



# Civil society organizations to promote human rights in mental health and related areas

## WHO QualityRights guidance module

QualityRights



World Health  
Organization

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

Civil society organizations to promote human rights in mental health and related areas. WHO QualityRights guidance module

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# Contents

Acknowledgements.....	ii
Foreword.....	x
Supporting statements.....	xi
What is the WHO QualityRights initiative? .....	xvii
WHO QualityRights – Training and guidance tools.....	xviii
About this training and guidance .....	xix
Preliminary note on language.....	xxi
1. Introduction .....	1
2. What is a civil society organization? .....	1
3. Setting up a civil society organization .....	2
4. Day-to-day operations of the organization .....	24
5. Monitoring, evaluation and reporting .....	33
6. Sustainability.....	35
References.....	36
Annex.....	39
Annex 1: United Nations human rights instruments and corresponding treaty bodies.....	39



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## Foreword

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

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

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

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

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

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

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

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



**Dr Tedros Adhanom Ghebreyesus**

*Director-General*

*World Health Organization*



# Supporting statements

**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

This guidance module aims to assist people with psychosocial, intellectual or cognitive disabilities, as well as their supporters, in setting up and operating a civil society organization to address issues and needs they have identified as relevant. Depending on their purpose, civil society organizations may consist solely of people with psychosocial, intellectual or cognitive disabilities or may have a variety of stakeholders.

This guidance module contains information and suggestions for structuring a civil society organization, designing its programmatic focus and day-to-day operations, and monitoring, evaluating and reporting progress.

## 2. What is a civil society organization?

The term “civil society organization” is used to describe a non-state (independent from government) organization, association or group that aims to advance a common interest of its members. For the purpose of this guidance, that common interest is to work together to bring about important change in an area that people with psychosocial, intellectual or cognitive disabilities have identified as being central to improving their lives.

Organizations made up of persons with disabilities – including persons with psychosocial, intellectual or cognitive disabilities – are commonly known as “organizations of persons with disabilities” or “disabled persons’ organizations” (known as DPOs for short). However, civil society organizations working in this field that are predominantly made up of other types of members – e.g. families, care partners or health practitioners – are not considered as DPOs.

Disability organizations are often organized separately but they may decide to organize together or take part in forming cross-disability organizations open to all people with disabilities.

Civil society organizations in general, which are often at the forefront of advocating for social justice and human rights, play an increasingly influential role in setting and implementing agendas around the world (1),(2). Although there has been an increase in the number of civil society organizations addressing health and social issues, there still remains a need for such organizations in mental health and related areas.

### **Mental Health Peer Connection (MHPC), United States – a peer driven advocacy organization (3),(4)**

MHPC is a peer-driven advocacy organization that is dedicated to facilitating self-directed growth, wellness and choice through genuine peer mentoring. MHPC’s members are peers who are in recovery from mental health issues and/or substance abuse and who can relate to the individuals they are serving. MHPC provides various services and programmes to assist people in their recovery process.

The film “Not without us” (2013) by MHPC and Sam Avery deconstructs the complex issues surrounding the stigmatization and discrimination of people living with psychosocial disabilities in the USA. The film portrays what happens when a group of people, often portrayed as a problem to be solved by society, comes together to stand up for their rights by redefining the nature of the problem and reclaiming their status as integral members of society.



To watch “Not Without Us”, see: <https://youtu.be/fv9jbKFANZc> (accessed 9 April 2019)

To learn more about MHPC, see: <http://www.wnyil.org/Mental-Health-PEER-Connection/>

### 3. Setting up a civil society organization

#### Understanding the need for the organization

The motivation for forming a civil society organization will generally stem from people identifying an unmet need that they believe should be addressed. This unmet need may be something that has been identified from the personal experience of an individual or group of individuals with psychosocial, intellectual or cognitive disabilities, a group of family members and/or alternatively, practitioners who have recognized the importance of addressing human rights in mental health and disability-related areas. The specific motivation driving the organization’s initial formation will inform the organization’s vision and objectives.

Once there is clarity about the vision and purpose of the organization, it becomes possible to assess the degree to which it differs from other organizations in the community and to offer something new. This could be in the form of a different service being provided or even a different perspective or method for championing human rights.

It is also useful to consider whether the organization should be set up as a stand-alone body or whether it could potentially be a branch of an established civil society organization that wishes to incorporate work on the human rights of persons with psychosocial, intellectual or cognitive disabilities and their families and/or care partners into its agenda.

This video tells the story of how a group of people came together, grew and facilitated change: <https://youtu.be/bGb70PoiXDk>

“This is the Story of a Civil Rights Movement”, Inclusion BC, Canada (3:43) accessed 9 April 2019

#### Determining who are the members of the organization

The people whom the organization is intended to benefit, as well as those who can become members, should be clearly defined from the outset. Depending on the purpose of the group, membership may be open to all people with lived experience, families and care partners, practitioners and supporters, or it could alternatively be restricted to only one of these groups.

When membership is based solely on the wish to promote and advocate for a cause that is common to people with psychosocial, intellectual or cognitive disabilities, family members, care partners and others, the focus may be on attracting a wide membership.

On the other hand, self-representation and leadership of people with disabilities is crucial in any civil society organization working for the rights of people with disabilities. This is particularly important with respect to people with psychosocial, intellectual or cognitive disabilities who have experienced others speaking for them and about them both in their personal lives as well as politically. Therefore, people with psychosocial, intellectual or cognitive disabilities may find the need to organize and advocate in a separate organization.

As an organization evolves over time, so might its vision, objectives and actions, which in turn will have implications for the group's membership. An organization's success depends on the need to be flexible and motivating in order to ensure high commitment and engagement of the organization's members. Members play a critical role in promoting and sustaining an organization, as well as in carrying out the activities to meet its goals and objectives.

### **Normal Difference Mental Health, Kenya – Identifying the need for a civil society organization and setting it up (5)**

Until recently, there have been no public mental health services in the Kariobangi and Kisumu slum areas in Kenya. Respecting, empowering and initiating support for people suffering from trauma and emotional distress has been identified as a critical need to improve the well-being of many people in Kenya – especially in view of the trauma inflicted by the post-election violence of 2007 and 2008.

Persons who have experienced trauma need a safe and healing place in their community where they have the opportunity to cope and to overcome traumatic experiences. The organization Normal Difference Mental Health in Kenya has provided this place by offering a drop-in centre that includes self-help groups, counselling, support and creative activities. The goal is to give people a chance to find positive and empowering ways to deal with their concerns, regain strength and self-confidence, and live self-determined lives in their communities. This is particularly challenging given rising poverty levels.

The project was initiated in February 2009 when a group of four people in Kariobangi, one of the many ghettos in Nairobi, founded the community-based self-help organization Normal Difference Mental Health Kariobangi. In August 2009 the Normal Difference Mental Health idea spread to Kisumu, Kenya's third biggest city situated near Lake Victoria.

By integrating local African beliefs into supportive services, Normal Difference Mental Health seeks to promote healing and well-being by addressing individual experiences of trauma and distress that often require special attention and intervention. The organization recognizes that from an African point of view these issues can be caused by a variety of factors – including traumatic events in the past (e.g. loss of job, death of a loved one, abuse), witchcraft, ancestral spirits, drug abuse, disease (e.g. cerebral malaria) and genealogically passed trauma.

In October 2009, Intervoice, the International Hearing Voices Network gave Normal Difference Mental Health membership status at its annual meeting in Maastricht, Netherlands.

For more information about Intervoice, see: <http://www.intervoiceonline.org/>.

### **Defining core values and a vision**

Defining and agreeing on a set of core values for the organization will provide the foundation that will guide the contribution of every member as well as the organization as a whole. The core values can be defined as beliefs, principles or standards that people feel are important and which govern the way they think and act. They can include, but are not limited to, equality, respect, dignity, solidarity, trust, well-being, connectedness, shared understanding, recovery, self-determination, empowerment, hope, protection, compassion, diversity, inclusion, participation, open-mindedness and reliability. The agreed core set of values should be reflected in a vision statement that the organization establishes for itself.

The vision sets high expectations for what the organization hopes to achieve and the overall outcomes that it is working towards. The vision needs to be understood and shared by all members of the organization. The vision should be broad enough to encompass a variety of perspectives, easy to communicate within and beyond the organization, and inspiring and uplifting in order to motivate all members to participate with a sense of ownership and commitment. For example, an organization's vision could be "A society where people with dementia have equal rights with others and can fully participate in society."

### PANUSP's declaration (6)

An International Congress was held 13 – 15 October 2011 in Cape Town, South Africa, where the Pan African Network of Users and Survivors of Psychiatry PANUSP) discussed the importance of the United Nations Convention on the Rights of Persons with Disabilities (2008) and mental health reform on the African continent.

The Congress culminated in the Cape Town Declaration of October 2011 which was read at the Second Summit of the Movement for Global Mental Health (Cape Town, 17 October 2011) and the World Congress of the World Federation for Mental Health (Cape Town, 18–21 October 2011):

"We recognise that people with psychosocial disabilities have been viewed in bad ways, with derogatory words being used to describe us such as mentally disturbed, having unsound minds, idiots, lunatics, imbeciles and many other hurtful labels.

We are people first! We have potentials, abilities, talents and each of us can make a great contribution to the world. We in the past, presently and in the future, have, do and will continue to make great contributions if barriers are removed.

We believe in an Africa in which all people are free to be themselves and to be treated with dignity. We are all different, unique and our differences should be appreciated as an issue of diversity. We need all people to embrace this diversity. Diversity is beautiful.

There can be no mental health without our expertise. We are the knowers and yet we remain the untapped resource in mental health care. We are the experts. We want to be listened to and to fully participate in our life decisions. We must be the masters of our life journeys.

We want, like everyone else, to vote. We want to marry, form relationships, have fulfilled family lives, raise children, and be treated as others in the workplace with equal remuneration for equal work.

For as long as others decide for us, we do not have rights. No one can speak for us. We want to speak for ourselves.

We want to be embraced with respect and love.

We are deeply concerned about the extent of suffering experienced by our brothers and sisters on our vast continent. Poverty, human rights violations and psychosocial disability go hand in hand. We know that there can be no dignity where poverty exists. No medicines or sophisticated western technology can eradicate poverty and restore dignity.

The history of psychiatry haunts our present. Our people remain chained and shackled in institutions and by ideas which our colonisers brought to our continent.

We want everyone to acknowledge their participation in calling us names and treating us as lesser beings. These are the barriers to our full enjoyment of life. These barriers are disabling us and these prevent us from fully participating in society.

We wish for a better world in which all people are treated equally, a world where human rights belong to everyone. We invite you to walk beside us. We know where we want to go.”

PANUSP is now formally known as PANPPD – Pan African Network of People with Psychosocial Disabilities

### Focus areas and activities

Once the organization has defined its membership, core values and vision, the group can decide on the organization’s primary areas of focus and what activities will be carried out. In general, activities are the concrete answer to the question, “What does the civil society organization do?” Activities should lead to tangible outcomes that support the organization’s vision and help it meet its objectives. It is generally advisable for all members of the organization to help design and implement these activities in the spirit, and with the aim, of inclusiveness.

#### **USP Kenya – advocating for rights and promoting community-based, peer-supported recovery**

Users and Survivors of Psychiatry Kenya (USP Kenya) is a civil society organization associated with the World Network of Users and Survivors of Psychiatry. It was established in 2009 and is run by and for persons with lived experience.

The overall objective of USP Kenya is to promote and advocate for the rights of persons with psychosocial disability, enabling them to live and work as productive members of society. USP Kenya also works to promote the welfare of persons with psychosocial disabilities through awareness education, advocating for legislative change and facilitating peer support services. The organization has peer support groups in Eldoret, Kiambu, Nairobi, Nakuru and Nyeri that aim to provide support, build capacity and lead social change to promote greater inclusion at national and community levels.

More specifically, USP Kenya’s objectives are:

1. To promote the welfare of persons with psychosocial disabilities, including
  - a. Establishing and facilitating community-based peer support groups
  - b. Advocacy, awareness-creation and public education
  - c. Advocating for access to services within their communities on an equal basis with others.
2. To build a robust user and survivor movement in Kenya for persons with psychosocial disability.
3. To engage in law reform processes to ensure that issues affecting persons with psychosocial disability are mainstreamed in the domestic legal framework in line with the Convention on the Rights of Persons with Disabilities.
4. To build strategic relationships with relevant stakeholders to advance the human rights discourse for persons with psychosocial disability.

To learn more, visit: <http://www.uspkenya.org>

## **Northamptonshire People First – Making sure that the voices of people with learning difficulties are heard (7)**

We were set up in 1990 by a group of people with learning difficulties who wanted more than just to be stuck in a day centre. We started so that people with learning difficulties could have a voice. We helped them to understand their rights and to make other people understand we were not a disability – we are people first.

There are lots of groups that use the name “people first”. We all do similar things but we are independent from each other. We help people who live around Northamptonshire.

We do lots of work to make sure people's voices are heard. We do our own research, we go on campaigns, we help people on a one-to-one basis, we speak up at meetings, we do training and we get involved with organizations to make sure the things that they do are good for people with learning difficulties.

### **Our aims and objectives**

- To help people with learning difficulties and/or autism speak up for themselves, with help and support if needed.
- To work towards doing away with labels which affect our lives in a bad way.
- To make sure that all people with learning difficulties and/or autism are respected for who they are and for what they say.
- To make sure that people with learning difficulties and/or autism:
  - know about their rights
  - can get their rights
  - have the same rights as everybody else.
- To tell people and groups in Northamptonshire and in other places about the needs and concerns of people with learning difficulties and/or autism.
- To make sure that people with learning difficulties and/or autism are involved, at all stages, in the planning and development of the services they receive.
- To encourage and support the growth of People First and Speaking Up for Yourself groups.

To learn more, see: <https://www.peoplefirst.org.uk/about>.

The activities that the organization undertakes may be broad or more focused. Below is a list of activities that can be undertaken by an advocacy organization. This is not an exhaustive list; it is intended to serve as a starting point that may be useful, depending on the organization’s vision and objectives.

### **Systemic advocacy and campaigns**

Systemic advocacy means advocating for change on a systemic level and can include:

- Promoting the rights of people with psychosocial, intellectual or cognitive disabilities.
- Lobbying for law reform to eliminate substitute decision-making, coercive practices in mental health services, and other discriminatory legislation.

- Lobbying to promote in governmental policies, plans, laws and/or regulations a human rights-based approach to mental health, which respects each individual's autonomy, self-knowledge and decision-making.
- Advocating for better services and supports for people with psychosocial, intellectual or cognitive disabilities that have human rights at their core. This can include services and supports that meet the needs of groups or segments of the population who often experience multiple forms of marginalization (e.g. women experiencing violence; lesbian, gay, bisexual, transgender, queer, and intersex individuals; people who experience substance use).
- Promoting different ways to understand distress and different care and support options and services.

Advocacy campaigns refer to the implementation of activities designed to influence, challenge or change an existing situation, policy or law and are an important means through which systemic advocacy is implemented.

For more information on how to carry out an advocacy campaign, see the QualityRights module *Advocacy for mental health, disability and human rights*.

#### **Koshish, Nepal, engages in systemic advocacy to promote the rights of people with psychosocial disabilities (8)**

“Koshish” which means “making an effort” in Nepali, is a rights-based NGO registered in the District of Kathmandu. Koshish was started by people with psychosocial disabilities who recognized the need to improve mental health systems in Nepal. The NGO seeks to create a society in which people experiencing emotional distress can live a dignified life.

Through advocacy and self-advocacy efforts, Koshish is working to realize the rights of the people with psychosocial disabilities. Recognizing that the participation of people with psychosocial disabilities in public affairs has been restricted as a result of various forms of stigma and discrimination, Koshish has been conducting advocacy to encourage people with psychosocial disabilities to publicly come out with their experiences and become actively involved in actions to advocate for their rights.

Koshish draws its policy guidance from a holistic perspective and works in coordination and collaboration with organizations working on mental health issues across a variety of sectors and domains. As part of its advocacy actions, Koshish engages in the following activities:

- Review of laws, policies and programmes relating to mental health and social services to ensure they are in line with international human right standards.
- Mobilization of the media and promoting awareness of issues affecting people with psychosocial disabilities.
- Networking and collaboration with other organizations and stakeholders.
- Preparing human rights defenders and self-advocates through support and capacity-building.

For more information, see: <http://koshishnepal.org/content/sub/program/1>



## **Individual advocacy for persons with psychosocial, intellectual or cognitive disabilities**

Sometimes people with psychosocial, intellectual or cognitive disabilities or their families and/or care partners can find it helpful to have advocates guide them through issues for which they wish to receive assistance. Individual advocates are people with lived experience or specific expertise to help others work through issues that arise. This can include:

- **Providing information about rights and entitlements for people with disabilities and any chosen care partners they may have.** For instance, providing information on their human rights, legal or other issues (e.g. on what to do if one's rights have been violated). This might be done in person, through helplines or through online communication.
- **Attending meetings with people.** For instance, providing support and guidance during doctors' appointments, social security appointments and/or family meetings.
- **Facilitating communication** among people with psychosocial, intellectual or cognitive disabilities, families/care partners and relevant services (e.g. medical services, housing, education, or the criminal justice system) through letters, emails and meetings. This might include assisting people with letters of complaint.
- **Advocacy for release of people who have been admitted and/or treated involuntarily in mental health or social services.** Actions may include attending and supporting people during review hearings, help in obtaining legal assistance or assistance in accessing international human rights mechanisms, as well as direct advocacy for the person's release.
- **Supporting people to self-advocate.** This includes capacity-building of people with psychosocial, intellectual or cognitive disabilities and their families and/or care partners to ask questions and self-advocate on issues that are important to them.

## **Providing education and training**

Organizations may provide education and training programmes to different groups, including mental health and related practitioners, people with psychosocial, intellectual or cognitive disabilities, NGOs, policy-makers, and service providers. Topics can include, but are not limited to:

- Aligning policy, laws, services and practices with international human rights standards such as the Convention on the Rights of Persons with Disabilities (CRPD).
- Supported decision-making in mental health and social services (see QualityRights module *Supported decision-making and advance planning*).
- Realizing recovery-oriented care in mental health and social services (see QualityRights modules *Recovery and the right to health* and *Recovery practices for mental health and well-being*).
- Strategies to end seclusion and restraint (see QualityRights modules *Freedom from violence, coercion and abuse* and *Strategies to end the use of seclusion and restraint*).
- Different ways to understand emotional distress, including suicidal thoughts, hearing voices, and other personal experiences.
- The importance of addressing inclusion, diversity and non-discrimination. For example, this can include training in how to address gender-based violence or access barriers faced by populations experiencing multiple forms of marginalization and discrimination.
- The use of respectful, non-medicalized and empowering language to overcome stigma and increase empowerment of people with psychosocial, intellectual or cognitive disabilities.
- Organizing public speaking events or film screenings on these or other relevant topics.

### **Dementia Alliance International – Support and advocacy by and for people with dementia (9)**

Dementia Alliance International (DAI) is a registered nonprofit organization whose membership is exclusively for people with a medically confirmed diagnosis of any type of dementia from all around the world. DAI seeks to represent, support and educate persons living with dementia and the wider dementia community. DAI strives to provide a unified voice of strength, advocacy and support in the fight for individual autonomy and improved quality of life for people with dementia. DAI is a global group of, by and for people with dementia, advocating for the voice and needs of people with dementia.

**DAI's mission is to build a global community of people with dementia that collaborates inclusively to:**

- Provide support and encouragement to people with dementia to live beyond the diagnosis of dementia.
- Model living beyond the diagnosis to other people with dementia and the wider community, and show what “living with purpose” with dementia looks like.
- Advocate for people with dementia and build their capacity to advocate for themselves and others living with the disease.
- Reduce the stigma, isolation and discrimination of dementia, and enforce the human rights of people with dementia around the world.

**To fulfil its mission, DAI conducts the following activities:**

- Promoting connection and dialogue between people with dementia.
- Combating isolation and exclusion of people with dementia.
- Providing opportunities for support and education for people with dementia.
- Promoting a shared sense of living beyond the diagnosis of dementia.
- Working to ensure that the voices of those with dementia are listened to and honoured.
- Working with other organizations and with governments to create change in issues and policies that affect people with dementia now and in the future.

To learn more visit: <http://www.dementiaallianceinternational.org/>.

### **Providing peer support**

Peer support provides a platform for people with psychosocial, intellectual or cognitive disabilities to connect with others who have been through similar experiences. Peer support aims to support people on the issues they see as important for recovery in a way that is free from assumptions and judgement. Peer supporters, who are experts by experience, are able to relate to, connect with and support individuals going through challenges in a unique way because of their experience.

Peer support can be provided in a variety of ways, including:

- Peer support groups set up by and for people with lived experience or peer support groups for their families and/or care partners.
- Individualized one-to-one peer support to promote recovery, share experiences, or help with a range of individual needs provided to people with lived experience within different settings and organizations.

For more information on providing peer support, see the QualityRights modules *One-to-one peer support by and for people with lived experience* and *Peer support groups by and for people with lived experience*.

### **Inclusion Europe: Project TOPSIDE – Training opportunities for peer supporters with intellectual disabilities in Europe (10)**

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

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

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

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

For more information, see: <http://www.peer-support.eu/about-the-project/>.

### **Promoting recreation, entertainment and sport**

Recreation, entertainment and sport can be powerful tools for reaching an organization's goals and objectives. For instance, activities that can be carried out by organizations can include the creation of choirs, dance groups, actors' societies and sports teams. These events offer unique opportunities to promote human rights for people with psychosocial, intellectual or cognitive disabilities in a way that is non-traditional, fun and inclusive.

In Sardinia (Italy), for example, there are two active associations run by people with psychosocial disabilities, that use sport and recreation as ways to advance the well-being and rights of people with disabilities and to reduce stigma and discrimination. One promotes the practice of sailing for people with psychosocial disabilities (11). The other association undertakes trekking expeditions to promote well-being, provides guided treks for tourists throughout the island and conducts activities in schools

to promote trekking among children and adolescents – a way also to address stigma among young people concerning mental health issues (12).

### **Special Olympics uses sports to transform lives and perceptions (13)**

Special Olympics is the world's largest sports organization for people with intellectual disabilities and focuses on transforming lives through sport. Through the power of sports, people with intellectual disabilities discover new strengths, abilities, skills and success. Athletes find enjoyment, confidence and fulfillment on the playing field and in life. They also inspire people in their communities and elsewhere to open their hearts to a wider world of human talents and potential.

#### **Changing attitudes**

Special Olympics raises awareness about the abilities of people with intellectual disabilities. Through sports, the skills and dignity of athletes are showcased. At the same time, Special Olympics brings people with and without intellectual disabilities together to see and take part in the transformative sports.

Special Olympics fights negative stereotypes and misperceptions. The programme educates people from all over the world about the skills and gifts of athletes. Educational experiences are provided for coaches, volunteers and teachers to enhance their knowledge and show them how the Special Olympics experience can transcend all aspects of their lives.

#### **Building communities**

Special Olympics works to spread compassion and acceptance in a way that can unite the world. The goal is to awaken everyone -- and every community -- to each person's common humanity. This vision of inclusion starts at the local level and it is expanding on a global scale.

Special Olympics does this through a wide range of training sessions, competitions, health screenings and fundraising events. Special opportunities have also been created for families, community members, local leaders, businesses, law enforcement, celebrities, dignitaries and others to team together to change attitudes and support athletes.

### **Income-generation and livelihood activities**

Some organizations may have a goal or objective to support members or beneficiaries of programmes to become financially independent. Income-generation and livelihood initiatives encourage opportunities to end the cycle of poverty and disability and also contribute to the inclusion of people with disabilities in their local communities. Activities can be wide-ranging and will depend on the local context. They should include a broad spectrum of activities that build on people's strengths and skills.

#### **Examples of income-generation and livelihood activities**

Milesh Hamalai on how the Parivartan project transforms lives through employment (14),(15)  
The Altruist is an organization in Gujarat, India, that facilitates access to services and supports for people with psychosocial disabilities.

In January 2016, with the financial support of a Lodge Fellowship, we started the Parivartan Project to offer training, guidance and help with employment for people with psychosocial disabilities. “Parivartan” in English means “transformation”; hence, the primary objective of Parivartan is to transform the lives of people with psychosocial disabilities so that they can live with meaning, fulfillment, dignity and respect.

Through focus group discussions we learned that people with psychosocial disabilities wanted to work so that they could earn a living and lead a good life. We also learned that families felt confused and sometimes helpless about how best to support their family members living with a disability.

As Parivartan is based in a rural area, opportunities for jobs are few: we therefore needed to identify options for work that were accessible, safe and lucrative. This is why we came up with the tea masala initiative. Masala, which is a natural, healthy ingredient, is mixed with tea to give it a pleasant, savoury flavour. The work requires people to follow a recipe (e.g. mixing spices together), to package the tea, and then sell the final product.

Initially we identified 5–6 persons who were interested in making the tea masala. They were then trained on how to mix and package the ingredients. Today approximately 15 people have been employed in this work and many others are ready to join. They report satisfaction with the money they are earning and are happy to be involved in this process.

The outcomes of the Parivartan project are many and include:

For families and communities:

- Families realize that their relative can work and earn wages, which has helped to challenge misconceptions and stigma surrounding mental health conditions.
- There is better understanding, respect and support between family members. As a result, family relationships have improved and families report feeling more at peace.
- The community began to recognize persons with psychosocial disabilities as contributing, capable members of society, hence reducing stigma and discrimination surrounding disability. The community has started to recommend persons with psychosocial disabilities for work and people have started to buy their masala tea.

For people with psychosocial disabilities:

- Individuals report feeling more respected, valued and productive in their families and communities.
- As employees they receive individualized support, which helps them feel more confident in their work.
- They have started to earn money which helps them to live with dignity and self-respect.
- They have realized that their suggestions are listened to, which helps to build their work capacity.

The Parivartan project is not only about work but also about developing a community that offers mutual support and respect. Employees feel valued and productively contribute to their families and communities. Tea masala is only the beginning – we plan to add more spices and more work opportunities with the intention of creating a brand.

### **Timothy's story, Ghana (16)**

Timothy is a Ghanaian farmer who had an accident that affected his brain. His wife left him and he attempted suicide before he received treatment and support. Timothy now works with animals such as guinea fowls, raising them and selling the goods they produce to generate income and to provide him with a routine. He participates in and helps a support group by and for people with psychosocial disabilities.

For more information, see: <https://youtu.be/wVGEcXYFOLo> (accessed 9 April 2019)

### **Los Perejiles – A group of friends run a business in Buenos Aires, Argentina**

Four friends with Down's syndrome, with support of an association, opened a pizzeria catering business in Buenos Aires in 2016 called "Los Perejiles". Since the launch in 2016, business has grown and they have undertaken hundreds of events in which other people were hired by them to be part of this business. Los Perejiles website: <http://www.losperejileseventos.com.ar/>.

For more information about the experience, see: <https://youtu.be/k-ESm2LEyK0> (accessed 9 April 2019)

### **Restaurant Le reflet – a restaurant run by people with Down's syndrome**

In Nantes (France) a restaurant run by people with Down's syndrome has become very successful. A second restaurant is expected to open in Paris and a book has been published to tell the story. The restaurant "Le reflet" was created in 2016 by Flore Lelièvre, the sister of a man with Down's syndrome. She first created an organization to raise funds and, through crowdfunding, managed to raise enough money to open the restaurant.

The staff consists of six persons with intellectual disability, a professional chef and a manager. The architecture of the place and the design of the objects have been conceptualized in a way to facilitate the work of the employees.

Special mouldings have been made in the plates to improve their handling and customers are invited to stamp their own orders so the waiters are not under pressure. Staff are employed on a permanent basis.

Employees said they gained confidence and are very motivated. Very importantly clients enjoy their meals and recommend the place!

For more information: <https://www.restaurantlereflet.fr>.

## **Advising the government and health services**

Civil society organizations can also play an important role as advisors to government on policy, planning, legislation, services and other issues affecting them. The types of activities carried out can include:



- Partnering with government for the development of policy, plans and laws related to the rights of people with disabilities and implementation of the CRPD, including the transformation of mental health and social services and supports and the repeal of legislation authorizing coercive practices.
- Providing advice to government staff and/or mental health and related professionals on how to reform existing services and models of care for people with psychosocial, intellectual or cognitive disabilities and their families and/or care partners. This may include suggestions on how to improve the quality of care of services (e.g. teaching and learning alternative ways to think about people with disabilities, incorporating a recovery-oriented approach) or how to better protect the human rights of people using mental health and social services.
- Promoting initiatives to the government highlighting the important work being carried out by people with psychosocial, intellectual or cognitive disabilities and work by others that people with disabilities endorse as good practice. For instance, showcasing to government officials projects being carried out in the local community and their impact (e.g. the benefits of peer support services), inviting government staff to visit the organization to observe first-hand the activities that are being put in place, or presenting the work of the organization at government-organized forums, meetings and conferences.

### **Civil society in Peru has a major impact in influencing law reform to promote legal capacity (17)**

In 2018, Peru achieved a milestone reform in the recognition of the right to legal capacity of persons with disabilities. On 4 September 2018, the Peruvian government published the Legislative Decree No. 1384, which recognizes the full legal capacity of all persons with disabilities, abolishes guardianship for persons with disabilities, removes restrictions on their legal capacity (e.g. to marry or to make a will) and introduces different regimes for supported decision-making.

Civil society was a key player in the law reform process leading to this outcome. Civil society proposed and advocated for the adoption of the 2012 General Law on Persons with Disabilities, which inter alia ordered the creation of a Congress Special Committee to review the legislation related to the legal capacity of persons with disabilities. Between 2014 and 2015, organizations of persons with disabilities actively participated in this Special Committee and successfully advocated for the unanimous adoption of a draft bill proposing the abolition of all forms of guardianship and its replacement by systems of support for legal capacity. While the bill was formally submitted and sent to the Standing Committee on Justice and Human Rights in June 2015, it was filed without being adopted because the parliamentary period ended.

With this experience, during the 2016 presidential and parliamentary campaign, civil society advocated for the inclusion of the law reform on legal capacity in the different parties' platforms and proposals. Thanks to these efforts, the three main political parties in the Congress submitted in January 2017 a new multiparty bill drafted by civil society and based on the Special Committee's draft bill. This last proposal was the main input for the Legislative Decree No. 1384.

### **Engaging with the international human rights system**

Civil society organizations can play a vital role in promoting human rights by engaging with the international human rights system. One key role played by organizations is to become involved in the work of human rights treaty monitoring bodies. Each United Nations convention has a treaty body that is responsible for overseeing the implementation of the convention for which it is responsible (See Annex 1 United Nations human rights instruments and corresponding treaty bodies).

Governments that have ratified conventions agree to report every four to five years to the responsible treaty monitoring body on the steps that they have taken to implement the provisions of the convention. This is known as the state reporting mechanism. Similarly, civil society organizations can also submit reports (sometimes known as parallel reports) to the treaty monitoring body which reviews these reports along with those submitted by the government.

Based on the reports submitted by both the state and civil society, the treaty monitoring body will discuss the human rights situation with the government and subsequently issue its concluding observations, which include recommendations on measures the government must take to improve its implementation of the convention or treaty.

The reports submitted by civil society organizations to the treaty monitoring body are important because they can offer a key opportunity to:

- Raise concerns and undertake advocacy at the international level.
- Ensure that the treaty monitoring body is getting a full and accurate picture of the human rights situation in the country and not relying solely on the report(s) of the government.
- Ensure that governments are being held accountable for issues that are important to the organization; thereby, creating increased pressure and a sense of urgency to address these issues.
- Work in coalition with other organizations with similar focuses and concerns.

Civil society organizations can also engage with another key human rights mechanism within the United Nations system – the United Nations Human Rights Council. The council has its own state reporting mechanism known as the *Universal periodic review*, which allows for the involvement of NGOs, DPOs and others. Similar opportunities and mechanisms also exist within the regional human rights systems, including the African, Inter-American and European human rights mechanisms.

Civil society organizations can usefully engage with the CRPD national monitoring mechanisms. These mechanisms, which are required to be established by all countries that have ratified the CRPD, are independent national bodies tasked with supporting and monitoring the implementation of the convention. In many countries these mechanisms come under the functions of national human rights institutions, where these exist.

Civil society organizations can also engage with national preventive mechanisms (NPMs) established under the Optional Protocol to the United Nations Convention Against Torture. NPMs are mandated to conduct regular visits to all types of settings where persons are deprived of liberty – such as hospitals, social care facilities, prisons and psychiatric institutions. The aim of these visits is to prevent torture or inhuman or degrading treatment or punishment. NPMs provide recommendations to improve the protection of people who are detained in these settings and can also have an input into law and policy reform processes and provide recommendations for reform.

## Networking and building relationships

Networking is the process of developing and maintaining relationships with a wide range of stakeholders. Stakeholders are individuals or groups who have an interest in the organization or any influence on topics of importance for an organization. This interest may be positive (they support the organization's actions as it makes their life better or aligns with their own priorities) or negative (they do not support the organization's actions or it conflicts with their priorities). Networking may, for

instance, involve key representatives from the organization attending relevant forums or meetings with other figures and organizations such as advocates, other NGOs or DPOs, human rights defenders, government departments responsible for health, disability and social services, and staff of mental health and social services.

The importance of networking to garner support for the organization's activities should not be overlooked as the organization may struggle to succeed if isolated (18). Exchange and collaboration with other organizations can contribute knowledge and expertise, increase resources and effectiveness, and help gain stakeholder support for key actions of the organization.

### **Developing actions: 32nd International Conference of Alzheimer's Disease International, April 2017, Kyoto, Japan (Alzheimer's Disease International) (19)**

One example of action undertaken by associations, organizations and groups are meetings and conferences. Alzheimer's Disease International (ADI) and [Alzheimer's Association Japan \(AAJ\)](#) hosted the 32nd International Conference of Alzheimer's Disease International in Kyoto, Japan, in 2017. The conference was attended by 3000 delegates, including people with dementia, family care partners, researchers, professional carers, clinicians and staff and volunteers of Alzheimer associations from over 70 countries. The final message of this conference was "for governments everywhere to support the implementation of the WHO global action plan on dementia".

### **Stakeholder analysis**

A stakeholder analysis can identify stakeholders that have a vested interest in the organization's goal(s) and objectives, as well as stakeholders whose interests and priorities may conflict or even jeopardize the organization's success. Knowledge of both can be pursued strategically to advance the goals of the organization. Particular attention must be given to people with psychosocial, intellectual or cognitive disabilities whose interests are directly affected by the actions of the organization. They should have effective power to ensure that the organization is meeting their goals, interests and needs, and to make changes in structure and policy as needed.

Some examples of types of stakeholders include:

- **Audiences:** This refers to the people or group the organization will be directed towards. There are two types of audiences:
  - **Primary audiences** are those people or institutions with influence to change the situation and further address the organization's priorities.
  - **Secondary audiences** are those people who exert pressure on primary audiences to make a decision.
- **Beneficiaries:** Those people who will benefit from the organization.
- **Potential partners:** Other advocates who may be able to assist in carrying out the organization's activities and objectives.

The primary audiences or targets for the advocacy actions of an organization will be often policy-makers, officials or others that have the power to influence change. When primary targets cannot be engaged or influenced, it is still possible to have an impact by influencing secondary audiences/targets instead. The secondary targets can then, in turn, influence primary audiences/targets. It is always more effective to be specific in identifying targets – e.g. a person, newspaper, department or committee, rather than "the public" or "the government" which are too general to be targets (20).

### **Examples of types of audiences, beneficiaries and/or partners (21)**

- People with psychosocial, intellectual or cognitive disabilities
- Families and/or care partners
- Politicians (local, provincial, national)
- Ministry officials
- Voters
- United Nations agencies
- Businesses or business leaders
- Spouses of politicians
- Speech-writers
- Opinion leaders
- Labour organizations
- Health services
- Health practitioners
- Academics/universities
- Nongovernmental organizations
- Community groups
- Women's organizations
- Religious groups/churches/faith-based organizations
- Other professionals
- Media

### **Engaging stakeholders**

Promoting an organization and spreading awareness of what it offers can raise interest and support from stakeholders and the broader community.

Some ways to engage all relevant stakeholders (including DPOs, NGOs, policy-makers, health workers, interested community members and those being served by the organization) are to:

- Provide regular updates about progress.
- Actively seek input and feedback to improve the organization while identifying which stakeholders/groups may require improved engagement.
- Respond promptly to any concerns raised.
- Identify champions or advocates within the community who will promote the organization.

In promoting one's organization it may become apparent that some people or organizations working in similar areas may have competing interests and, for that reason, may not wish to support the organization and may even take action that undermines the organization's goals and objectives. Reasons for this may include:

- Some professional associations may fear that the organization's actions may have a negative impact on the power, prestige, privileges or resources they have.
- In other cases, some may see the organization as competition and therefore be unwilling to promote or endorse it among their members and networks

- The stigma and discrimination associated with psychosocial, intellectual or cognitive disabilities may result in some organizations or individuals not wanting to associate with or support organizations run by and for persons with disabilities.

## Organizational structure

It will be important to consider how the organization should be structured; agreeing on these structural elements will enable the organization's operations to run more smoothly. Organizations can be formal or informal in structure and both models have benefits.

Key questions to consider when determining and setting up the organizational structure include:

- **What size will it be?** Initially, the organization may be an informal gathering of people who have heard about it by word of mouth. The size of the organization may vary but, whatever the size, its effectiveness depends on how it operates. Generally, a small, compact organization has a more family-like or "friendship group" atmosphere, while a large organization usually requires a more structured format and members who have skills that are suited for its purpose. Organizations aiming to expand their membership need to consider strategies to disseminate information about their existence.
- **Will it be formal or informal?** Informal organizations generally have less hierarchy and bureaucracy, allowing members to get involved in multiple facets of the organization and allowing people to take on varying and dynamic roles. Another advantage is that they allow for more flexibility in planning and implementing activities. Formal organizations typically have more delineated roles and responsibilities within their structure, which tend to be hierarchical in nature. This type of structure can lead to more efficient decision-making and implementation of activities, particularly in larger organizations. However, both formal and informal organizations can have an efficient decision-making process so long as they have a structure that aligns with their vision and objectives.
- **Will it be open or closed?** In an open organization, membership is open to everyone. However, in a closed group, membership may be restricted. There may also be criteria that one has to meet before being eligible to join.

## Legal issues

Legal issues need to be taken into consideration when setting up a new organization. Sometimes, depending on the context, legal structures, issues or policy can act as a barrier, particularly if the process to set up an organization formally is expensive or complex. However, it is also possible that having formal legal status may facilitate the work of the organization – e.g. by opening up funding possibilities, and through establishing credibility and standing as an official organization.

The following questions can help one to make decisions about whether or not to establish the organization as a legal entity:

- What laws and regulations have to be followed when setting up a formal organization (or will it be an informal organization)?
- What will be the internal management structure? Will there be a board of directors or shareholders, and what are the duties that flow from this? What internal documentation is required?
- What types of legal or governmental partnerships can the organization explore?

- Broadly, will creating a separate legal entity benefit or restrict the work of the organization? For instance, will it limit the personal liability of members? Will it allow the organization to attend official events? Will it add significant costs to operate the organization as a separate legal entity? Will the organization be bound by local laws or its own constitution/board, which may limit the running of the organization?
- What are the organization's liabilities? How will people be protected in the event that incidents may occur, particularly within the target group? What type(s) of insurance are required?
- Is the organization supported by an existing NGO or other service and, if so, is it covered/bound under that NGO's or service's respective policies?
- What are the organization's financial needs? Will it be beneficial to open a bank account? Will formal reporting be required? How does the organization intend to invest any funds? Can the organization work with lawyers or accountants to do so in accordance with official regulations?
- What are the organization's taxation liabilities? Are there any available taxation concessions based on the legal status of the organization?

Legal issues and structures will vary from country to country and, in some cases, at the regional, state or local levels. It is imperative to consult local legislation or persons who can advise on legal issues to ensure that the organization operates in accordance with the law.

It may be difficult to find the legal advice or assistance needed to navigate these questions, particularly if the organization has limited resources. Concerns about legal formalities required when setting up organizations should not stop people with psychosocial, intellectual or cognitive disabilities from engaging in activities for which a formal organization is not necessary. For instance it is not necessary to be a part of an organization in order to engage with political or other activities, and people with disabilities have the right to express themselves and to participate in decision-making processes on all matters affecting them.

## Policies and procedures

Sound governance of the organization is important and, to achieve this, clear policies, procedures and guiding documents need to be defined. Ethical guidelines are an important frame for describing the organization's core values and standards. When appropriate, the organization should review and learn from the organizational policies and procedures of other similar groups and organizations according to the local context and purpose of the organization.

Ethical issues might include:

- Who can speak for the organization and would any prior consultation with the membership be needed?
- How will the organization make decisions about policy, procedures and day-to-day activities?
- If the organization includes non-disabled staff or supporters, how does the organization ensure that people with disabilities have effective power to set policy and oversee the day-to-day operations?
- How will the organization deal with conflicts between members about policy or procedures within the organization?
- How will the organization deal with any potential allegations of discrimination, abuse or violence among members of the organization?



- What aspects of the organization's work will be public and what aspects will be kept confidential? What are members' and staff obligations with respect to confidentiality? (With respect to formal organizations, are there legal obligations relating to confidentiality and/or public disclosure that might impede the organization's work or conflict with its values? If so, how will this conflict be addressed?)
- Will the organization restrict its sources of funding (e.g. not accepting money from pharmaceutical, tobacco or armaments companies)?

When the organization grows, some additional written policies and procedures may include (22):

- Volunteer procedures and support
- Occupational health and safety regulations
- Logistical procedures, such as running meetings
- Budget and cash handling
- Conflict of interest.

Documentation should be regularly checked and updated, particularly whenever any substantial change occurs within the organization. For instance, employing a paid worker may require submitting paperwork to relevant government departments.

### Financial issues, including budget and funding

Procuring and managing funds for activities and other operations is a pressing issue for new civil society organizations. As the organization develops its goal(s), objectives and activities, it is helpful to keep in mind that the type and extent of activities that the organization can implement will depend on available resources. Understanding budgets and funding issues will help determine what is realistic and what is beyond reach.

Resources may be so limited that even securing a venue or space for meetings can be difficult. Overcoming barriers such as this often takes a degree of creativity, but organizations can do a great deal with limited funds. Organizations of people with psychosocial, intellectual or cognitive disabilities with limited or no financial resources have met in public places such as parks or cafeterias, or in a village square. Reaching out to various stakeholders (e.g. faith-based organizations, local council offices, health services spaces, local market spaces, and existing NGOs or civil society organizations) to see whether they might be willing to share a space can offer a solution to this challenge. Social media and web hosting are available for free, and Internet access may be free in spaces such as public libraries. Drawing upon and utilizing existing resources in the community can enable organizations with limited resources to grow and develop.

There are advantages and disadvantages to operating with limited funds; it allows for greater independence and allows the organization to concentrate on substantive work rather than fundraising, but it can also isolate groups and limit the scope of activities.

Ensuring transparency of finances and accountability of leadership with regard to the budget is key to the sustainability of the organization.

## **Budgets**

Planning the annual budget is a very important part of setting up a civil society organization, regardless of its membership composition, size or organizational structure. The budget should cover all the costs necessary for the functioning of the organization and its activities. The organization needs to be transparent about its financial management and should share financial information with members. Reporting on financial issues may also be done as part of the overall monitoring/reporting process (see sections on *Monitoring and evaluation* and *Reporting*).

Depending on the organization's activities, some of the costs may include (22):

- Set-up costs
- Administrative needs (e.g. computers, software, telephones and telephone services, stationery, printing costs, postage, and other supplies and materials)
- Training and education
- Wages
- Promotional costs
- Costs related to activities and events
- Travel
- Room hire
- Operational costs (e.g. insurance, human resources and fiscal costs).

Budgets should be reviewed annually and should be used as the basis for creating a new budget for the following year. During this review, some helpful questions to ask include:

- Were there enough funds to keep the group running?
- Will new activities be undertaken?
- Will more people be hired?
- Are more funds necessary for the upcoming year?

Note also that some banking systems provide bank accounts for NGOs or DPOs, so this can be a way to reduce or eliminate additional costs.

## **Funding**

Funding for activities can enhance the ability of the organization to achieve its objectives. It is important to have a clear strategy and understanding of where funding will come from and how it will be allocated within the organization. In addition, specific requirements for funding sources need to be noted as they can have an impact on how and what activities are carried out. For instance, funding received from a donor with specific interests in certain activities will shape how the organization can use the funds received.

In contrast, funding from donors without specific interests can allow for more flexibility in working procedures and activities. It is advisable to ensure transparency when accepting and acknowledging funding sources and to ensure that there are no conflicts of interest, as these can diminish an organization's integrity and credibility (23).

Funding can be obtained from a variety of sources, and organizations should be creative with the types of donations (monetary or in-kind) they solicit, given their relationships, partnerships and connections with the community. Some potential sources of funding are:

- **In-kind donations, such as supplies and refreshments, from local businesses:** Soliciting in-kind donations is a great way to cut costs and develop relationships with local organizations and establishments, such as stores and businesses. Often, many of the needed smaller items (e.g. office supplies, refreshments, paper products etc.) can come from in-kind donations.
- **Crowd-funding:** Use of the Internet, particularly social media platforms, can have a big impact on securing independent funding for social and community-oriented initiatives. Crowd-funding is the practice of funding an organization or a project by raising money from a large number of people through Internet-mediated registries (e.g. CauseVox). This strategy can reach a large audience in a short period of time (24).
- **Subscriptions and/or donations from members:** After the organization has proven that it can deliver and its popularity begins to increase, it could be appropriate to impose a manageable subscription fee for members, or to solicit donations from them. This is often difficult when the organization is first being created because there is little guarantee that the money will be put to good use; however, after the organization becomes more established, people tend to be more amenable to this idea.
- **Benevolent grants from foundations and other organizations:** These grants are for specified purposes that align with the organization's goals and objectives. They can come from groups that include (25):
  - Bilateral organizations or government agencies that provide development aid (mainly funding) from a single country and that are accountable to the government and parliament of that country.
  - Multilateral organizations including all United Nations agencies, The World Bank, and regional development banks such as the Asia Development Bank, the Africa Development Bank and the Inter-American Development Bank. These are agencies established by intergovernmental agreements and use pooled donations from different countries' governmental and nongovernmental sources to provide technical and/or financial assistance to recipient countries.
  - The European Commission, which technically is a multilateral organization although its funding and operating procedures most closely resemble those of bilateral organizations.
  - Global public-private partnerships, such as the Global Fund for AIDS, Tuberculosis and Malaria.
  - Private foundations (international and national) that focus specifically on providing financial support to DPOs, such as the Disability Rights Fund.
- **Government projects:** The government may want to contract the organization to deliver services when these align with national priorities. For instance, a government that has reformed its national law or policy to align with the CRPD may contract the services of an organization to build capacity on the rights of persons with disabilities among key national actors and stakeholders.
- **Charitable and religious organizations:** Both of these types of organizations are generally amenable to helping and supporting groups who experience marginalization. An organization that champions the rights of people with psychosocial, intellectual or cognitive disabilities or that provides psychosocial support is well suited to partner with charitable or religious organizations.
- **Sponsors:** Sponsors may provide assistance or advice in a variety of areas, including providing equipment, technical, management or legal support and publicity. Sponsors can also offer grants or in-kind donations for such things as snacks, social outings and excursions. A civil society organization may receive support from a sponsor, but it is advisable that the organization continues to function autonomously to avoid potential conflicts of interest.

- **Businesses and industry:** Resources from the private sector can often be very helpful in allowing the organization to carry out its planned activities. Private-sector funding can come from a variety of sources, including foundations, corporations and individual donors. If the organization does partner with or acquire funds from a business or an industry, it is important to be sure that there is no conflict of interest between the organization and that business, particularly with regard to the pharmaceutical, tobacco and arms industries (26).
- **Other fundraising activities:** These will vary according to the resources available to the organization, the cultural context and the target audience. Some common activities include music or theatre shows; auctioning of services such as dance lessons, sewing classes, or sports instruction; “cooking-for-a-cause” or raffle or lottery evenings with fees for participation; and more.

If the organization needs to complete a formal application for additional funding, the group will need to explain how the additional funding will contribute to expected achievements and outcomes. In this context, the organization should describe its current activities and what it has achieved so far (see section *Monitoring and evaluation*).

In completing a funding application, it is useful to reference current research which supports the need for, and effectiveness of, the activities being implemented by the organization. For example, there is a growing body of evidence suggesting the benefits of providing peer support services and having people with psychosocial, intellectual or cognitive disabilities lead advocacy actions (27) and advise government on the direction and evaluation of mental health and social services, policy and law.

Enlisting people who are skilled in grant writing or providing training to members of the organization who wish to take on this task can increase the likelihood of successful applications.

#### **Sam Badege on how the National Organization of Users and Survivors of Psychiatry (NOUSPR), Rwanda, was able to raise funds (28)**

When NOUSPR was founded, all the members were poor and no-one had an income. The first meetings of NOUSPR were held under the shade of trees or on verandas. Rainstorms often disrupted our gatherings and many of our records were destroyed by rain. We had no papers, pens or tables. Carrying on life like this for more than a year, meeting under these harsh conditions, was enough to win the trust of local authorities who provided a desk belonging to a staff member who spent most of his time in the field. This was in the same building as the executive secretary of our sector.

By having an official address, NOUSPR fulfilled the eligibility criteria for being identified as a VSO (Voluntary Service Overseas) organization, which allowed us to recruit an international volunteer to provide support to our organization and its operation. In the beginning, there was a heated debate on who should have the seat in the office.

Finally, we agreed that the volunteer should be the one seated in the office, since he was the one in charge of planning. The volunteer was located in the office and used half of his time to help us raise funds, so we were able to rent a house with five rooms, buy adequate furniture and provide a one-year salary for three staff members – all this within only 8 months.

#### **Heartsounds Uganda gets creative with managing its start-up needs (29)**

Heartsounds was founded in 2008 through collaboration between people who use services and mental health providers from Uganda and the United Kingdom. The organization is led by people

with psychosocial disabilities and its programmes and projects aim to minimize the negative social, cultural and economic effects on people with psychosocial disabilities.

Founder Joseph Atukunda describes the process of setting-up Heartsounds Uganda (30)

I first opened up my home to be the resource centre of the organization and all our initial meetings were held there at no cost. I then called my old schoolmates from Kings College Budo with whom we held discussions on a Yahoo! group of Old Budinians (called the “Kafunda” which means “to help”. Those who were interested supported me both morally and financially. Most are professionals in various fields and they gave advice. Additionally, they gave some donated computers for our Internet café, and others donated books for our library and money for operating costs.

In 2010, the organization I was working for before resigning to start Heartsounds was closing down in Uganda, and they gave me a small consultancy to help wrap up the logistics department. I used this opportunity to apply for donations of office furniture, telephones, a safe, a PABX machine and old files, as well as other small items of office equipment such as staplers, hole-punching machines, office trays, etc. These donated items helped us a great deal. Meanwhile our friends in London plus other friends we made in Britain were also supporting us with finances, computers, cameras, etc. With a fully furnished office, we started making bids for grants and were successful with a number of them.

## 4. Day-to-day operations of the organization

Once a civil society organization has been established, a new set of considerations enters into play and needs to be addressed in order to effectively manage the organization’s day-to-day operations – including leadership, members’ responsibilities, conducting meetings, communication within the organization, and effective promotion to build and strengthen the organization and its activities.

### Leadership

Effective leaders contribute to an organization’s success. Leadership should be sensitive to social and cultural factors such as relevant community, cultural and gender norms. For instance, some organizations may implement activities that are appropriate only for women (or may even be composed only of women) or have branches that are targeted specifically toward young people.

Leadership of the organization is important and should be discussed with all members, as should the leadership structure – e.g. whether it is formal or informal and the types of rules and procedures governing the organization and its activities. While the organization is still being established, someone may already be acting in the role of group leader. This may be because the person is the founder of the organization or because the person is taking on important responsibilities. Subsequently, it may be decided to rotate the leadership among different group members, or to elect one member as the leader to make the process more democratic. Even if all members are considered equal within the group and there is no official leader, one or several people may take on more responsibilities or exercise more power than others – e.g. when organizing meetings or activities. Regardless of whether the organization is formal or informal, some type of leadership structure needs to be established in order for the organization to function effectively.

## Sharing responsibilities

Many organizations are run by their members voluntarily, and many rely on volunteers to drive and implement core activities. Policies on managing and working with volunteers should be clarified while the group is setting up the organization (see section 3 on *Policies and procedures*). Regardless of policy or organizational structure, the idea of “sharing responsibilities” will be important for any organization as this creates a sense of collective ownership and is often important for the daily operations of an organization.

Shared responsibilities among members may include:

- Acquiring, setting up, and cleaning up meeting spaces.
- Writing and disseminating the agenda and meeting invitations.
- Taking minutes – these should not be a complete narrative, but rather be limited to including important decisions that are made.
- Chairing and facilitating meetings.
- Organizing projects and activities.
- Collecting and sharing relevant information.
- Promoting the organization.
- Treasurer and book-keeping responsibilities.
- Speaking for the organization, representing the organization at external meetings or events.

Members will bring different experiences and skills to the group, and therefore specific members may be more suited to particular tasks. As the organization evolves and grows, it may be helpful to divide responsibility between different committees which can manage different areas of responsibility – such as accounting, funding, events, communications and human resources.

## Communicating with members of the organization

Regular communication with members regarding activities, forums, events and meetings is essential to running an effective organization. The organization should designate a responsible person or team for communication of information and should identify the different means through which communication should take place. For instance, some organizations may prefer communicating via text messaging while others may prefer telephone calls. However, some may prefer to avoid communicating via telephone altogether for reasons such as lack of access. Other methods of communication include email, social media platforms and simple word-of-mouth. Depending on the group’s preferences and constraints, members will have to decide carefully what is the best means of communicating with one another.

Encouraging attendance of members at meetings can be challenging and a lot of work and follow-up is required to encourage high levels of attendance. It can be helpful to send reminders to members that the meeting is due to take place, remind them of the time and place, and share the agenda prior to the meeting in order to encourage attendance. It is also important to check with members – particularly those who may not be attending – on potential barriers to their attendance (e.g. time of day, need for child care, transport, location).



## Running meetings

The frequency, style (e.g. formal or informal) and content of meetings will depend on the organization's structure and, most importantly, its goals. In general, meetings are an effective way of sharing important information within the group and deciding on key organizational issues and actions – such as setting or reviewing ground rules for conducting day-to-day operations or planning advocacy events and activities. Here are some important considerations when running meetings.

### Meeting preparation

Adequate planning ensures that meetings are well organized and efficient:

- **Agenda:** Preparing an agenda based on inputs from members can be helpful for running the meeting more smoothly.
- **Place, date and time for the meeting:** The setting needs to be adapted to the meeting and should be convenient for members.
- **Supplies and refreshments:** For example, flipcharts, markers, pens, paper, nametags as well as food and drinks.

Meetings can also take place virtually. This online option may be particularly relevant if organizations are national, regional or international in scope, if members do not live near each other, if members prefer a virtual platform or if it is not feasible to convene in person. A mix of face-to-face and virtual meetings is also an option to consider.

### Function of meetings

In general, meetings offer opportunities for members to share ideas, concerns, successes, feedback, and relevant information; however, more specific functions of meetings will be determined by the group's goal(s) and objectives. For example, a working group dedicated to promoting human rights may use meetings as opportunities to plan key advocacy events and activities, while organizations aimed at providing peer support services may use meetings as a way to liaise with members in the community who have benefited from, or are currently involved in, peer support services as a way to build the capacity of all members.

The function and purpose of meetings will vary from organization to organization and should be both specific and relevant to the work being carried out. While some organizations may find it appropriate to share and disseminate important information relating to the priority issue, others may find it more useful to invest this time in planning activities and events, linking with other people, stakeholders, or organizations in the community, hosting guest speakers, or identifying existing community resources. Regardless of the group's purpose and activities, meetings offer the opportunity for members to share valuable input and to contribute to the overall work and vision of the organization.

## Privacy and confidentiality

It is important to be thoughtful and careful about how the organization stores and uses private information – whether it is the personal information of members or information collected as part of research or advocacy (e.g. names, addresses, feedback etc.). This includes keeping email lists and

contact details private. Members or participants in certain activities or events may wish to keep their participation confidential, and this confidentiality needs to be respected and protected (31).

### Welcoming and engaging new members

New members should be welcomed and made to feel comfortable as part of the organization. People contributing to the organization should be valued and encouraged. Sending a welcome letter and a certificate of membership can be a way to initiate new members and to let them know that their participation is valued. It is also important to point out that people who have experienced discrimination or human rights violations may not feel confident about joining a group or may face social or structural barriers to joining. It should be made clear from the outset that participation in activities is voluntary and that members can choose to leave the group or opt out of activities at any time.

Each member will have something unique to offer the organization. How members are engaged in the organization should depend on the unique talents, experiences, skills and strengths that they bring, as well as on the nature of the activities being conducted. In order for members to make the greatest contribution it is important to link individual strengths and skills with specific activities. For instance, members with strong writing skills will be good candidates for writing grant proposals or keeping meeting notes, members who are creative can take the lead on creating and designing promotional events or group activities, members with strong organizational skills may be a good fit to manage community events or activities, while members with specific experience or expertise related to a particular issue may develop materials or plans related to that issue.

### Promoting the organization

Promoting the organization is an important activity that will contribute to its overall growth and success. The primary goal of promotion is to spread awareness of the group and share information about its goals and objectives with stakeholders, the target audience and the wider community. By increasing the public's knowledge of the organization and its activities, more support can be gained from the community, including stakeholders, persons of influence, and other organizations with similar interests. While many dissemination strategies are listed below it may be preferable to focus on a few strategies in order to implement them effectively, rather than attempting to implement all of them.

#### Official launch or information session

An official launch can be a helpful means to promote the organization. A launch does not necessarily take place at the very beginning of an organization's existence; it depends on whether and at what point the group decides that publicity is desirable. When planning a launch, it is useful to invite important stakeholders and to solicit media interest in the organization and the issue(s) it is addressing. As for any meeting or event, it is helpful to plan ahead. Some questions that can aid the group's planning include:

- What is the purpose of the launch/session?
- Where will it be located?
- Who should attend, and what will make the event appealing to attract a large crowd (e.g. a high-profile guest speaker or food and drinks provided)?
- Will the event be accessible to different population groups?

- Will the organization require any materials or resources? If so, how will these be acquired?
- What will take place at the event (i.e. agenda)?
- Will the organization require licences, insurance or other sorts of permission to host the event or use the location? From whom, and how will the group attain these?
- How will the event be promoted (e.g. reaching out to local or national media and involving them in advocacy/promotion of the event and the organization)?

Additionally, finding and taking advantage of strategic opportunities to announce the creation of the organization to the public can help make the launch more successful. For instance, launches often receive more attention, and therefore reach a wider audience, if they are paired with important calendar dates, events or announcements related to the organization's goal(s) and objectives. Examples of globally celebrated events include World Health Day (7 April), International Day In Solidarity with Survivors of Torture (26 June), Mad Pride/Bastille Day (14 July), World Alzheimer's Day (21 September), Psychiatric Survivors Week (5–10 October), World Mental Health Day (10 October), International Day of Persons with Disabilities (3 December), Human Rights Day (10 December) and Mad Pride Day (32). (Note that Mad Pride may be celebrated any time but is most often observed in the month of July, usually on or around 14 July).

#### **National Organization of Users and Survivors of Psychiatry (NOUSPR), Rwanda – launch on World Mental Health Day October 10 (28)**

The launching of NOUSPR took place on World Mental Health Day (10 October). We wanted people to know that, apart from physical disabilities, there are “hidden disabilities” that are less prominent and not as easily recognized, such as emotional distress or mental health conditions. For the celebrations we invited DPOs, NGOs and government officials.

We chose a kite as a symbol of hope and reliance on people with psychosocial disabilities. The message, in summary, was “Like a kite in the air I am swayed to and from what you call a reality. I run through the strange world, my dreams are never true, I am going astray... so you say, but the string that connects me with my roots is strong ... enough to keep me a human being. I need to keep being valued with trust and dignity.”

Other activities can also be put in place to promote the organization on an ongoing basis. Such activities include information sessions, expression of interest and membership forms, brochures and flyers, posters and notices (in mental health and related service areas in addition to community venues), newsletters, national and local media outlets, websites and/or social media platforms. These activities are described in more detail below.

#### **Expression of interest and membership forms**

“Expression of interest” forms are used to identify people who are interested in taking part in the group or finding out more about it (31). “Membership forms” on the other hand, are applications to become a member of the organization. These forms can have different formats depending on the organization. These forms can also be included as a part of, or alongside, the organization's brochure or newsletter, or can be disseminated at events and gatherings.

Membership and expression of interest forms should provide space for:

- People's names

- Preferred methods of communication (telephone, email, or mail)
- Preferred methods of participation;
- Details on how the form can be returned to the group.

### **Brochures and flyers**

The organization may wish to inform the broader community about its activities and attract new members and support via brochures and/or flyers. Before the group starts designing and writing this material, it is useful to ask the following questions (31):

- What does the organization need to say? Try to keep it short and simple, including only the main points.
- Who is it written for? It is important that the style and content is relevant to the target group(s), or group(s) that the organization is trying to engage. Consider the use of pictures and graphic representations for settings where literacy rates are low. Also consider accessibility – e.g. by using braille.
- How should the brochure or flyer look? For instance, should it look professional, simple, welcoming etc.? Who will design it?
- How will the organization get the flyer or brochure printed? How much will it cost? How many should be printed? What happens if the supply runs out?
- Where will it be distributed? Consider strategic locations to capture the target audience.

Information contained within the brochure or flyer may include:

- Name and purpose of the organization.
- Goals and objectives of the organization.
- Type of organization (open or closed membership, etc.).
- Meeting time(s) and place(s).
- How to contact the organization.
- Seeking information from the community on issues of concern and ideas to prioritize.

### **Posters and notices**

Posters and notices are a great way to advertise the group. When creating posters and notices it is important to consider using designs and appropriate images to convey key messages that persuade and motivate the target audience to take action to engage in and support the organization. Key messages should be positive, persuasive and relevant to the local culture and context. Some important questions to ask when creating posters and notices include:

- Who is the organization trying to reach?
- What is the benefit of the group for potential members?
- What does the organization want the audience to do? Some intended action items include attending a support group, signing up for the organization's newsletter, visiting the organization's headquarters, or engaging in advocacy actions.

As in the case of brochures and flyers, posters and notices should be placed and/or distributed in strategic locations in order for them to be most effective and accessible – e.g. in community and mental health and related service venues visited by the target groups (such as clinics, community centres, churches, libraries and social service agencies).

## **Newsletters**

Newsletters can be an effective strategy for reaching a large audience, as they are often easy to create and distribute. For instance, a short bulletin can be distributed via mail or email (31).

Content of the newsletter can include:

- Reports of events and meetings.
- A calendar of upcoming meetings and events.
- News relating to the individual members of the organization (with their permission).
- Articles, opinions, reports of current debates, quotes, cartoons, photos etc.
- Members' poetry, jokes, essays, thoughts, ideas, descriptions of personal experiences, art etc.

The tasks of writing the newsletter can be rotated among members and should follow some simple editorial rules. Examples may include:

- Within the bounds of respectful discussion, open debate on issues of policy or other matters relevant to the organization will be encouraged.
- Statements that could put the group at risk of legal action will be avoided or, if important to the organization's work, the risks will be mitigated following legal advice.
- Statements that in any way undermine the rights and dignity of people with disabilities will be rejected.

## **Websites, blogs and social media platforms**

Websites, blogs and social media platforms such as Facebook, Twitter and LinkedIn can be effective ways to communicate with members and stakeholders and promote the organization. The content can include the organization's vision, objectives and activities, contact details, important news, regular updates and/or developments, upcoming events, campaigns, or stories from members who wish to share successes or personal experiences.

Maintaining websites with up-to-date, well organized information can be used as a means of educating the public and decision-makers about the organization's goal(s), objectives, activities and priority concerns. In addition, websites can be used to conduct online polling of public attitudes to the organization's priority concerns which in turn can provide useful information about policies or interventions which might be best suited to address those concerns. This information can then become the basis for future activities (33).

The use of social media platforms has a number of benefits, including the low cost (sometimes even free of charge), the ability to deliver instantaneous messaging to target audiences, and the opportunity to monitor an organization's activities and their effectiveness (e.g. via online polls, discussion forums, or feedback from the target group). Different social media platforms will target different audiences, so research into the demographics of platform users can help identify the best fit between the organization's goals and the social media platform. Some general strategies to keep in mind when using social media include (34):

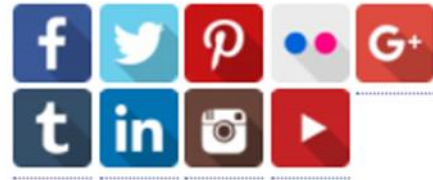
- Selecting specific platforms which will not only be most effective but also manageable in terms of time and effort.
- Posting only relevant content and ensuring that this content comes from credible, reliable sources.
- Posting regularly. If an account is not updated regularly with new information it is likely that the audience will lose interest quickly.
- Setting clear objectives for how the social media platform will be used (e.g. to share information about important events and/or engage broadly with a target audience on the priority issue, or both).



## The Autistic Self Advocacy Network uses e-advocacy to advance its mission

The Autistic Self Advocacy Network (ASAN) is a nonprofit organization run by and for people with autism. ASAN advocates on issues relating to autism and other disabilities; it aims to ensure the meaningful involvement of people with autism in making policy at all levels, to promote a culture of inclusion and respect for all, to enforce the rights of people with autism to have equal opportunities at school and at work, and to improve funding for community services and supports along with research into how they can best be provided.

ASAN uses a variety of social media platforms including Facebook, Instagram, Twitter, YouTube, Tumblr, Pinterest, Flickr, Google Plus and LinkedIn to advance its mission and goals, as well as to advocate, raise funds, promote events and disseminate important information and resources.



For more information, see: <http://autisticadvocacy.org/>.

The screenshot displays the ASAN social media presence. At the top is the ASAN logo, a colorful geometric shape. Below it, the profile name 'autisticselfadvocacy' is shown with a 'Follow' button. Statistics indicate 519 posts, 1,504 followers, and 95 following. The bio states: 'Autistic Self Advocacy Network ASAN seeks to advance the principles of the disability rights movement with regard to autism. Nothing About Us, Without Us! autisticadvocacy.org'. Three featured posts are visible: 'ASAN Official Statement on the Charlottesville Terror Attack', 'A SPECIAL MESSAGE FOR EVERYONE!', and 'ACTION ALERT! ALMOST THERE ON HEALTH CARE!'. Below this is a larger banner for the 'Autistic Self Advocacy Network' with the ASAN logo and a 'FOLLOW' button. The 'Posts' section shows two recent updates: one from 8h ago about barriers to friendship with a link to a Broad Reach Training article, and another from 10h ago about abuse investigations in state institutions with a link to a Oneida Dispatch article.

## 5. Monitoring, evaluation and reporting

Monitoring refers to the routine tracking of key elements of the organization's activities, while evaluation refers to a process of systematically assessing the value and effectiveness of an activity. Evaluation is essential for understanding whether the organization is having the impact that is anticipated. Both monitoring and evaluation will also help to identify factors that are facilitating the organization's goal(s) and objectives or acting as barriers to achieving them.

The following are different aspects of an organization that should be monitored and evaluated.

### **Overall functioning of the organization, its programmes and activities**

It is useful to understand the overall functioning of the organization through monitoring, for instance, whether:

- The planned activities have been completed.
- The time frames that were originally planned have been met.
- The human and financial resources used were available and sufficient to meet the organization's needs.

### **Participation**

The organization can track and record simple statistics in order to monitor the level of participation. Examples include:

- Number of attendees.
- Type of participants (e.g. people with disabilities, family, care partners, mental health and other practitioners, people across diverse social positions etc.).
- Frequency of participation.
- Length of time a person participates.
- Satisfaction with membership and attendance.

Monitoring participation will provide an understanding of the most popular activities, whether numbers are increasing or decreasing over time, who generally wants and is able to participate in the organization's work, and whether target groups are participating as planned.

### **Impact of the organization's work**

In general, it is important to be clear about what the organization wishes to achieve and to continually collect information and evidence to track progress – for instance, by recording group activities and obtaining internal and external evaluations of these activities (e.g. what worked versus what did not work). Evaluation methods can take many different forms – including surveys, focus groups and individual structured interviews. Case study and photo essays can also be used to collect qualitative data and document outcomes. The evaluation method selected should depend on the objectives of the actions, activities, services or programmes implemented and the feasibility of collecting and analysing these data.

It should be emphasized that, in general, organizational activities are expected to produce changes in knowledge, attitudes and behaviour and/or an improvement in well-being, quality of life or empowerment at the individual level, or changes in policy and legislation at systemic levels. Consequently, careful evaluation of each of the activities is required to ensure that the organization is having its desired and intended impact. For example, when an organization conducts advocacy actions to eliminate discrimination against people with psychosocial, intellectual or cognitive disabilities, it is helpful to understand – for each service, programme or action that the organization has initiated – the degree to which people have participated, the impact of the initiative on knowledge, attitudes and/or practices, and/or the overall impact of the action on the well-being of the target group (i.e. did it benefit them in the intended way or did it benefit some more than others?) It is also important to identify strategies and mechanisms to integrate evaluation results into the organization's functioning in order to achieve meaningful improvements.

Sometimes donors will require a more formal evaluation of an organization and its activities, functions and processes, as well its impact and outcome measures relating to the programmes or services that are in place. For instance, donors may wish to see an analysis of the organization's finances, including budgeting allocations and what specific funds and funding sources the group may need in the future. If such reporting is required, completing these evaluations in a timely and accurate manner will be important for the organization's overall success (see section on *Reporting*).

## Reporting (35)

Reporting to funders, partners and others who are likely to help the organization is important if the organization wants their continued support. Evaluation should form the basis of these reports. If the organization has received funding from a government or benevolent grant scheme, then there may also be specific requirements in reporting that need to be met. This might include reporting on:

- Achievement of agreed milestones and progress in implementing the objectives of the organization.
- Stories of successes (or challenges).
- Budget income and expenditure and links with expected outputs (including audit report where relevant).
- Number of people engaged within a predetermined time frame.
- Recruitment of new members or volunteers.

It is essential that all reports are completed as required and are aimed at the needs and interests of the target audience. For example, a report to a funder would need to include a summary of how funds were used; a report to an advocacy target needs to emphasise advocacy messages; a report to members needs to report against planned priorities for the year. It is usually more efficient to produce a single report that needs to fulfil all these purposes.

Ongoing communication with donors and other supporters is necessary. It is critical to inform funding bodies as early as possible of any potential setbacks or challenges with regard to timely reporting in order not to jeopardize the organization's ongoing funding or endorsement.

### Examples of reports

- CBM Annual Review 2015–2016 can be found at: <http://www.cbmun.org.uk/wp-content/uploads/2016/04/MU21187-CBM-Annual-Report-accessible.pdf>.
- MindFreedom Ireland Annual Report 2015 can be found at <http://www.mindfreedomireland.com/index.php/annual-reports>.

## 6. Sustainability

Aside from funding, the motivation and engagement of members is essential to sustaining an organization and its activities.

### Keeping people motivated

People may have many different reasons for joining an organization. However, they will remain involved only if they feel they are gaining or contributing something meaningful through their participation.

Some motivating factors to stay involved in an organization may stem from:

- A sense of belonging from being part of a community and being with others.
- Satisfaction from helping others in a meaningful way.
- Receiving positive feedback about the work being carried out.
- Members deriving a sense of ownership of the organization, a feeling that their inputs and contributions matter and that they are driving the goals, directions and activities of the organization.
- Feeling that there is transparency and integrity in the organization's leadership and decision-making processes.
- Opportunities for members to actively participate and even become leaders.

Generally, one of the roles of the leader is to make sure that members are satisfied with their involvement in the organization. This may be achieved through (35):

- Ensuring that the organization's purpose and activities are meaningful.
- Allowing members to enjoy social interaction with others.
- Making sure to allocate and share responsibility and to support members in their tasks.
- Making sure that no one is left aside and that every member is able to contribute.
- Providing members with adequate skills training and competence development.
- Encouraging members to share ideas for improvement and new projects.
- Being able to settle potential conflicts within the organization.
- Encouraging and rewarding achievements.

### Celebrating achievements

Organizations may have ambitious goals; however, setting goals that are unrealistic or unachievable will lead to disappointment and can be demoralising for everyone in the group. The likelihood of success can be enhanced by setting smaller, more readily achievable objectives – even if this means that goals may take a longer amount of time to reach.

It is also important for all members to celebrate successes and achievements, no matter how small. It can take a great deal of energy and time to achieve results; therefore, celebrating accomplishments will keep people motivated and will encourage them to remain engaged. Publicizing successes will also build support from others who will appreciate the good work being carried out by the organization.

## References

1. A guide to civil society organizations working on democratic governance [online publication]. New York (NY): United Nations Development Programme (UNDP); 2005. ([http://www.undp.org/content/dam/aplaws/publication/en/publications/democratic-governance/oslo-governance-center/civic-engagement/a-guide-to-civil-society-organizations-working-on-democratic-governance-/3665%20Booklet\\_heleWEB\\_.pdf](http://www.undp.org/content/dam/aplaws/publication/en/publications/democratic-governance/oslo-governance-center/civic-engagement/a-guide-to-civil-society-organizations-working-on-democratic-governance-/3665%20Booklet_heleWEB_.pdf), accessed 15 February 2017).
2. Kleintjes S, Lund C, Swartz L. Organising for self-advocacy in mental health: experiences from seven African countries. *Afri J Psychiatry*. 2013;16(3):187–95.
3. Mental Health Peer Connection [website]. Buffalo (NY): Mental Health Peer Connection (MHPC). (<http://wnyl.org/Mental-Health-PEER-Connection>, accessed 15 February 2017).
4. Avery S, Mental Health Peer Connection (MHPC). Channels 2013, “Not without us” [video]. Western New York (WNY): Squeaky Wheel; 2013. (<https://vimeo.com/62705552>, accessed 15 February 2017).
5. Normal Difference Mental Health Kenya (NDMHK). About us [website]. Kenya: Normal Difference Mental Health Kenya. ([http://www.normal-difference.org/?page\\_id=15](http://www.normal-difference.org/?page_id=15), accessed 15 February 2017).
6. Pan African Network of People with Psychosocial Disabilities (PANUSP). Announcement, 27 October 2011, from an International Congress held in Cape Town, South Africa, 13–15 October 2011. (<http://www.globalmentalhealth.org/sites/default/files/docs/PANUSP%20Cape%20Town%20Declaration%2010.2011.pdf>, accessed 13 July 2018).
7. Northamptonshire People First [Website]. Kettering: Northamptonshire People First; 2018. (<https://www.peoplefirst.org.uk/about>, accessed 12 March 2018).
8. Advocacy and awareness [website]. Kathmandu: National Mental Health Self-help Organisation (KOSHISH); 2015. (<http://koshishnepal.org/content/sub/program/1>, accessed 15 February 2017).
9. Dementia Alliance International [website]. Ankeny (IA): Dementia Alliance International (DAI); 2014/2015. (<http://www.dementiaallianceinternational.org/>, accessed 15 February 2017).
10. TOPSIDE [website]. Brussels: Training Opportunities for Peer Supporters with Intellectual Disabilities in Europe (<http://www.peer-support.eu/about-the-project/>, accessed 15 February 2017).
11. Carta MG, Maggiani F, Pilutzu L, Moro MF, Mura G, F Sancassiani et al. Sailing can improve quality of life of people with severe mental disorders: results of a cross over randomized controlled trial. *Clin Pract Epidemiol Ment Health*. 2014;10:80–6. doi: <http://www.dx.doi.org/10.2174/1745017901410010080>.
12. Carta M. Personal communication. 2017.
13. Special Olympics. What we do [website]. Washington (DC): Special Olympics; 2017. ([http://www.specialolympics.org/Sections/What\\_We\\_Do/What\\_We\\_Do.aspx](http://www.specialolympics.org/Sections/What_We_Do/What_We_Do.aspx), accessed 15 February 2017).
14. Altruist. About us [website]. Ahmedabad: Altruist. (<http://thealtruist.org/about-us/>, accessed 15 February 2017).

15. Hamlai M. Personal communication. 2017.
16. Timothy [video]. CBM Australia; 2017. (<http://www.endthecycle.info/wpdm/timothy-video/>, accessed 15 February 2017).
17. Vasquez A. Personal communication. 2017.
18. Goodwin R, Patton M. Tools for creating and maintaining safe and successful peer-led groups for adults with histories of sexual abuse [online publication]. Ottawa: 1in6 & The Men's Project; 2007, accessed 16 February 2017).
19. Dementia – Together towards a new era. 32nd International Conference of Alzheimer's Disease International, Kyoto, Japan (26–29 April 2017) [web page]. London: Alzheimer's Disease International (ADI); 2017. (<https://www.alz.co.uk/ADI-conference-2017>, accessed 20 November 2018).
20. Straight to the Point: Mapping an Advocacy Strategy, p. 5 [online publication]. Watertown (MA): Pathfinder International; 2011. (<http://www.pathfinder.org/publications/straight-to-the-point-mapping-an-advocacy-strategy/>, accessed 16 February 2017).
21. Sharma RR. An introduction to advocacy training guide [online publication]. Washington (DC): Academy for Educational Development; 1997. ([http://wikiciv.org.rs/images/8/89/An\\_Introduction\\_to\\_Advocacy.pdf](http://wikiciv.org.rs/images/8/89/An_Introduction_to_Advocacy.pdf), accessed 16 February 2017).
22. Centre of Excellence in Peer Support Mental Health. Considerations when setting up a peer support group [online publication]. Victoria: Association for the Relatives and Family of the Emotionally and Mentally Ill (ARAFEMI); 2013. (<http://www.peersupportvic.org/index.php/2-uncategorised/30-starting-a-peer-support-service-or-group>, accessed 16 February 2017).
23. Community Tool Box. Developing a plan for financial sustainability [website]. Lawrence (KS): University of Kansas; 2014. (<http://ctb.ku.edu/en/table-of-contents/finances/grants-and-financial-resources/financial-sustainability/main>, accessed 16 February 2017).
24. Garecht J. How to use crowd-funding sites to raise money for your non-profit [website]. Philadelphia (PA): The Fundraising Authority; 2016. (<http://www.thefundraisingauthority.com/internet-fundraising/crowd-funding-your-non-profit/>, accessed 16 February 2017).
25. Mental health and development: targeting people with mental health conditions as a vulnerable group. Geneva: World Health Organization; 2010. ([http://apps.who.int/iris/bitstream/10665/44257/1/9789241563949\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/44257/1/9789241563949_eng.pdf), accessed 2 February 2017).
26. Private-sector funding sources [online publication]. Washington (DC): Centre for Community Change. (<http://www.campusactivism.org/server-new/uploads/privfund.pdf>, accessed 16 February 2017).
27. Evidence for peer-run crisis alternatives [website]. Lawrence (MA): National Empowerment Centre (NEC); 2013. (<http://power2u.org/evidence-for-peer-run-crisis-alternatives/>, accessed 15 February 2017).
28. Badege S. Personal communication. 2016.
29. Heartsounds: About [Facebook page]. Kampala: Heartsounds. ([https://www.facebook.com/pg/Heartsounds-Uganda-182799188438059/about/?ref=page\\_internal](https://www.facebook.com/pg/Heartsounds-Uganda-182799188438059/about/?ref=page_internal), accessed 24 February 2017).
30. Atukunda J. Personal communication. 2015.



31. The Starter Kit for Consumer Developed Initiatives [online publication]. Melbourne: Our Community. (from <http://www.ourconsumerplace.com.au/files/thestarterkit.pdf> accessed 16 February 2017).
32. Mad Pride FAQs [web page]. Eugene (OR): MindFreedom International; 2018. (<http://www.mindfreedom.org/campaign/madpride/other-info/frequently-asked-questions/mp-faq>, accessed 20 November 2018).
33. Public Health Advocacy Institute of Western Australia (PHAIWA). Public health advocacy toolkit, Third Edition [online publication]. Perth: Curtin University; 2013. (<http://www.phaiwa.org.au/wp-content/uploads/2015/08/PHAIWA-Advocacy-in-Action-Toolkit-3rd-Edition.pdf>, accessed 16 February 2017).
34. Davidson R. Social media 201: leveraging social media to increase your visibility [website]. Washington (DC): American Association of University Women. (<http://www.aauw.org/resource/how-to-use-social-media-for-advocacy/>, accessed 16 February 2017).
35. The kit: A guide to the advocacy we choose to do - a resource kit for consumers of mental health services and family carers [online publication]. Canberra: Commonwealth Department of Health and Family Service; 1999. (<http://www.healthissuescentre.org.au/images/uploads/resources/Guide-to-advocacy-we-choose-the-kit.pdf>, accessed 16 February 2017).

## Annex

### Annex 1: United Nations human rights instruments and corresponding treaty bodies

United Nations human rights instruments	United Nations treaty monitoring body
International Covenant on Civil and Political Rights	Human Rights Committee <a href="https://www.ohchr.org/en/hrbodies/ccpr/pages/ccprindex.aspx">https://www.ohchr.org/en/hrbodies/ccpr/pages/ccprindex.aspx</a>
International Covenant on Economic, Social and Cultural Rights	Committee on Economic, Social and Cultural Rights <a href="https://www.ohchr.org/en/hrbodies/cescr/pages/cescrindex.aspx">https://www.ohchr.org/en/hrbodies/cescr/pages/cescrindex.aspx</a>
Convention on the Rights of Persons with Disabilities	Committee on the Rights of Persons with Disabilities <a href="https://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx">https://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx</a>
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment	Committee Against Torture <a href="https://www.ohchr.org/en/hrbodies/cat/pages/catindex.aspx">https://www.ohchr.org/en/hrbodies/cat/pages/catindex.aspx</a>
Convention on the Rights of the Child	Committee on the Rights of the Child <a href="https://www.ohchr.org/EN/HRBodies/CRC/Pages/CRCIndex.aspx">https://www.ohchr.org/EN/HRBodies/CRC/Pages/CRCIndex.aspx</a>
International Convention on the Elimination of All Forms of Racial Discrimination	Committee on the Elimination of Racial Discrimination <a href="https://www.ohchr.org/EN/HRBodies/CERD/Pages/CERDIndex.aspx">https://www.ohchr.org/EN/HRBodies/CERD/Pages/CERDIndex.aspx</a>
Convention on the Elimination of All Forms of Discrimination against Women	Committee on the Elimination of Discrimination against Women <a href="https://www.ohchr.org/en/hrbodies/cedaw/pages/cedawindex.aspx">https://www.ohchr.org/en/hrbodies/cedaw/pages/cedawindex.aspx</a>

#### For more information see:

- Office of the High Commissioner for Human Rights. General information about the UN human rights treaty system:  
<http://www.ohchr.org/EN/Issues/IPeoples/IPeoplesFund/Pages/TreatyBodies.aspx>
- International Disability Alliance (IDA). Guidance document on parallel reports:  
<http://www.internationaldisabilityalliance.org/resources/guidance-document-parallel-reporting>



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

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

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

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



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