



# Peer support groups 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

Peer support groups by and for people with lived experience. WHO QualityRights guidance module

ISBN 978-92-4-151677-8

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University of São Paulo (Brazil); Rio de Janeiro Public Prosecutor's Office (Brazil); Patricia Brogna, National School of Occupational Therapy, (Argentina); Celia Brown, MindFreedom International, (United States of America); Kimberly Budnick, Head Start Teacher/Early Childhood Educator (United States of America); Janice Cambri, Psychosocial Disability Inclusive Philippines (Philippines); Aleisha Carroll, CBM Australia (Australia); Mauro Giovanni Carta, Università degli studi di Cagliari (Italy); Chauhan Ajay, State Mental Health Authority, Gujarat, (India); Facundo Chavez Penillas, Office of the United Nations High Commissioner for Human Rights (Switzerland); Daniel Chisholm, WHO Regional Office for Europe (Denmark); Louise Christie, Scottish Recovery Network (United Kingdom); Oryx Cohen, National Empowerment Center (United States of America); Celline Cole, Freie Universität Berlin (Germany); Janice Cooper, Carter Center (Liberia); Jillian Craigie, Kings College London (United Kingdom); David Crepaz-Keay, Mental Health Foundation (United Kingdom); Rita Cronise, International Association of Peer Supporters (United States of America); Gaia Montauti d'Harcourt, Fondation d'Harcourt (Switzerland); Yeni Rosa Damayanti, Indonesia Mental Health Association (Indonesia); Sera Davidow, Western Mass Recovery Learning Community (United States of America); Laura Davidson, Barrister and development consultant (United Kingdom); Lucia de la Sierra, Office of the United Nations High Commissioner for Human Rights (Switzerland); Theresa Degener, Bochum Center for Disability Studies (BODYS), Protestant University of Applied Studies (Germany); Paolo del Vecchio, Substance Abuse and Mental Health Services Administration (United States of America); Manuel Desviat, Atopos, Mental Health, Community and Culture (Spain); Catalina Devandas Aguilar, UN Special Rapporteur on the rights of persons with disabilities (Switzerland); Alex Devine, University of Melbourne (Australia); Christopher Dowrick, University of Liverpool (United Kingdom); Julian Eaton, CBM International and London School of Hygiene and Tropical Medicine (United Kingdom); Rabih El Chammay, Ministry of Health (Lebanon); Mona El-Bilsha, Mansoura University (Egypt); Ragia Elgerzawy, Egyptian Initiative for Personal Rights (Egypt); Radó Iván, Mental Health Interest Forum (Hungary); Natalia Santos Estrada, Colectivo Chuhcan (Mexico); Timothy P. Fadgen, University of Auckland (New Zealand); Michael Elnemais Fawzy, El-Abbassia mental health hospital (Egypt); Alva Finn, Mental Health Europe (Belgium); Susanne Forrest, NHS Education for Scotland (United Kingdom); Rodrigo Fredes, Locos por Nuestros Derechos (Chile); Paul Fung, Mental Health Portfolio, HETI Higher Education (Australia); Lynn Gentile, Office of the United Nations High Commissioner for Human Rights (Switzerland); Kirsty Giles, South London and Maudsley (SLaM) Recovery College (United Kingdom); Salam Gómez, World Network of Users and Survivors of Psychiatry (Colombia); Ugnė Grigaitė, NGO Mental Health Perspectives and Human Rights Monitoring Institute (Lithuania); Margaret Grigg, Department of Health and Human Services, Melbourne (Australia); Oye Gureje, Department of Psychiatry, University of Ibadan (Nigeria); Cerdic Hall, Camden and Islington NHS Foundation Trust, (United Kingdom); Julie Hannah, Human Rights Centre, University of Essex (United Kingdom); Steve Harrington, International Association of Peer Supporters (United States of America); Akiko Hart, Mental Health Europe (Belgium); Renae Hodgson, Western Australia Mental Health Commission (Australia); Nicole Hogan, Hampshire Hospitals NHS Foundation Trust (United Kingdom); Frances Hughes, Cutting Edge Oceania (New Zealand); Gemma Hunting, International Consultant (Germany); Hiroto Ito, National Center of Neurology and Psychiatry (Japan); Maths Jespersen, PO-Skåne (Sweden); Lucy Johnstone, Consultant Clinical Psychologist and Independent Trainer (United Kingdom); Titus Joseph, Centre for Mental Health Law and Policy, Indian Law Society (India); Dovilė Juodkaitė, Lithuanian Disability Forum (Lithuania); Rachel Kachaje, Disabled People's International (Malawi); Jasmine Kalha, Centre for Mental Health Law and Policy, Indian Law Society (India); Elizabeth Kamundia, National Commission on Human Rights (Kenya); Yasmin Kapadia, Sussex Recovery College (United Kingdom); Brendan Kelly, Trinity College Dublin (Ireland); Mary Keogh, CBM International (Ireland); Akwatu Khenti, Ontario Anti-Racism Directorate, Ministry of Community Safety and Correctional Services (Canada); Seongsu Kim, WHO Collaborating Centre, Yongin Mental Hospital (South Korea); Diane Kingston, International HIV/AIDS Alliance (United Kingdom); Rishav Koirala, University of Oslo (Norway); Mika Kontiainen, Department of Foreign Affairs and Trade (Australia); Sadhvi Krishnamoorthy, Centre for Mental Health Law and Policy, Indian Law Society (India); Anna

Kudiyarova, Psychoanalytic Institute for Central Asia (Kazakhstan); Linda Lee, Mental Health Worldwide (Canada); Itzhak Levav, Department of Community Mental Health, University of Haifa (Israel); Maureen Lewis, Mental Health Commission (Australia); Laura Loli-Dano, Centre for Addiction and Mental Health (Canada); Eleanor Longden, Greater Manchester Mental Health NHS Foundation Trust (United Kingdom); Crick Lund, University of Cape Town (South Africa); Judy Wanjiru Mbutia, Uzima Mental Health Services (Kenya); John McCormack, Scottish Recovery Network (United Kingdom); Peter McGovern, Modum Bad (Norway); David McGrath, international consultant (Australia); Emily McLoughlin, international consultant (Ireland); Bernadette McSherry, University of Melbourne (Australia); Roberto Mezzina, WHO Collaborating Centre, Trieste (Italy); Tina Minkowitz, Center for the Human Rights of Users and Survivors of Psychiatry (United States of America); Peter Mittler Dementia Alliance International (United Kingdom); Pamela Molina Toledo, Organization of American States (United States of America); Andrew Molodynski, Oxford Health NHS Foundation Trust (United Kingdom); Maria Francesca Moro, Columbia University (United States of America); Fiona Morrissey, Disability Law Research Consultant (Ireland); Melita Murko, WHO Regional Office for Europe (Denmark); Chris Nas, Trimbos International (the Netherlands); Sutherland Carrie, Department for International Development (United Kingdom); Michael Njenga, Users and Survivors of Psychiatry in Kenya (Kenya); Aikaterini - Katerina Nomidou, GAMIAN-Europe (Belgium) & SOFPSI N. SERRON (Greece); Peter Oakes, University of Hull (United Kingdom); David W. Oaks, Aciu Insitute, LLC (United States of America); Martin Orrell, Institute of Mental Health, University of Nottingham (United Kingdom); Abdelaziz Awadelseed Alhassan Osman, Al Amal Hospital, Dubai (United Arab Emirates); Gareth Owen, King's college London (United Kingdom); Soumitra Pathare, Centre for Mental Health Law and Policy, Indian Law Society (India); Sara Pedersini, Fondation d'Harcourt (Switzerland); Elvira Pértega Andía, Saint Louis University (Spain); Dainius Pūras, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of health (Switzerland); Thara Rangaswamy, Schizophrenia Research Foundation (India); Manaana Kar Ray, Cambridgeshire and Peterborough NHS Foundation Trust (United Kingdom); Mayssa Rekkis, faculty of Medicine, Tunis El Manar University (Tunisia); Julie Repper, University of Nottingham (United Kingdom); Genevra Richardson, King's college London (United Kingdom); Annie Robb, Ubuntu centre (South Africa); Jean Luc Roelandt, EPSM Lille Metropole, WHO Collaborating Centre, Lille (France); Eric Rosenthal, Disability Rights International (United States of America); Raul Montoya Santamaría, Colectivo Chuhcan A.C. (Mexico); Jolijn Santegoeds, World Network of Users and Survivors of Psychiatry (the Netherlands); Benedetto Saraceno, Lisbon Institute of Global Mental Health (Switzerland); Sashi Sashidharan, University of Glasgow (United Kingdom); Marianne Schulze, international consultant (Austria); Tom Shakespeare, London School of Hygiene & Tropical Medicine (United Kingdom); Gordon Singer, expert consultant (Canada); Frances Skerritt, Peer Specialist (Canada); Mike Slade, University of Nottingham (United Kingdom); Gregory Smith, International consultant, (United States of America); Natasa Dale, Western Australia Mental Health Commission, (Australia); Michael Ashley Stein, Harvard Law School (United States of America); Anthony Stratford, Mind Australia (Australia); Charlene Sunkel, Global Mental Health Peer Network (South Africa); Kate Swaffer, Dementia International Alliance(Australia); Shelly Thomson, Department of Foreign Affairs and Trade (Australia); Carmen Valle, CBM International (Thailand); Alberto Vásquez Encalada, Office of the UN Special Rapporteur on the rights of persons with disabilities (Switzerland); Javier Vasquez, Vice President, Health Programs, Special Olympics, International (United States of America); Benjamin Veness, Alfred Health (Australia); Peter Ventevogel, Public Health Section, United Nations High Commissioner for Refugees (Switzerland); Carla Aparecida Arena Ventura, University of Sao Paulo (Brazil); Alison Xamon, Western Australia Association for Mental Health, President(Australia).

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## WHO administrative and editorial support

Patricia Robertson, Mental Health Policy and Service Development, Department of Mental Health and Substance Abuse (WHO, Geneva); David Bramley, editing (Switzerland); Julia Faure (France), Casey Chu (Canada) and Benjamin Funk (Switzerland), design and support

## Video contributions

We would like to thank the following individuals and organizations for granting permission to use their videos in these materials:

### **50 Mums, 50 Kids, 1 Extra Chromosome**

*Video produced by Wouldn't Change a Thing*

### **Breaking the chains by Erminia Colucci**

*Video produced by Movie-Ment*

### **Chained and Locked Up in Somaliland**

*Video produced by Human Rights Watch*

### **Circles of Support**

*Video produced by Inclusion Melbourne*

### **Decolonizing the Mind: A Trans-cultural Dialogue on Rights, Inclusion and Community**

(International Network toward Alternatives and Recovery - INTAR, India, 2016)

*Video produced by Bapu Trust for Research on Mind & Discourse*

### **Dementia, Disability & Rights - Kate Swaffer**

*Video produced by Dementia Alliance International*

### **Finger Prints and Foot Prints**

*Video produced by PROMISE Global*

**Forget the Stigma**

*Video produced by The Alzheimer Society of Ireland*

**Ghana: Abuse of people with disabilities**

*Video produced by Human Rights Watch*

**Global Campaign: The Right to Decide**

*Video produced by Inclusion International*

**Human Rights, Ageing and Dementia: Challenging Current Practice by Kate Swaffer**

*Video produced by Your aged and disability advocates (ADA), Australia*

**I go home**

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**Inclusive Health Overview**

*Video produced by Special Olympics*

**Independent Advocacy, James' story**

*Video produced by The Scottish Independent Advocacy Alliance*

**Interview - Special Olympic athlete Victoria Smith, ESPN, 4 July 2018**

*Video produced by Special Olympics*

**Living in the Community**

*Video produced by Lebanese Association for Self Advocacy (LASA) and Disability Rights Fund (DRF)*

**Living it Forward**

*Video produced by LedBetter Films*

**Living with Mental Health Problems in Russia**

*Video produced by Sky News*

**Love, loss and laughter - Living with dementia**

*Video produced by Fire Films*

**Mari Yamamoto**

*Video produced by Bapu Trust for Research on Mind & Discourse*

**Mental health peer support champions, Uganda 2013**

*Video produced by Cerdic Hall*

**Moving beyond psychiatric labels**

*Video produced by The Open Paradigm Project/ P.J. Moynihan, Digital Eyes Film Producer*

**'My dream is to make pizza': the caterers with Down's syndrome**

*Video produced by The Guardian*

**My Story: Timothy**

*Video produced by End the Cycle (Initiative of CBM Australia)*



**Neil Laybourn and Jonny Benjamin discuss mental health**

*Video produced by Rethink Mental Illness*

**No Force First**

*Video produced by Mersey Care NHS Foundation Trust*

**No more Barriers**

*Video produced by BC Self Advocacy Foundation*

**‘Not Without Us’ from Sam Avery & Mental Health Peer Connection**

*Video produced by Mental Health Peer Connection*

**Open Dialogue: an alternative Finnish approach to healing psychosis (complete film)**

*Video produced by Daniel Mackler, Filmmaker*

**The Open Paradigm Project – Celia Brown**

*Video produced by The Open Paradigm Project/ Mindfreedom International*

**Open Paradigm Project – Dorothy Dundas**

*Video produced by The Open Paradigm Project*

**Open Paradigm Project – Oryx Cohen**

*Video produced by The Open Paradigm Project/ National Empowerment Center*

**Open Paradigm Project - Sera Davidow**

*Video produced by The Open Paradigm Project/ Western Mass Recovery Learning*

**Ovidores de Vozes (Hearing Voices) Canal Futura, Brazil 2017**

*Video produced by L4 Filmes*

**Paving the way to recovery - the Personal Ombudsman System**

*Video produced by Mental Health Europe ([www.mhe-sme.org](http://www.mhe-sme.org))*

**Peer Advocacy in Action**

*Video produced and directed by David W. Barker, Createus Media Inc. ([www.createusmedia.com](http://www.createusmedia.com))*

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**Planning Ahead – Living with Younger Onset Dementia**

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**Quality in Social Services - Understanding the Convention on the Rights of Persons with Disabilities**

*Video produced by The European Quality in Social Service (EQUASS) Unit of the European Platform for Rehabilitation (EPR) ([www.epr.eu](http://www.epr.eu) – [www.equass.be](http://www.equass.be)). With financial support from the European Union Programme for Employment and Social Innovation “EaSI” (2014-2020) – <http://ec.europa.eu/social/easi>.*

*Animation: S. Allaey – QUIDOS. Content support: European Disability Forum*

**Raising awareness of the reality of living with dementia,**

*Video produced by Mental Health Foundation (United Kingdom)*

**Recovery from mental disorders, a lecture by Patricia Deegan**

*Video produced by Patricia E. Deegan, Pat Deegan PhD & Associates LLC*

**Reshma Valliappan** (International Network toward Alternatives and Recovery - INTAR, India, 2016)

*Video produced by Bapu Trust for Research on Mind & Discourse*

**Rory Doody on his experience of Ireland's capacity legislation and mental health services**

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*Video produced by Self Advocacy Online (@selfadvocacyonline.org)*

**Social networks, open dialogue and recovery from psychosis - Jaakko Seikkula, PhD**

*Video produced by Daniel Mackler, Filmmaker*

**Speech by Craig Mokhiber, Deputy to the Assistant Secretary-General for Human Rights, Office of the High Commissioner for Human Rights** made during the event 'Time to Act on Global Mental Health - Building Momentum on Mental Health in the SDG Era' held on the occasion of the 73rd Session of the United Nations General Assembly.

*Video produced by UN Web TV*

**Thanks to John Howard peers for support**

*Video produced by Cerdic Hall*

**The Gestalt Project: Stop the Stigma**

*Video produced by Kian Madjedi, Filmmaker*

**The T.D.M. (Transitional Discharge Model)**

*Video produced by LedBetter Films*

**This is the Story of a Civil Rights Movement**

*Video produced by Inclusion BC*

**Uganda: 'Stop the abuse'**

*Video produced by Validity, formerly the Mental Disability Advocacy Centre (MDAC)*

**UN CRPD: What is article 19 and independent living?**

*Video produced by Mental Health Europe ([www.mhe-sme.org](http://www.mhe-sme.org))*

**UNCRPD: What is Article 12 and Legal Capacity?**

*Video produced by Mental Health Europe ([www.mhe-sme.org](http://www.mhe-sme.org))*

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*Video produced by the Office of the United Nations High Commissioner for Human Rights*

**What is Recovery?**

*Video produced by Mental Health Europe ([www.mhe-sme.org](http://www.mhe-sme.org))*

**What is the role of a Personal Assistant?**

*Video produced by Ruils - Disability Action & Advice Centre (DAAC)*

**Why self advocacy is important**

*Video produced by Inclusion International*

**Women Institutionalized Against their Will in India**

*Video produced by Human Rights Watch*

**Working together- Ivymount School and PAHO**

*Video produced by the Pan American Health Organization (PAHO)/ World Health Organization - Regional Office for the Americas (AMRO)*

**You can recover (Reshma Valliappan, India)**

*Video produced by ASHA International*

## **Financial and other support**

WHO would like to thank Grand Challenges Canada, funded by the Government of Canada, the Mental Health Commission, Government of Western Australia, CBM International and the UK Department for International Development for their generous financial support towards the development of the QualityRights training modules.

WHO would like to thank the International Disability Alliance (IDA) for providing financial support to several reviewers of the WHO QualityRights modules.

## 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

**Dévora 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/](http://www.who.int/mental_health/policy/quality_rights/en/)

# WHO QualityRights – Training and guidance tools

The following training and guidance modules and accompanying 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 provide guidance on how to build and strengthen peer support groups, sometimes called “self-help groups”, for and by people with psychosocial, intellectual or cognitive disabilities, and also groups for and by families and/or care partners

While this module focuses on group peer support, one-to-one peer support (see the module on *One-to-one peer support by and for people with lived experience*) and Internet- and media-based peer support can also be beneficial. Not everyone will be able – or want – to meet up or attend regular meetings in person, so telephone discussions, video calls, online forums, websites and social media can be potential alternatives.

An example of online peer support is shown in the following video:

Interview with Reshma Valliappan, The Red Door, India. At INTAR India 2016, 26-28 November 2016, Lavasa, India. <https://youtu.be/8lNkDRTpqq4> (16:09).

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

## 2. What are peer support groups?

Peer support groups bring together people who have similar concerns 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 may be considered by group members as alternatives to, or complementary to, traditional mental health services. They are run by members for members so the priorities are directly based on their needs and preferences. Peer support groups should ideally be independent from mental health and social services, although some services may facilitate and encourage the creation of peer support groups.

Peer support groups also allow members to benefit from naturally occurring social support and networks in the community in order to form unique relationships that may not otherwise have been possible.

Sometimes peer support groups may gradually expand their scope to include other activities (e.g. income-generation activities, advocacy) that make them harder to define.

*“In peer support we get members together to talk to each other, support each other, give each other the much-needed love. As you know in mental health there is a lot of loneliness, you lose your social circles, but you gain them again through your peers” (1).*

*“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” (2).*

*“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” (3).*



*“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” (4).*

*“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” (5)(6).*

### 3. Benefits of peer support groups

(7)

#### **Experience of peer support group Mental Health Peer Support Champions, Uganda, 2013**

In Uganda, HeartSounds Peer Support programme provides training for peer support workers “who are empowered to take an active role in the provision of mental health care by supporting and advising fellow service users and their families”. The video link below shows peer support workers and those who are being supported giving their points of view of about this process.

See: <https://youtu.be/BzHINRBkdSw> .

The benefits of group peer support are wide-ranging. They 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 and promote hope and recovery;
- the opportunity to build new relationships and to strengthen social support networks, helping 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 (e.g. helping others complete administrative procedures to access social and disability benefits, employment programmes etc.);
- contributing to overall health and well-being.

The many forms of exclusion and stigmatization that people can face – related, for instance, to disability, gender, sexual orientation etc. – can be mitigated within peer support groups. The safe space that peer support groups can provide contributes to the empowerment and resilience of those involved. Some of the benefits of peer support groups are highlighted in the examples below.

#### **Member of a self-help group for parents, Ghana**

*“This week our group discusses school and the importance of all of our children going to school. Kwasi and Ayishetu both tell the group that they tried to enroll their children in the local primary school but the school rejected their applications. Ayishetu said the principal was quite rude, saying that you can’t teach fools anything.*

*I explain that I have been successful in enrolling my son Nii in school and, since enrolling him, he has learned to read and write some words. His communication skills have improved greatly and he is more relaxed around new people. I see all the parents sitting forward on their chairs, listening to me eagerly. They all want their children to attend school as well. But how can we do it? I realize that together as a group we have some power.*

*I suggest that we approach the principal of the school my son attends to ask whether they can take more enrolments of children with intellectual disabilities. Toufic says it is the right of every child to attend school but, until joining this group, he had never seen the point of his son attending school. He says that all this is going to change now and he will use his influence to lobby the school as well. Ayishetu is excited and says that she will do whatever she can. We agree that next week we will make a clear plan of how to approach the school and what each of us can do. We agree that we won't rest until each of our children is in school" (8).*

### **Member of a peer support group, Brazil**

*"First of all, I have to say that I did not like [to participate in] groups. Deep down, I felt I was in treatment, which was embarrassing to me. [But] the mutual help and support group is different. In spite of having some basic rules of conduct, I participate in the group of my own volition and/or my need, and nothing more. I'm not put under pressure. And when I talk about my issues, I'm not alone anymore. Because, in the group, my participation makes a difference. And through listening and speaking, I discover things and feelings that help me to best take myself in a world of 'normal' people.*

*Within the group I have learned to accept my conditions (previously, I used to cry a lot when, not on purpose, they made me realize how different I was). I have learned that the act of taking care, of caring for someone with affection, has amazing power and makes anyone realize their potential more naturally. This goes beyond expectations.*

*Nowadays, I can write like this. I have been through unexpected experiences but I have been able to count on help from people who believed on me; then, gradually I have acquired knowledge with the group participants. Two years ago I would not been in an emotional condition to even start [writing] a line. It makes me happy [to know that] there are people fighting to give dignity and voice to us in our daily suffering, while we try to exist and to fulfill our dreams, even though society still looks at us with a cautious and frightened look ..." (9)*

### **Members of Maitri, a peer support group led by and for people with psychosocial disabilities, India (10),(11)**

*"Since I started communicating my needs and desire to my peers in the Maitri group, I realize that I have been able to open up for new changes and challenges, which earlier I could not do. Now I ask for help when I need it... The Maitri group has motivated me to understand my right to stay in the community. I have also become assertive to ask for what I need because I consider it as a right to have it" (10).*

*"When I come to these group meetings I feel happy because it makes me feel that I belong to some place and that I have someone to support me. I have learned that there are many other people like me" (11).*

### **Members of Saathi, a peer support group led by and for families and caregivers, India (12),(13)**

*“The Saathi group...has helped us [my husband and I] to find a place to share [our experiences] and to gain courage. Also, by regularly going to the group, we feel that we are able to help other caregivers who lack information and guidance” (12).*

*“The Saathi meetings help me to understand my son’s illness better.... [Ranjitbhai] has gotten better over time. ...After coming to the Saathi group and listening 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 about including him in the daily business and this gives me hope that one day he will be able to work” (13).*

### **Anne’s story (14)**

Anne is a 45-year-old woman from Douglas, a small town in the Northern Cape province of South Africa where unemployment, poverty, stigma and discrimination are rife. She received a diagnosis of major depression some years ago and receives treatment at the clinic in her community.

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 a 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 the initiative to start 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.

## **4. Setting up a support group**

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

### **Identified need or common purpose**

Most groups start in response to a need identified by one or more persons affected by similar needs or situations. Often, this need is not addressed by traditional mental health and social services. This brings purpose to the group and helps to establish what will be shared and achieved. Peer support groups can have different aims and can 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 (15).

### **Better lives for people in Leeds, United Kingdom – peer support for people living with dementia (16)**

In Leeds, a range of peer support network groups for people with dementia has been developed. The peer support groups – including women-specific, men-specific and mixed groups – hold informal meetings in which people can share experiences, exchange ideas and offer mutual support. Also, there is an art group in which members can 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” is 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 welcome everyone living with dementia in the local area, irrespective of social factors such as gender, sexuality, disability, ethnic origin, and cultural and religious beliefs.

## Attending to diversity

Recognizing and attending to the diversity of those involved or potentially involved in peer support groups can facilitate inclusion. For instance, peer support groups that reflect the needs of particular populations – such as young people, black or minority ethnic communities, LGBTIQ – have shown success in promoting recovery, addressing stigma and discrimination, increasing the diversity of who gets involved, and improving access to support for people who often face barriers to peer support (17),(18),(19),(20). Overall, assessing which groups or segments of the population may not be participating and why is key to identifying potential barriers to participation in peer support.

## The facilitator's role (21)

When peer support groups are established, facilitators may be in charge to lead and facilitate discussions and to take responsibility for the development and functioning of the group. It is important to note that having formal facilitators is not fundamental to creating and operating a peer support group and a lot of groups works well without having a person in charge.

In groups that decide to have facilitators, these should organize meetings, arrive on time, open and close the meeting, provide guidance and listen to group members, and they should arrange for a substitute if they are not able to attend. Rotating facilitation can be a way to share responsibility and minimize power imbalances within the group members.

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 if they are absent or no longer able to continue. When the group is large it is useful to have a co-facilitator. Supervision or peer support structures can be beneficial to advise and support group facilitators.

Being a facilitator is not the equivalent of being the main “supporter”, helping others in the group. In peer support groups everyone supports and everyone receives support.

### Hints and tips for facilitation (15)

- Pay attention to members as they talk about their personal experiences.
- Be nonjudgemental.
- Facilitate discussion and allow everyone to speak who wishes to.
- Ensure that people adhere to the agenda and keep to time.
- Share tasks.
- Encourage a sense of security within the group.
- Know your own boundaries.
- Seek feedback from the group.
- Manage conflict.
- Make sure members feel supported and included; and ensure that their inputs and knowledge guide group decision-making.

Certain power dynamics experienced by those involved in peer support groups (both within and outside the group setting) might make some people reluctant to express their views. In general, the facilitator should emphasize the importance of listening to the diverse views of all participants and should stress that everyone brings a unique set of strengths, experience and knowledge to the table. This can be recognized at the inception of the peer support group, along with the establishment of other basic ground rules (e.g. listening, respect, confidentiality, critical reflection, nondiscrimination, being nonjudgmental) to refer to when needed (also see “Ground rules” below).

In addition, training and education for both facilitators and peer support group members can promote inclusion. Such training should include attention to “structural competence” which involves taking account of the ways in which structural and institutional factors – such as racism, marginalization, welfare policies and other socioeconomic issues - combine to influence the risk for certain conditions and ultimately influence pathways to care, attitudes to treatment, availability of social support and outcomes. Structural competence helps de-emphasize an individual’s problems or “deficits” and focuses on the uniqueness of individuals and their recovery.

### Membership of the group

The peer support group can have open or closed membership depending on its purpose. Each type of group has its own advantages.

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

If membership is closed, only people who have been accepted into the group are allowed to attend meetings. People interested in joining 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 for sharing 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 person’s presence in the group. For some people, it can be important for their recovery to know that their presence and inputs are meaningful for the other members.

Another option is to start the peer support group with an open membership and then close the group when members have come to know each other and if they do not wish to include more people.

Either form of membership can provide people with a sense of purpose and connectedness. From the beginning, it is important to be clear about the type of membership.

### New members (15)

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

If it is decided that new members should be met in advance in order to understand their personal needs and expectations, this should be done by the facilitator or a member(s) of the group who feel(s) comfortable giving details of the peer support group, explaining its purpose and orienting the new member. The new group member can be provided with contact details (for telephone calls, text or WhatsApp messages, emails) for questions or information about meetings. The potential member needs to be helped to decide whether the group is a good fit for them, as well being informed of any particular needs for joining the group (e.g., physical access needs, language needs, etc.).

New members may also find useful to know in advance the following:

- Who to contact if they wish to join the group.
- Meeting times, duration, venue and topics.
- Values and principles, particularly in relation to confidentiality.
- Any ground rules that may have been established by the group.
- A brief description of the process of meetings.
- A brief insight into what peer support means and how it might be of benefit.

### Structure of the group

The aims of the peer support group can be fulfilled in many different ways. It may be through formal meetings or informal meetings with less structure as well as through more recreational activities (e.g. outings or sports). Before starting, it can be helpful to picture what the group might look like in order to decide on its structure and whether it 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. Informal peer support groups generally have more flexibility, 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 both necessary and beneficial. A group's structure can influence the group's dynamics and understanding how to navigate these dynamics can be helpful. For instance, in a structured group with one facilitator and many members, a power imbalance exists. There should be openness and transparency about this imbalance and awareness that these roles may change and evolve as the group develops.

### Ground rules

A set of ground rules and principles for the operation of meetings can be developed and documented by the group members. However, depending on the situation, this may not be necessary. Setting ground rules will let members know what to expect from the group and will help to provide a safe place for people to meet. Copies of the document should be distributed to the group and people attending the group should be regularly reminded about the rules.

Each group should come up with its own set of ground rules but some principles for consideration are listed below as an illustration (15):

- Maintaining confidentiality. Group members should not disclose information about other members outside the group.
- Refrain from expressing judgement or being critical of other members.

- Respect 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 should accept that. People should not feel they have to talk or share anything to join the group.
- Do not be intrusive. Respect how much or how little closeness people want to have with other group members.
- Appreciate that each person’s feelings and experience are unique and group members need to respect and accept, without discrimination, what members have in common and what is specific to each individual,
- Respect the right of all the members to express themselves, and to do so without interruption. However, people who may be in crisis may be allowed more time to talk through their issues.
- Share responsibility by taking turns in various roles such as coffee-maker or facilitator.

### **Evolving structure of a peer support group (22)**

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 realized that others would benefit from the support offered within the group.

They agreed and they 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 person who organized the meetings and invited participants, but over time all the members of the group were helped to become leaders and most were 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 one member of the group will volunteer to facilitate the group for that session.

### **Sihaya Samooh – The changing nature of a peer support group (A) (23)**

In the spring of 1992 in Pune, India, three people came together to plant the seed for a new “community”. They were around the age of 50 and had all received different diagnoses of depression, bipolar disorder and schizophrenia. In order to cope up with their ups and downs, they needed the support of one another. The three members started meeting weekly and eventually 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 its largest attendance of around 25 persons in 1995, which seemed unmanageable. They decided to split into two subgroups. One group started meeting in the canteen on the fringe of a college campus while the second 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. They realized their combined strength and agreed that, if they could put all their talents together, they would create a recognizable strength.

## Confidentiality issues

Respect for the privacy of others within peer support groups is particularly important. People often share personal stories and are often able to do so only 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, people's participation in the group (24).

If someone wants to gather information about group members, they should first ask for the group member's consent. The person should clearly explain to them why they would like this information and how it will be used.

Information about members (e.g. contact details) 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) (15).

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 these situations should be approached will depend on the law of the country (24).

## External support for group members (15)

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 to build a file on the possible sources of support that might be beneficial for group members.

At times, the group members may feel that they are facing limitations in terms of the support they can provide to their fellow members. This needs to be discussed. Exploration of external resources may be a potential way to address this issue. Discussing external support may also take pressure off the members of the group who are taking responsibility for issues they feel are beyond them.

## Promoting support groups

Information about the group can be disseminated to key community organizations as well as to NGOs, disabled persons organizations, social services, local community centres, markets, village meeting points, local television and radio, newspapers, mental health and social services, etc. The information may include regular contact and discussions with people working in these organizations and services but also involves disseminating flyers and brochures in all relevant places in the community where potential members are likely to visit (e.g. mental health and social services). Consideration of potential members who may face barriers in accessing services is also important. 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, 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 running peer support group meetings. The steps outlined below are suggestions that are designed to help groups get started; they are not meant to be prescriptive (25).

### A peer support programme in Nepal

KOSHISH, a nongovernmental organization working in Nepal, has been operating peer support groups since 2008. KOSHISH began peer support programmes to address the needs of the beneficiaries and to provide a platform where they could gather in a safe, secure, confidential and trustworthy environment. The KOSHISH programme connects peer supporters to people with similar problems so they can share their experiences, express their feelings and discuss issues concerning their well-being.

### Location and frequency of meetings (26)

In deciding a location for the peer support group meetings, it is useful to consider:

- Accessibility – Can people get there easily? Consider physical, logistical and financial issues (e.g. time of day, location, transport required).
- Size – Is the meeting place large enough? Are there enough chairs?
- Comfort – Is it quiet, welcoming and private enough to allow for a comfortable exchange between group members?
- Convenience – Are there toilets/washrooms?
- Cost – Is there a charge to use the meeting room?
- Refreshments – Will anything be offered at meetings? Note that refreshments can contribute to creating a relaxed atmosphere.

Possible locations may be community centres, schools, places of worship, coffee shops, libraries or mental health and social services. It is important to use the same place whenever possible so that group members know where to meet, feel comfortable and become familiar with that particular space. In addition, there should be clear boundaries between the normal activities of the place where meetings will take place and the activities of the support group (e.g. the group can benefit from a private room so that meetings are not interrupted by people who are not group members).

Another consideration is how often the group will meet. The frequency of meetings and the time will need to be agreed. It depends on what is most convenient for the members of the group. This may need collective discussion and a period of experimentation during which arrangements can be adjusted.

### **The Dragon Café – an open community space for meeting others with lived experience (27),(28)**

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

The founder, Sarah Wheeler, started the first mental health café in the United Kingdom following a three-year period of experiencing psychosis. When Sarah was in distress she spent a lot of time in cafés. 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 wellbeing activities, all of which are free and open to all. No enrolment is required for groups, and people can just turn up and take part, as much or as little as they like. The café is run by volunteers, many of whom 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 (24)**

The first meeting of a support group is important and often sets the tone for future meetings of 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 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 difficult to find, make sure signs are posted directing people to the meeting.

#### **Greet people**

It is a good idea to have the facilitators or other members at the door to welcome people.

#### **Discuss ground rules**

Ground rules are important as they set out how people are expected to interact with each other in order for the group to run more effectively for everyone. For more information, see the section on *Ground rules*.

#### **Share stories**

Many people will be nervous or reluctant to speak at the first meeting, so it is really helpful for facilitators to open the conversation. When stories are shared it is useful to remind people about the

importance of *confidentiality* (for instance, 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:

- Fear of what others will think and potential stigma if it becomes known that they are participating in the group.
- Experiences of discrimination and exclusion.
- Home or family responsibilities.
- Being too burned out due to life circumstances to participate in meetings.
- Nervousness 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 to identify how the group will try to address them.

### **Encourage sharing between members**

Sharing within the group provides common ground on which people can start to identify with others and trust that they are not alone in the personal and social challenges that they confront. It can also help people to understand that not everyone is 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 members of the group to become comfortable speaking about the specific ideas, experiences and needs that they have.

### **Identify common experiences**

There may be quite a range of experiences and challenges that bring people to a support group. It is important to try to identify common elements and allow for differences as every individual's experience is unique and equally important.

### **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 on the first occasion, so it is important to let them know that they do not have to. Facilitators can also distribute their own contact details.

### **Identify communication needs**

It is 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 telephone calls, text messages, WhatsApp messages, or other group messaging services that may be accessible for all group members. Listening to group members and knowing their preference for

communication is important in keeping the group together and functioning well. The preferred method of contact can be included on the sign-up sheet to identify the best options.

### **Meeting closure**

It is often helpful to ask each member of the group if anyone would like to add any closing thoughts. For instance:

- Something specific that they gained from the group meeting that was especially meaningful, and why.
- Something that they were grateful for.
- Something that was not addressed that could have been useful.
- Something that can be improved or done differently to enable group members to feel more at ease.

For those who may have concerns or suggestions that they feel uncomfortable sharing in front of the group, an additional method for feedback should be available (e.g. written note, one-to-one meeting with the facilitator).

## **General guidance for all meetings (24)**

### **Starting the meeting**

Reminding members of the purpose and principles of the group and the importance of confidentiality may be a good way to open meetings. A relaxed atmosphere that favours confidence and discussion can be facilitated by offering beverages and food to members, planning a creative ice-breaker or telling a personal story. If members of the group wish to start the meeting by talking about a particular issue or by sharing their own reflection on a specific topic, they should be encouraged to do so. Having a welcome and warm environment that is conducive to sharing will be critical to the success of meetings.

### **Taking breaks**

It is a good idea to take a break during the meeting to allow people to move around. This will also provide an opportunity for people to talk one-to-one, which is particularly useful for those who find it difficult to speak in a group. It can also contribute to creating a more relaxed and informal atmosphere where group members can connect on different levels.

### **Content of meetings**

The 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 on external resources and speakers from time to time in line with the needs and wishes of group members.

Group members should be encouraged to discuss freely 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 about possible ways of handling challenging situations and resilience strategies. At the same time, it is important to

promote conversation that flow both ways and is not just advice-giving. It is also important to listen attentively without interruption and maintain a neutral attitude, allowing objective listening without invalidating or trying to change people's feelings(29).

Group members should avoid making discriminatory, offensive or insensitive comments, including sexual remarks or offensive jokes.

Members should feel free not to take part in discussions in which they do not feel comfortable. There should be no pressure to share experiences. Some members may just like to observe and listen to others in the first few meetings and this may also benefit them. It is important to respect the fact that each experience is unique to the individual (21).

If group members feel distressed during certain discussions, the facilitator and other members should be mindful of this and should accommodate and support the person according to the person's wishes and preferences.

### **Contributing as a group member and sharing responsibilities**

Listening, being open and supporting group members as they discuss their experiences and feelings is an important aspect of peer support groups. Furthermore, sharing the responsibilities in a peer support group can help prevent burn-out and create mutuality within the group. One way to identify and clarify roles is to create a volunteer sign-up sheet to identify tasks and responsibilities that different group members are comfortable with doing.

### **Topics and speakers**

Group members may find it beneficial to have guest speakers to share their experience or expertise on different topics of interest to the individuals within the group.

Speakers may include, for instance, people with lived experience, people who identify as being survivors of psychiatry, care partners, human rights advocates, mental health and other practitioners, government health officials, persons representing a range of disabilities, lawyers or other relevant persons.

#### **Maitri meetings – a place to share wellness and recovery strategies, Gujarat, India (30)**

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 to manage her anger. In the meeting she demonstrated how she does this and encouraged others to try this for themselves.

### Hints and tips for a successful group

- Everyone should have an opportunity to speak without interruption and talking over people should be discouraged. Ensure that all voices are valued and heard.
- Any comments or observations after the speaker has finished speaking should be nonjudgemental and non-discriminatory.
- 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 the discussions. A facilitator may, however, intervene if there are factual mistakes, if group principles or rules have been violated or if disagreements become disruptive.
- Sometimes people feel that they too should be following some type of “normal” recovery progression. Experience suggests that people develop their own time frame for healing and recovery. Expecting a person with lived experience to meet someone else’s time frame may lead to unnecessary pressure and problems.
- Everyone should be allowed to express emotions. A lot of people stop themselves from showing emotion in public. All group members need to know – and understand – that it is normal to experience emotion in many forms and it is acceptable to show emotions within the group.

### Challenges and sustainability of peer support groups

Reflection (31) and ongoing evaluation are critical inputs that can help the group remain responsive and sustainable over time.

Members should systematically set aside time to explore whether the group is meeting the needs of its members, whether activities are aligned with the original principles and intentions, and if improvements can be made to enhance the responsiveness of the group to members’ needs.

A criticism or a complaint from one member does not mean that the group and its activities are not valuable. However, such concerns should be heard and taken into consideration. In particular, if many members agree that changes need to be implemented, it may be necessary to discuss with all members why this needs to be done and to explore how improvements can be made. Organizing regular scheduled meetings to discuss the usefulness of activities may be a helpful way to obtain feedback and new ideas. This will help ensure that a group continues to provide a beneficial service to its members (32).

#### **Sihaya Samooh – The evolution of a peer support group (B) (23)**

Sihaya Samooh is a mental health self-help and support group based in Pune, India. It was established in 1992. Below is a description of how it has evolved over time.

#### **What were the benefits to Sihaya group members?**

Through the group, people gained support to cope with and overcome distressing phases or episodes in their lives. Being accepted, listened to and respected improved the self-esteem of the different members. Two members later took up caregiving vocations because of the liberating experience and encouragement they received in the Sihaya Samooh group.

### **What were the shortcomings and limitations of Sihaya?**

There was a lack of structure and methodology in the group which depended on members' collective common sense, varied personal experience and listening and sharing. The group struggled with certain issues. In addition, just listening to each other's stories was not enough to overcome certain challenges that individual group members were facing. Many came with high hopes but were not able to obtain the help that they expected; some were not able to continue to come for various reasons. Many women experienced particular barriers to accessing the group, in comparison to men who were physically and socially more mobile.

### **How did the Sihaya Samooh gatherings come to an end?**

Several members who held the group together moved on to other areas or other jobs. One member chose to launch a larger mental health self-help support initiative. The Sihaya Samooh group lost some members over time (...) One member married and moved on, another member turned to focus her energies on a Women and Health Training Programme, and yet another member began her long battle with cancer. The group kept on meeting for a further two years with numbers depleting over time.

Nevertheless, a number of members of the old Sihaya group still meet each other from time to time or remain in touch by telephone (...) They have indicated that they miss the sensitive protected space that they made and hope someday it will be recreated – not in a single place but in the many different places where many other survivors may need a group like Sihaya Samooh.

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

This was the first organized mental health self-help support group in Pune and was a pioneer in India. It demonstrated the creation of a safe social space that could keep at bay the stigma and oppression of society. The group 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 that it does not need to meet indefinitely for it to be a success. In Sihaya Samooh, the members gained support from each other and created a space where they could listen and share experiences.

### **Self-management and peer support groups, Mental Health Foundation, Wales, United Kingdom (33)**

The Mental Health Foundation, a nongovernmental organization in the United Kingdom, developed and delivered a national programme of peer support groups with a focus on self-management for people who had used mental health services across Wales.

In order to keep peer support groups going over time, the foundation identified the characteristics of a good peer support group and the potential barriers to sustainability. The consultation included a questionnaire and two consultation days. A questionnaire was developed with the aim of gathering ideas about what would make people want to attend a peer support group, what makes such a group successful and long-lasting, and what the barriers are to playing a full role in the group. The consultation included existing participants and other interested organizations. The two consultation days were carried out in different areas of Wales. The process identified the following elements:

- One (or ideally more than one) person needs to take responsibility for keeping a group going.
- This person (or people) should come from the group, not from outside the group.
- The group needs to have a clear purpose; setting and reviewing goals were regarded as important.
- Groups need to have agreed ground rules.
- Groups need to have opportunities to share learning with other groups.

### **Possible challenges for developing peer support groups, Uganda**

Joseph Atukunda, a service leader of HeartSounds in Uganda, explains in a short video what a peer support group is and talks about his experience of running a peer support initiative in Uganda, describing the challenges involved in this process.

Video (4:46 min.) is available at <https://youtu.be/xpyjTmUDhHs> (accessed 9 April 2019).



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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.