide on the words that others use to describe them. It is an individual choice to self-identify or not, but human rights still apply to everyone, everywhere.

Above all, a diagnosis or disability should never define a person because we are all individuals, with a unique personality, autonomy, dreams, goals and aspirations and relationships to others.

The choice of terminology adopted in this document has been selected for the sake of inclusiveness.

The term psychosocial disability includes 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 people's full and effective participation in society.

We use the terms "people who are using" or "who have previously used" mental health and related services to also cover people who do not necessarily identify as having a disability but who have a variety of experiences applicable to this guidance.

In relation to mental health, some people prefer using expressions 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 stigmatising.

In addition, the use of the term "mental health and related services" in these modules refers to a wide range of services including for example, community mental health centres, primary care clinics, outpatient care provided by general hospitals, psychiatric hospitals, psychiatric wards in general hospitals, rehabilitation centres, day care centres, orphanages, homes for older people, memory clinics, homes for children and other 'group' homes, as well as home-based services and supports provided by a wide range of health and social care providers within public, private and non-governmental sectors.

1   Introduction

The purpose of this module is to provide guidance on how to build and strengthen peer support groups for and by people with psychosocial, intellectual and cognitive disabilities and also groups for and by families and/or care partners. We have included both as the audience for this document because the purpose of both these types of groups and practical implementation issues are similar.

While this module focuses on group peer support, one-to-one peer support and internet and media based peer support can also be beneficial. Not every person will be able to or want to meet up in person, so phone discussions, online forums, websites, and social media can be potential alternatives.

Peer support services can be provided by different organisations. However, the value of using independent peer run organisations to deliver services should be emphasized in terms of using their unique capacity to create a space for people to connect outside structured one-to-one or group interactions. Through this community organizing approach, people can form natural relationships with people of their choice in their environments, independent of any formal structures or settings. This module should be used in conjunction with all other QualityRights training and guidance modules related to recovery and human rights.

2   What are peer support groups?

Peer support groups are a valuable service and resource that brings together people affected by a similar concern so they can explore solutions to overcome shared challenges and feel supported by others who have had similar experiences and who may better understand each other's situation. Peer support groups are run by members for members so the priorities are directly based on their needs. Peer support groups also allow members to benefit from natural occurring social support in the community in order to form unique relationships that may not otherwise have been possible. Peer support groups can be provided on a formal basis with paid 'specialist' trained peer group facilitators or on a more informal basis with volunteer peer facilitators.

> *"When people find affiliation with others they feel are 'like' themselves, they feel a connection. This connection, or affiliation, is a deep, holistic understanding based on mutual experience where people are able to 'be' with each other without the constraints of traditional (expert) relationships." (1)*

> *"Peer support [within a group setting]… is based on the belief that people who have faced, endured and overcome adversity can offer useful support, encouragement, hope, and perhaps mentorship to others facing similar situations."* (2)

> *"Peer support is generally understood to be a relationship of mutual support where people with similar life experiences offer each other support especially as they move through difficult or challenging experiences."* (3)

"Peer support is where individuals who have lived experience of life issues … provide support to others who are dealing with similar issues. By listening empathetically, sharing their experiences and offering suggestions based on that experience, people with lived experience of these issues are uniquely able to support others." (4)

3   Benefits of peer support groups (5)

The benefits of group peer support are wide-ranging and can include the provision of a safe environment to freely express and share emotions and thoughts about one's current situation and challenges; sharing of information and experiences and learning from others in similar situations that can help provide ideas and solutions to overcome challenges that group members are facing; the opportunity to build new relationships and strengthen social support networks which helps to reduce isolation and feelings of loneliness; sharing of knowledge about available community resources and practical support to help group members access resources and support, for example, helping others complete administrative procedures to access social and disability benefits, employment programs and so on.

> **Members of Maitri, a peer support group led by and for people with psychosocial disabilities, India** (6),(7)
>
> *"Since I have started communicating my needs and desire to my peers in the Maitri group, I realise that I have been able to open up for new changes and challenges, which earlier I was not. Now I ask for help when I need it... The Maitri group has motivated me to understand my right to stay in the community. Also I have become assertive to demand what I need as I consider it as a right to have it."* (6)
>
> *"When I come for these meetings I feel happy because it make me feel like I belong to some place and that I have someone to support me. I have learnt that there are so many other people like me."* (7)
>
> **Members of Saathi, a peer support group led by and for families and caregivers, India** (8),(9)
>
> *"The Saathi group…has helped us* [my husband and I] *find a place to share* [our experiences] *and gain courage, also by constantly going to the group we feel that we are able to help other caregivers who lack information and guidance."* (8)
>
> *"The Saathi meetings help me to understand my son's illness better….* [Ranjitbhai] *has gotten better over time. …After coming to the Saathi group I listen to others I have realized that this is MY son, and I have to continue taking care of him. Sometimes others have given me advice of including him in the daily business and this gives me hope that he will be able to do work one day."* (9)

> **Scenario: Anne's story** (10)
>
> Anne is a 45 year old woman from Douglas, a small town in the Northern Cape province of South Africa where unemployment, poverty and stigma and discrimination is rife. She received a diagnosis of major depression some years ago and receives treatment at the clinic in her community.
>
> Recently, Anne participated in an Empowerment Session hosted by the South African Mental Health Advocacy Movement (SAMHAM), which is a project of the South African Federation for Mental Health, where she learned about the basic understanding of psychosocial and intellectual disabilities and human rights – this sparked a strong determination in her to support and improve the lives of persons diagnosed with mental disorders in her community. She took great initiative and started a peer support and advocacy group. In a short space of time the group has grown to almost 50 members. Anne has now started to get another group together in a different community and are reaching out to neighbouring towns.
>
> The role Anne plays to group members and the community is by first of all being a role model, proving that recovery is possible and that her experiences can be applied in a positive manner. The group she established forms a support structure that adds great value to each of the group members, especially considering the limited services and opportunities available in the community of Douglas. Anne has become an ally to the people who frequently approach her for support and advice and she has built a good relationship with them.
>
> SAMHAM recruited Anne as a leader and supports her remotely with information and advice wherever is needed, and keep in regular contact with her via telephone and email. Not only does Anne bring comfort to her group members and mental health care users, her involvement in the work she does has helped her finding her purpose in life – helping others to achieve what they want to be through empowering them. Her work also compliments the mental health services most persons with psychosocial disability access at the local clinic, where clinic nursing staff are overwhelmed by a high caseload and the psychiatrist's only visits once a year to see clients. They now have someone they can relate to and can voice their concerns, needs and challenges and together work towards a solution.

4   Setting up a support group

Sound planning lays the foundations for a successful peer support group. The issues below may need to be considered.

Identified need or common purpose

Most groups start in response to a need identified by one or more people affected by a similar situation. This brings purpose to the group and helps to establish what will be shared and achieved. Peer support groups can have different aims and be operate in a variety of ways. What works well for one group may not work well for another. The important point is that the group functions successfully for its community of peers (11).

> **Scenario: Better lives for people in Leeds – peer support for people living with dementia** (12)
>
> In Leeds, a range of peer support network groups for people with dementia has been developed by Adult Social Care working with partner organisations. The peer support groups, both gender-specific and mixed groups, consist of informal meetings in which people can share experiences, exchange ideas and offer mutual support. Also, there is an art group in which members can come and unleash their creative side and a "Life Story group" in which members can support each other in building a picture of their lives to help them cherish memories. The finished "life story" will be for the member to keep and enjoy and potentially share with others so they can learn about one's unique life story.
>
> The peer support groups are open to anyone living with dementia in the local area irrespective of gender, sexuality, disability, ethnic origin, cultural and religious beliefs.

The facilitator's role (13)

Facilitators lead and facilitate discussions in a group and take responsibility for the development and functioning of the group. They should organize meetings, show up on time, open the meeting, provide guidance and listen to group members and arrange for a substitute if they are not able to attend.

Facilitators may have lived experience, but they are not expected to have answers to all the questions that come up during group meetings.

Once a group is established and has regular participants, the facilitator may look for members who can take over when they are absent or not able to continue any more. When the group is large it is very useful to have a co-facilitator. Supervision or peer support structures can be beneficial to advise and support group facilitators (see section *Peer support structures, mentoring and supervision*).

> **Hints and tips of facilitation** (11)
>
> - Pay attention to members as they talk about their personal experiences
> - Be non-judgemental and mindful of the process
> - Facilitate discussion and allowing everyone to speak who wishes to
> - Ensure people are adhering to the agenda and keeping to time
> - Share tasks
> - Encourage a sense of security within the group
> - Know your own limitations and boundaries
> - Seek feedback from the group
> - Manage conflict
> - Make sure members feel supported
> - Know when to advise group members for additional support
> - Summarise key issues and decisions that are made
> - Provide information on other potentially useful support services available outside of the group

Membership of the group

The peer support group can have open or closed membership depending on the purpose of the group. There are advantages to each type of group.

With open membership, anyone who would like to participate can join. Members generally attend and stop attending according to their own needs. This type of membership allows people to attend meetings whenever they would like, and enables people to seek out peer support with short notice.

With closed membership, only people who have been accepted into the group are allowed to attend meetings. People interested in joining the group may meet current members before the start of the peer support meeting in order to understand needs and expectations, and whether there is a good fit with the purpose of the group. This type of membership allows members to get to know each other better over time, resulting in trusting relationships and a secure environment to share confidential experiences. For some group members, being in a closed group where the members stay the same may be the only kind of space in which they feel comfortable sharing their stories. It can be helpful to talk about the significance of the group as an entity and each other's presence in the group. For some people, it can be important for their recovery to know that their presence is meaningful and important for the other members. Membership of a group can provide people with a sense of purpose and connectedness. Due to the members' attachment to and reliance on the group and its members, the facilitator must inform the group in advance when a member is not able to attend a meeting. From the beginning, it is important to be clear about the type of membership.

Scenario: Being a member of an open family support group (14)

"I attended a family support group for about nine months. It was good for me and it helped me cope with my son who was using drugs and causing a lot of upset in our home. I used to go to the meetings and they gave me information that helped. The situation seemed to get better, our son said he had stopped using and things seemed settled.

I stopped going to the family support meetings. I think I just drifted away. I missed a few meetings and then just felt I could not go back.

That was fine for a while until disaster struck... one night the police came knocking at the door. They had found our son on the street with his friends, all high as kites.... I couldn't believe it at first, he had relapsed. There were the symptoms again. Strange sleeping patterns, out late, staying on his own in his room for days. I really couldn't believe it. The nightmare was back.....I eventually decided to go back to the family support group...there was nowhere else I could turn.

They welcomed me back and were as kind, compassionate and supportive as they had been before.....there was no judgement, just support....I know they are always there for me."

New members (11)

Members have different reasons for joining support groups. For example, a person may have reached a crisis point in their lives, feeling like they can no longer cope alone with their situation, or they may simply want join because they have heard about it from other people.

If it is decided that new members should be met in advance in order to understand personal needs and expectations, it should be done by the facilitator or a member(s) of the group who feel comfortable explaining the peer support group and orienting the new member. They can provide the new group member with a way to contact them (phone call, text or WhatsApp message, email) for questions or information about meetings.

New members may find it useful to know the following:
- Who to contact if they wish to join the group;
- Meeting times, duration and venue;
- Values and principles, particularly around confidentiality;
- Guidelines around punctuality and confirming attendance;
- Brief description of the process of meetings and the facilitation role;
- Brief insight into what peer support means and how it might be of benefit.

Structure of the group

The purpose of the peer support group can be fulfilled in many different ways. It may be through formal meetings, informal meetings with less structure as well as more recreational activities (e.g. outings or sport activities). Before getting started, it can be helpful to picture what the group might look like in order to decide on the structure of the group and whether the group should be more formal or informal.

Formal peer support groups generally have more delineated roles and responsibilities within their structure, such as a specific facilitator for each meeting. This structure can lead to more efficient decision-making and implementation of activities. Informal peer support groups generally have less hierarchy, allowing members to have varying and dynamic roles. They can also allow for more flexibility in planning and implementing activities.

Discussing the structure with other group members and listening to their input is beneficial. Group structure can influence group dynamics and understanding how to navigate these dynamics can be helpful. For example, in a structured group with one facilitator and many members, a power imbalance exists. There should be honesty and transparency about this imbalance, and awareness that these roles may change and evolve as the group develops.

Code of ethics

A "code of ethics" or set of ground rules for the operation of meetings should be developed by the group members. Setting boundaries will let members know what to expect from the group and help to provide a safe place for people to meet. Copies should be distributed to the group and people attending the group should be regularly reminded about the code of ethics.

Some principles for consideration are listed below as an illustration, though each group should come up with a code of ethics of its own (11):

- Maintaining confidentiality. Group members leave only with the shared knowledge and wisdom of group members' lived experiences rather than names or other personal information that would identify people.
- Recognizing that thoughts and feelings are neither right nor wrong.
- Not being judgemental or critical of other members, and will showing acceptance.
- Having the right to share feelings or not. People should be encouraged to speak during the meetings, but if they wish just to "be there" at times the group will accept that.
- Having empathy (fully comprehending the impact, having experienced the situation)
- Having awareness of not overstepping each other's boundaries and should promote empowerment to encourage independence, not dependence.
- Appreciating that each person's feelings are unique to that person and need to respect and accept what members have in common and what is specific to each individual.
- Respecting the right of all the members to have equal time to express themselves, and to do so without interruption. However, allowing people who may be in crisis to have more time to talk through their issues.
- Sharing responsibility by taking turns in various roles such as coffee-maker or facilitator

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Scenario: Evolving structure of a peer support group (15)

Two friends set up a family support group over 15 years ago. They were joined by two others in a similar situation and met in each other's houses every week for about six years. During this time they talked, listened and supported each other. They realised that others would benefit from the support offered within the group. They approached the Local Drugs Task Force and got access to a comfortable room for meetings.

They agreed and wrote out their principles or code of ethics. They let acquaintances know about the group, where it met and how often it met. Initially, the group was 'led' by one individual in that they called and organised the meetings but over time all the members of the group were helped to become leaders and most trained to be facilitators. The group now has over 20 members. It meets every week for around two hours. It is open to new members. At the start of each meeting a member of the group will volunteer to facilitate the group for that session.

Confidentiality issues

Respect for the privacy of others within peer support groups is particularly important. People often share personal stories and are often only able to do so after having developed a trusted relationship with group members. It is very important to respect this trust and for group members to keep all information and stories shared during meetings confidential, including, where requested, their participation in the group.(16)

If someone needs to gather information about group members, they should first ask for their consent. The person should clearly explain to them why they would like this information and how it will be used. It may be interesting to conduct research within the group, but members should not feel pressured to participate. The person's consent to reveal personal information to third parties (e.g. health workers, families) is also needed.

Information about members should be kept in a secure place to prevent others from having access to private information, even by accident (e.g. locked drawer or a password protected computer file)(11). It is necessary to be familiar with the data protection and privacy laws of the country.

There may be some situations where exceptions to confidentiality are made, such as when a child has been abused or a group member is hurting someone. How to approach these situations will depend on the law of the country(16).

External support for group members (11)

At times the group may identify that a member is struggling with a personal issue, and may need more support than what the group can provide.

If a group member would like more support, various options may be explored, such as the available support structures within the community. The person can be provided with information about additional support, which they may or may not choose to use. It can be useful to share resource information and over time collectively build a file on the possible sources of support that might be beneficial for group members.

Members of the group, either individually or collectively, can benefit from respite outside of the home environment. Respite can take many forms, e.g. having a group weekend away, going to a conference, doing workshops in self-care, engaging in holistic therapies.

Promoting support groups

Information about the group can be disseminated to key community organizations as well as mental health and related services through a variety of ways including regular contact and discussions with people working in these organizations and services, but also through disseminating flyers and brochures in all relevant places in the community where potential members are likely to visit. Flyers or brochures should state the purpose and activities of the group, as well as logistical information such as meeting dates, time and, location. Social media, including outlets such as Facebook and Twitter, can be an informal way of promoting support groups to a wider audience.

5   Running peer support group meetings

This section provides guidance for operating group meetings. The steps outlined below are suggestions designed to help groups get started –they are not meant to be prescriptive.

Location and frequency of meetings (17)

In deciding a location for the peer support group meetings, you might want to consider:
- Accessibility – Can people get there easily? Consider physical and logistical issues
- Size – Is the meeting place large enough? Are there enough chairs?

- Comfort – Is it quiet and private enough to allow for a comfortable exchange between group members?
- Convenience – Are there toilets/washrooms?
- Cost – Is there a charge for its use?
- Refreshments – Will anything be offered in meetings? Note, that refreshments can contribute to creating a relaxed atmosphere

Possible locations may be a community center, school, places of worship, coffee shops, libraries or mental health and related services. It is important to use the same place whenever possible so group members know where to meet and feel safe and familiar in that particular space.

How often the group will meet is another consideration. The frequency of meetings (weekly, or monthly) and the time (morning or afternoon) will need to be agreed upon. It all depends on what is most convenient for the members of the group. Usually members of the group will make this decision at the first meeting and most groups meet on a regular basis.

Scenario: The Dragon Café – an open venue for meeting others with lived experience (18),(19)

The Dragon Cafe in London is a weekly cafe and creative space with seminars, exhibitions, workshops and performances exploring issues around mental illness, recovery and well-being.

The Founder, the late Sarah Wheeler, started the first mental health cafe in the UK three years ago following a three year period of experiencing psychosis. When Sarah was in distress she spent a lot of time in cafes. The vision of the café is to be an antithesis to average mental health services, because people can do what they wish to do and there is no pressure to do anything at all. People can sing write, or paint if they wish to, but they can also just collapse on a bean bag and snore.

The Dragon Café provides a simple, affordable, healthy menu each week, and a wide range of creative and well-being activities, all of which are free and open to all. No enrolment is required for groups, just turn up and take part, as much or as little as you like. The cafe is run by volunteers. Many of the volunteers have lived experience with mental distress and seek to make "an open-hearted place" – a place that can seem like a kind of heaven when you have been in a kind of hell.

The first meeting (16)

The first meeting is important and often sets the tone for the group. The number of people attending should not be the main concern. What is more important is the connection with the people who do attend. Some of the steps to consider are outlined below, but these are only suggestions and the group may decide on other methods for running the group that may be more appropriate.

Set up

Bring a sign-up sheet, an agenda and any other resources the facilitator will need for the first meeting. It is important that the room feels welcoming. If the room is hard to find, make sure signs are posted directing people to the meeting.

Greet people

It is a good idea to have the facilitators at the door to welcome people

Sharing stories

Many people will be nervous or reluctant to speak at a first meeting, so it is really helpful for facilitators to open the conversation by sharing information about themselves and what they bring to the group, as well as describing their aims for the group. It is important to briefly discuss *confidentiality* at this point – for example, that the names of the group members should not leave the room – although it might be more appropriate to establish overall group rules at the second meeting.

Discuss barriers to attending support groups

It is important to understand and discuss with the group some of the challenges and feelings people have in relation to attending support groups. Barriers may include:

- Stigma of mental health;
- If they are a care partner, they may have no one else to stay with besides the person they care for;
- Too burned out to venture out to another meeting;
- Nervous about what might happen during the group sessions;
- Lack of availability of assistive and augmentative communication devices.
- Lack of trust that it will be a safe space where they can talk freely without repercussions

It is important to acknowledge these challenges and identify how the group will try to address them.

Scenario: National Organization of Users and Survivors of Psychiatry (NOUSPR), Rwanda – an example of reluctance to seek out support due to fear of stigma and discrimination (20)

At NOUSPR in its early days, members had to meet in an undisclosed place due to fear of stigma and many of the people attending would not disclose their status among themselves. Nevertheless, people were seeking support from the organisation, so they would communicate their needs by referring to other people. For example, by saying: ''I know someone who could really benefit from joining NOUSPR…..… He really needs your help, he does not have food, he sleeps outside of his home … if you want I can come with his medical documents in the next meeting''. After the support group gathering, the same person would approach a NOUSPR staff member and tell: ''That was me, but I don't want people to know.''

Encourage sharing between members

Sharing within the group provides a common ground on which people can start to identify with others and trust that they are not alone in personal challenges. It can also help people understand that everyone is not necessarily there for the same reason. For a while, people may say they just want to hear from other people. It may take some time for the group to become comfortable speaking about the specific needs that they have.

Identify common experiences

There may be quite a range of challenges that bring people to a support group and it is important to try to identify the most common experiences of the group so that people feel connected on various levels with each other.

Provide a contact sheet

The contact sheet allows the facilitator to contact participants on the list with future meeting information and general information. People may not feel comfortable putting their name down the first time, so it is important to let them know they do not have to.

Identify communication needs

It's important to have the group members identify how they would like to receive information. Email can be the most time-efficient, but there are other modes of communication that also work such as phone calls, text messages, WhatsApp messages, or other forms of group messaging services that are accessible for all group members. Listening to group members and knowing their preference for communication is important to keep the group together and functioning well. Preferred method of contact can be included on the sign-up sheet to identify the best options.

Meeting closure

It is often helpful to go around the group to see if anyone would like to say anything. This might include:
- If there was something in particular that they gained from the group meeting that was especially meaningful;
- Something that they were grateful for;
- Something that wasn't addressed that could have been useful;
- Something that can be improved or done differently for them to feel more at ease.

Hints and tips for starting conversations

The following phrases may help you start conversations in the peer support group.

"In my own experience, when I was first given a psychiatric diagnosis, I saw no hope, no future for myself.... Does anyone else have a similar experience?"

"The most challenging thing for me has been the shame and embarrassment society/my community has made me to feel. For example, [describe a personal experience you have had] happened to me. Has anyone else experienced something similar?"

The second meeting (16)

In addition to other regular agenda items, you may want to include a discussion of the group's ethical guidelines during this second meeting.

Discuss guidelines
Group guidelines / code of ethics are important as they set out how people are expected to behave with one another in order for the group to run more effectively for everyone. For more information see section *Code of ethics*.

How to be a good group member
Listening and supporting group members as they discuss their experiences and feelings is an important aspect of peer support groups. Being a good group member can encourage sharing and honesty, and be more beneficial for both the individual and the others in the group. For additional information, please review the hand-out, How to Be a Good Group Member, found in *Appendix 1*.

Sharing responsibilities
Sharing the responsibilities in a peer support group can help prevent 'burnout'. One way to identify and clarify roles is to create a volunteer sign-up sheet. It is important to create this list with your group and remind members that they will only be asked to do something if they can and are comfortable doing it.

Topics and speakers
Group members may find it beneficial to have guest speakers share information about topics of interest relevant to the individual and group. If there is interest, have members share what topics or speakers they would find meaningful.

Subjects may include: Human rights, recovery, supported decision making, communication skills, problem and crisis solving techniques, or lifestyle information like diet, physical exercise, and relaxation.

Speakers may include: People with lived experience, survivors, care partners, human rights advocates, mental health and other practitioners, government health officials, persons representing other disabilities, lawyers, philanthropists, or dieticians.

Scenario: Maitri meetings – a place to share wellness and recovery strategies (21)

Maitri group meetings are a space where people with lived experience talk about their own recovery and discuss strategies for self-care. Janaki Patel, a Peer Support Volunteer at the Hospital for Mental Health, Vadodara, has also been trained as an anchor person for the Maitri group meetings. "Anger management" was the topic of discussion for one of the meetings. Ms Patel shared her experience of using rhythmic breathing to help her calm down in times of distress, and manage her anger. In the meeting she demonstrated how she does this and encouraged others to try this for themselves.

Starting the meeting
Reminding members of the purpose of your group and saying a word about confidentiality may be a good way to open ongoing meetings. You also need to create a relaxed atmosphere that favours confidence and discussion. Telling a personal story may also be a good way to do so. Members may also want to start by talking about a particular issue or by sharing their own reflection on a topic. They should be encouraged to do so. Having a welcome and warm environment conducive to sharing will be critical to the success of your meetings.

Taking a break
It is a good idea to take a break during the meeting. Offer refreshments and encourage people to move in the room. It will provide an opportunity for them to talk one-on-one, which is particularly useful for those who find talking in a group difficult. Also, it can contribute to creating a more relaxed and informal atmosphere where group members can connect on different levels.

Content of the meetings
The actual content of meetings may include informal sharing as well as more formal components such as providing good quality up-to-date and locally relevant information, drawing upon external resources and speakers from time to time in line with needs and the wishes of group members. See section *Running peer support group meetings* for additional information on what subjects and speakers may include.

It is recommended that the group follow some basic rules to make sure that the content of the meetings remains relevant. Examples are included below, but other ones are likely to emerge over time as the group continues to evolve and change. Having a forum for these conversations and decisions is important – a monthly meeting is one way to involve everyone in the group.

Group members are encouraged to freely discuss any topic that is relevant to their life at that time, including sharing their experiences since the group met last, any problems that arose and how these were managed. Members should be encouraged to share their own views and possible ways of handling challenging situations, yet it is important to promote conversations that flow both ways and not just advice-giving. Listening attentively without interruption and maintaining a neutral attitude, always allowing objective listening without invalidating or trying to change people's feelings is important. This creates space for people to create their own meaning, seek input or just share based on their own choice.

Group members should avoid making offensive or insensitive comments, sexual remarks or jokes. If group members feel distressed during the discussion of a certain topic, they should feel free to step out until they feel able to participate again. There should be no pressure to share experiences. Some members may just like to observe and hear others in the first few meetings and this may also benefit them. It is important to respect that each experience is unique to the individual.(13)

Concluding the meetings (11)

Before the group meeting closes, it is important to go around the group to see if anyone would like to share anything or if there was something that they gained from the group meeting which was especially meaningful. It is important to end on something positive. This might also be a particular achievement of a group member or recount a personal story of how someone managed a particularly difficult situation depending on what is relevant for the kind of group. Ending on a positive note can bring hope, encouragement and confidence to other group members. You can also collectively decide to support a particular group member who feels unwell until the next meeting.

Hints and tips for a successful group

- Everyone has an opportunity to speak and cross-talk should be discouraged. Ensure all voices are heard.
- Any comments or observations after the speaker has finished speaking should be non-judgmental.
- Members should have the opportunity to share personal experiences. When a member shares their experience, others should listen attentively.
- The facilitator should avoid taking sides or interrupting in between the discussions. A facilitator may, however, intervene if there are factual mistakes or if disagreements become disruptive.
- Sometimes people feel that they or their relative too should be following some type of "normal" recovery progression. Experience suggests that people develop their own timeframe for healing and recovery. Expecting a person with lived experience to meet someone else's timeframe can lead to unnecessary pressure and problems.
- Everyone should be allowed to express emotions. A lot of people stop themselves from showing emotion in public. They need to know and feel that it is normal to experience emotion and acceptable to show emotions within the group.

Scenario: Sihaya Samooh – The evolution of a peer support group (1) (23)

In the spring of 1992 in Pune, three user survivors came together to found the seed of a 'community'. They were around the age of 50, and had received different diagnosis of depression, bipolar disorder and schizophrenia. In order to cope up with their ups and downs, they needed each other. The 3 members started meeting weekly and by and-by others joined. They grew into a sizeable group of persons with various forms of emotional and mental distress.

The group found solace in mutual support. From the original three, the Sihaya Samooh grew to the largest attendance of around 25 persons in 1995 which seemed unmanageable. They decided to split into two sub-groups. One group started meeting in the canteen on the fringe of a college campus. The other group found a niche in a tiny garden-restaurant in a different area. After a few months, the second group stopped meeting.

Sihaya Samooh was formed in a spirit of mutual aid with a concept of 'self-help'. Rather than being "patients" the group members chose to see themselves as "persons". In Sihaya they created a 'space' for themselves where they listened to each other, identified and affirmed the strengths in each of them that they could put together, making these into a recognisable strength.

Ongoing reflection is a process whereby members set aside some time to consider how their group and meetings are functioning with the idea of making sure that the group is meeting the needs of its members and whether it can be improved. Members might, for example, be invited to share how they felt about what invited speakers may have said and whether it was interesting and helpful.

A criticism or a complaint from one member does not mean that the group and its activities are not valuable. However, if many members agree that changes need to be implemented, it may be necessary to consider how activities and meetings could be improved. This should be discussed with all members. Organising regular meetings to discuss the usefulness of activities may be a helpful way to get feedback and new ideas. This will help ensure that groups continue to provide a beneficial service to its members (24).

Scenario: Sihaya Samooh – The evolution of a peer support group (2)(23)

What were the benefits to Sihaya group members?

They gained support to cope with and tide over their distressing phases or episodes. It helped their self-esteem to be accepted, listened to and respected. A couple of members later took up caregiving vocations because of the liberating experience and encouragement they received in the Sihaya Samooh group.

What were the short-comings and limitations of Sihaya?

They lacked a structure and methodology in the group, and depended upon their mutual common sense and varied personal experience. They groped where they didn't know enough, and believed too much in mere listening to and sharing with each other. Many came with high hopes but were not able to get the help that they expected; some were not able to continue to come for various reasons. Women found it harder to come, in comparison to men who were physically and socially more mobile. This was despite the kernel of feminist ethics in the group!

How did the Sihaya Samooh gatherings come to an end?

Several members who held the group together had to move on to other places, for geographic or vocational reasons. One member chose to launch a larger mental health self-help support initiative. The group lost a couple of members (…) One member married a man of her choice, and moved out. Another member turned to focus her energies on Women and Health Training Programme. One member began her long battle with cancer. The group kept on meeting for a couple of years more with depleted numbers.

A number of members of the old Sihaya group still meet each other or remain in touch over phone (…) They miss the sensitive protected space that they made, and hope someday it will be recreated – not in a single place, but with various names for many, many other survivors who need it at many places.

What is the significance of the Sihaya Samooh experience of seven years?

It was the first organized 'mental health self-help support' group in Pune and a pioneer in India. It demonstrated the 'creation' of a safe social space that could keep at bay the stigma and oppression of society. It harboured a vision of creating many such spaces in the future that with greater mass could play a role in building a better society.

Sihaya Samooh also illustrates that a peer support group can change and adapt to its members' needs over time, and does not need to meet indefinitely for it to be a success. It is more important that the group serves a useful purpose for its members at the time. In Sihaya Samooh, they gained support from each other, and created a space where they could listen and share experiences.

Peer support structures, mentoring and supervision

It is 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 the community an opportunity to come together to debrief, share knowledge and experiences, discuss improvements and provide emotional support.

In a safe and confidential space, peer supporters can have an 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 in the sense that peer supporters may be viewed more like friends than non-peer staff, since they disclose personal information and share intimate stories from their own lives. It is suggested that boundaries should be flexible and individually governed to avoid power imbalances.(1) Other challenges that may arise include power imbalances between peer supporters and other staff; stress for peer supporters; and maintaining the role of peer supporters.(25)

Provision of effective supervision is an important component in sustaining peer support roles. Peer roles may be met with resistance or confusion at first, and having the support of a supervisor who believes in peer support and the recovery approach is important. Ideally, a supervisor for a peer supporter is someone who has worked in peer roles before and therefore understands what the role of a peer supporter entails and the challenges that may arise.(26)

Another option is to reach out to local, regional, or national peer-to-peer organizations where they exist for supplemental 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. Technology such as phone calls or skype can also provide support to peer supporters who are not geographically close to other peer groups.(27) In cases where the supervisor has not worked in peer roles, additional training may be helpful.

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

Annex 1: How to be a good group member (28)

1. Keep what is said in the group confidential

A major concern for some members is having their privacy respected. Be clear about what confidentiality means for the group. Members should not be talked about in any identifiable way outside the group.

2. Ask people if they want advice or a suggestion before you give it

For many people, as soon as they hear a problem they have a tendency to start thinking about how to 'fix it.' However, sometimes people just need to say how they feel and aren't ready to start thinking about how to deal with the problem. Another thing to keep in mind is that one person's 'solutions' may not work for someone else.

3. Know that some people can be very intense and goal-oriented

At times, you may want to criticize or disagree with group members on their goals for treatment or recovery. Remember that people may have different opinions and that no one has the right to judge another member for what kind of decisions they make.

4. Neglect, malpractice or abuse

If there is a question of any neglect, malpractice or abuse, the laws of the country should be followed and the person referred to an organisation dealing with such issues.

5. Understand that people in the group will be at different stages

For those who are still coping with the feelings of helplessness that often accompany the diagnosis of a mental health problem, remember that they need to be and feel listened to and understood. It can often make someone feel worse when another person tells them to "cheer up."

7. Realize that people do not have to like everyone else in the group

People do not need to share the same philosophy of life nor the same level of education or income to have a right to be in the group. All members should be made to feel welcome irrespective of their social, economic, marital or other status.

8. Realize that peer support groups cannot solve all personal problems

Sometimes they can help people to clarify problems and find out where to get further support. Many problems or specific issues cannot be solved in the group. For example a caregiver of a child with a severe behaviour problem may be able to receive and benefit from suggestions, support or empathy, but they may also need to seek services of support outside the group.

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