Setting up and operating a civil society organization in mental health and related areas

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

(Pilot Version)

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What is the WHO QualityRights initiative?

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

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

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

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

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

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

WHO QualityRights - Guidance and training tools

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

Service assessment and improvement tools

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

Training tools

Core modules

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

Advanced modules

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

Guidance tools

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

This document has been developed to provide guidance on how to set-up and strengthen civil society organizations working to protect and promote human rights in mental health and related areas and in particular the rights of people with psychosocial, intellectual and cognitive disabilities.

Who is this guidance for?

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

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

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

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

The term psychosocial disability includes people who have received a mental health related diagnosis or who self-identify with this term. The terms cognitive disability and intellectual disability are designed to cover people who have received a diagnosis specifically related to their cognitive or intellectual function including but not limited to dementia and autism.

The use of the term disability is important in this context because it highlights the significant barriers that hinder people’s full and effective participation in society.

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

In relation to mental health, some people prefer using expressions such as “people with a psychiatric diagnosis”, “people with mental disorders” or “mental illnesses”, “people with mental health conditions”, “consumers”, “service users” or “psychiatric survivors”. Others find some or all these terms stigmatising.

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

This guidance module aims to assist people in setting up and operating a civil society organization to promote human rights in the field of mental health. Depending on their purpose, civil society organizations may be composed solely of people with psychosocial, intellectual and cognitive disabilities or solely of their families and/or care partners. At other times according to the context, it may be appropriate that organizations are developed and operated by both these groups and other interested parties, together.

Included in this guidance module is information and suggestions for structuring a civil society organization, designing its programmatic focus, its day-to-day operations, and monitoring, evaluating and reporting progress. Investing energy in the planning phase of organizational development will provide a strong base upon which the organization can successfully operate long-term and therefore make the most impact.

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. For the purpose of this guidance, that common interest is to work together to bring about important change in an area that the organization has identified as being central to improving the lives of people with psychosocial, intellectual and cognitive disabilities. Civil society organizations, in general, are often in the forefront of advocating for social justice and play an increasingly influential role in setting and implementing agendas across the globe. Although there has been an increase in the number of civil society organizations and scope of their activities, there remains a need for such organizations in mental health and related areas.

Scenario: Mental Health Peer Connection (MHPC), US – a peer driven advocacy organization

MHPC is a peer driven advocacy organization, 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 programs assisting 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 mental health conditions in America. The films 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” visit: https://vimeo.com/62705552

To learn more about MHPC visit: http://wnyi.org/mhpc.html
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 or alternatively mental health and related practitioners who have recognised the importance of addressing human rights in mental health. 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 existing organizations in the community and offers something new. This could be in the form of a different service being provided or even a different perspective on championing the rights of people with psychosocial, intellectual and cognitive disabilities.

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

Scenario: Alzheimer’s Disease International (ADI) - A civil society organization as a branch of an existing organization (4)

Alzheimer’s Disease International (ADI) is a federation of national Alzheimer associations around the world whose mission is to improve the quality of life of people with dementia and their carers, and to raise awareness of the disease.

One of ADI’s key roles is to support members in their activities and encourage the formation of new associations by disseminating information, supporting an annual international conference, encouraging research and stimulating public and political awareness at the national and international levels.

Creating an Alzheimer’s association is the most efficient way to achieve help for the largest possible number of people. An association helps to coordinate, guide and advise local activities and therefore creates valuable opportunities to increase public awareness on critical issues related to Alzheimer’s Disease.

Determining who are the members of the organization

The people for 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 or alternatively restricted to only one of these groups. Restrictions may even go further.
For example, rather than all people with psychosocial disabilities forming the membership of a group, it may be decided that only people who identify as, psychiatric users or “survivors” will form the group’s membership.

When membership is based solely on the wish to promote and advocate for a cause common to people with psychosocial, intellectual and cognitive disabilities, family members, care partners and others, the ability to attract wide and large membership is seen as more important than the specific groups who become members.

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

Scenario: Normal Difference Mental Health, Kenya - Identifying a need for a civil society organization and forming it (5)

Until recently, there have not been any public mental health services in Kariobangi and Kisumu’s 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 well-being for many people in Kenya– especially considering the trauma inflicted by the post-election violence in 2007 and 2008.

Individuals who have experienced trauma need a safe and healing place in their community where they have the opportunity to cope, and overcome traumatic experiences. 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 issues, regain strength and self-confidence, and live self-determined lives in their communities which 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 to address the growing burden associated with trauma and physiological distress. In August 2009 it spread to Kisumu, Kenya’s third biggest city situated by the Lake Victoria.

By integrating African beliefs into supportive services, Normal Difference Mental Health seeks to promote healing and wellbeing by addressing individual experiences of trauma and distress that often require special attention and intervention. 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 the annual meeting in Maastricht, Netherlands.

To learn more about Intervoice visit: 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 and characterize the contribution of every member and the organization as a whole. Values can be defined as beliefs, principles or standards that a person feels are important in their life and which govern the way they think and act and can include, but are not limited to equality, respect, dignity, trust, well-being, connectedness, shared understanding, recovery, empowerment, hope, protection, compassion, inclusion, open-mindedness, and reliability. The agreed upon core set of values should be reflected in a vision statement that the organization establishes for itself.

The vision sets high expectations for the work of the organization in terms of how the organization will function and what it aims to achieve or the overall outcome that the organization is working towards. The vision needs to be understood and shared by all members of the service. It 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 join in with a sense of ownership and commitment. For example, an organization’s vision could be “To promote recovery for people with psychosocial disabilities in our community by providing individualised and group peer support services.”

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 concretely answer 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 that all members of the organization help design and implement these activities, in the spirit of inclusiveness.

Included below is an introduction to some activities that the organization may undertake. These are not necessarily self-contained and may overlap. It is not an exhaustive list, but is intended to serve as a starting point that may be useful, depending on the organization’s vision and objectives.

Providing peer support

Peer support provides a platform for people with psychosocial, intellectual and 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 judgment. Peer supporters, who are experts by experience, are able to relate to, connect 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 but not limited to:

- Peer support groups set up by and for people with lived experience or peer support groups for their families and/or care partners.
• Individualised 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 QualityRights modules *Providing individualized peer support in mental health and related areas* and *Creating peer support groups in mental health and related areas*.

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**Scenario: Inclusion Europe: Project TOPSIDE - Training Opportunities for Peer Supporters with Intellectual Disabilities in Europe (6)**

TOPSIDE is an *Inclusion Europe* project aiming to develop peer support and training as a new component in informal adult education for people with intellectual disabilities. Since access to formal or informal adult education and training can be limited for individuals 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 to perform their role 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. The peer supporter learns to relate their own life experiences to the support they are providing and use these experiences and learning to support others. The training also examines different values that peer supporter can adopt, such as inclusion, person-centred thinking, valued roles and citizenship in the 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 shaped in such a way that all skills outlined in the curriculum are anchored and based in real life situations. Skills which 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 about topics such as inclusion, person centred thinking, valued social roles, and being a citizen in a community.
- **Pragmatic Skills** covering different life experiences and quality of life issues relative to inclusion- for example, home life, rights, work and social life.

To learn more visit: [http://www.peer-support.eu/about-the-project/](http://www.peer-support.eu/about-the-project/)

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**Systemic advocacy and campaigns**

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

- Promoting mental health as a human rights issue on government agendas.
- Lobbying to promote a rights-based approach to mental health in governmental policies, plans, laws and/or regulations.
• Advocating for better mental health and related services that have human rights at their core.

• Promotion of the rights of people with psychosocial, intellectual and cognitive disabilities, as well as their families and care partners.

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 actions to promote human rights in mental health and related areas.*

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**Scenario: Koshish, Nepal, engages in systemic advocacy to promote the rights of people with psychosocial disabilities (7)**

“Koshish” which means “making an effort” in Nepali, is a rights-based NGO registered in the District of Kathmandu that was started by people with psychosocial disabilities who recognised the need to improve mental health systems in Nepal. KOSHISH seeks to create a society where 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 stigma and discrimination, KOSHISH has been conducting advocacy to encourage people with psychosocial disabilities to publically 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:

- Reviews laws, policies and programs relative to mental health and related services to ensure they are in line with international human right standards;
- Mobilizes the media and promotes awareness of issues affecting people with psychosocial disabilities;
- Engages in networking and collaboration with other organizations and stakeholders; and
- Prepares human right defenders and self-advocates through support and capacity building.

To learn more visit: [http://koshishnepal.org/advocacy](http://koshishnepal.org/advocacy)
Individual advocacy for people with psychosocial, cognitive and intellectual disabilities

Sometimes, people with psychosocial, cognitive and intellectual 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 their care partners.** For example, 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 example, providing support and guidance during doctors’ appointments, social security appointments and/or family meetings.
- **Facilitating communication** among people with psychosocial, intellectual and 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.
- **Attending and supporting people during review hearings** in cases where people have been admitted to mental health or related services and treated involuntarily.
- **Supporting people to self-advocate.** This includes capacity building of people with psychosocial, intellectual and 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 programs to different groups and organizations, including mental health and related practitioners, people with psychosocial, intellectual and cognitive disabilities, NGOs, policymakers, and service providers. Topics can include, but are not limited to:

- Requirements for developing policies, programs, and services that are in line with the Convention on the Rights of Persons with Disabilities (CRPD).
- Supported decision making in mental health and related services (See QualityRights module Realizing supported decision making and advanced planning).
- Realising recovery oriented care in mental health and related services (See QualityRights modules Realizing recovery and the right to health in mental health and related services and Promoting recovery in mental health and related services).
- Strategies to end seclusion and restraint (See QualityRights modules Creating mental health and related services free from violence, coercion and abuse and Strategies to end the use of seclusion, restraint and other coercive practices).
- Different ways to understand emotional distress, including suicidal thoughts, hearing voices, and other personal experiences.
- The use of respectful, non-medicalized and empowering language to overcome stigma and increase empowerment of people with psychosocial, intellectual and cognitive disabilities.
- Organizing public speaking events or film screenings on these or other relevant topics.
**Scenario: Dementia Alliance International- Support and advocacy: by and for people with dementia (8)**

Dementia Alliance International (DAI) is a registered non-profit organization whose membership is exclusively for people with a medically confirmed diagnosis of any type of a dementia from all around the world. DAI seeks to represent, support, and educate others 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 living with purpose with dementia looks like.
- Advocate for people with dementia, and build the capacity of people with dementia 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:**

- Promote connection and dialogue between people with dementia.
- Combat isolation and exclusion of people with dementia.
- Provide opportunities for support and education for people with dementia.
- Promote a shared sense of LIVING beyond the diagnosis of dementia.
- Work to ensure that the voices of those with dementia are listened to and honoured.
- Work 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/](http://www.dementiaallianceinternational.org/)

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**Promoting recreation, entertainment, and sport**

Recreation, entertainment, and sport can be used as powerful tools to reach an organization’s goals and objectives. For example, 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 and cognitive disabilities in a way that is non-traditional, fun, and inclusive.

In Sardinia, for example, there are two active associations that use sport and recreation as a way to advance the wellbeing and rights of people with disabilities. One promotes the practice of sailing in for people with psychosocial disabilities (9), and the other helps guide tourists on treks throughout the island.(10) These associations lean on the idea of using sport as a way to engage people with
psychosocial, intellectual and cognitive disabilities in leisure activities, as well as to reduce stigma and discrimination.

Scenario: Special Olympics uses sports to transform lives and perceptions

Special Olympics is the world’s largest sports organization for people with intellectual disabilities and focuses on transforming lives through the joy of sport. Through the power of sports, people with intellectual disabilities discover new strengths and abilities, skills and success. Athletes find joy, 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 is showcased. At the same time, Special Olympics brings people with and without intellectual disabilities together to see and take part in the transformative power of sports.

Special Olympics fights negative stereotypes and misperceptions. The program 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 trainings, competitions, health screenings and fund-raising 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 that includes an element of supporting their members or target group 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. Examples include raising livestock and chickens, performing secretarial duties, and carrying out technical activities, such as spinning pottery, repairing shoes, recycling plastics, creating handicrafts, and setting up small businesses.
Examples of income generation and livelihood activities

Scenario 1: Milesh Hamlai on how the Parivartan project transforms lives through employment (12),(13)

The Altruist is an organization in Gujarat 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 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, savory flavor. The work requires people to follow a recipe (e.g., mixing spices together), package the tea, and then sell the final product.

Initially we identified 5-6 individuals 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 for 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 loved one 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 people with psychosocial disabilities for work and 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.
- They feel more confident talking about their mental health with others helping to reduce
At Parivartan, it is not only about work but also 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 idea of creating a brand.

**Scenario 2: Timothy’s story, Ghana (14)**

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 provide him with a routine. He participates in and helps a support group by and for people with psychosocial disabilities.


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**Advising the government and health services**

Civil society organizations, including those by and for people with psychosocial, intellectual, and cognitive disabilities or their families and/or care partners can play an important role as an advisor 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 mental health.** When civil society groups are actively engaged in advisory, drafting and evaluation committees around these actions they will be in a position to ensure that a human rights approach forms the basis for all of these actions.

- **Providing advice to government staff and/or mental health and related professionals on how to modify or change existing services and models of care for people with psychosocial, intellectual and 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., incorporating supported decision making into existing care or ensuring access to needed support services) or how to better protect the human rights of people using health services (e.g. ending seclusion and restraint in mental health and related services).

- **Promoting initiatives to the government highlighting the important work being carried out by and for people with psychosocial, intellectual and cognitive disabilities.** For example, 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 actions that are being put in place, or presenting the work of the organization at government-organised forums, meetings and conferences.
### Scenario: Civil society in Peru have major impact in influencing law reform to promote legal capacity

In Peru, civil society has been a key player in the ongoing law reform process on the legal capacity of persons with disabilities. They proposed and advocated for the adoption of the 2012 Law 29973, General Law on Persons with Disabilities, which inter alia ordered the creation of a Congress' Review Committee on the Civil Code with regard to the legal capacity of persons with disabilities (CEDIS).

Between 2014 and 2015, civil society organizations actively participated in the debates of the CEDIS and successfully advocated for the unanimous adoption of a draft bill that proposed the abolishment of all forms of guardianship and its replacement by systems of support for legal capacity. The bill was formally submitted and sent to the Standing Committee on Justice and Human Rights in June 2015.

Due to the parliamentary period ending, the bill was filed without being adopted. However, during the 2016 presidential and parliamentary campaign, civil society organizations advocated for the inclusion of the reform of the Civil Code on legal capacity in the different parties' platforms and proposals. Thanks to these efforts, the three main political parties at the Congress have submitted in January 2017 a new joint bill prosing again the abolishment of all forms of guardianship.

### 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 getting involved in the work of human rights treaty monitoring bodies. Each United Nations (UN) Convention has a human rights treaty body that is responsible for overseeing the implementation of Conventions and Treaties (See Appendix UN human rights instruments and corresponding treaty bodies).

Governments that have ratified Treaties and 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. Similar to this, civil society organizations can also submit reports (sometimes known as parallel reports) to the treaty monitoring body, who will review these reports along with those submitted by a 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 country;
• Ensure that governments are being held accountable for issues that are important to the organization; thereby, creating increased pressure and sense of urgency to address these issues; and
• 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 UN system – the UN 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.

At the country level civil society organizations can engage with National Preventive Mechanisms (NPMs). These are independent national bodies established in countries which are mandated to conduct regular visits to all types of settings where persons are deprived of liberty, for example, hospitals, social care facilities, prisons and psychiatric institutions. The aim of these visits is to prevent abuse, violence, and rights violations. NPMs give recommendations to improve the protection of people who reside in these services and can also make comments on laws and regulations and propose reforms. This human rights monitoring system is implemented as part of the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT), which states that torture and other cruel, inhuman or degrading treatment or punishment are prohibited and constitutes serious violations of human rights. (16)

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 example, 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, the government departments responsible for health, disability and social services and staff of mental health and related services, amongst others.

The importance of networking to garner support for the organization’s activities cannot be overlooked. Goodwin (2007, p.10) states, “Operating in isolation greatly increases the chances that the initiative will struggle to succeed.” (17) To the contrary, exchange and collaboration with other organizations can contribute knowledge, expertise, increase resources and effectiveness and help gain stakeholder support for key actions of the organization.

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.

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 priority issue.
  - *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.

Often the primary audiences or targets for advocacy actions of an organization will be policymakers, officials, or others that have the power to influence change. When primary targets cannot be engaged or influenced, it is still possible to have impact by influencing secondary audiences/targets instead who can then, in turn, influence primary audiences/targets. It is always more effective to be specific in identifying targets, for example, a person, newspaper, department, or committee, rather than the public” or “the government” which are too general. (18)

### Examples of types of audiences, beneficiaries, and/or partners (19):

<table>
<thead>
<tr>
<th>People with psychosocial, intellectual and cognitive disabilities and their families and/or care partners</th>
</tr>
</thead>
<tbody>
<tr>
<td>Politicians (local, provincial, national)</td>
</tr>
<tr>
<td>Ministry officials</td>
</tr>
<tr>
<td>Voters</td>
</tr>
<tr>
<td>United Nations agencies</td>
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<tr>
<td>Businesses or business leaders</td>
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<tr>
<td>Spouses of politicians</td>
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<tr>
<td>Speech writers</td>
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<tr>
<td>Opinion leaders</td>
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<tr>
<td>Labour organizations</td>
</tr>
<tr>
<td>Health services</td>
</tr>
<tr>
<td>Health practitioners</td>
</tr>
<tr>
<td>Academics/universities</td>
</tr>
<tr>
<td>Nongovernmental organizations</td>
</tr>
<tr>
<td>Community groups</td>
</tr>
<tr>
<td>Women’s organizations</td>
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<tr>
<td>Religious groups/churches/ faith-based organizations</td>
</tr>
<tr>
<td>Other professionals</td>
</tr>
<tr>
<td>Media</td>
</tr>
</tbody>
</table>
Engaging Stakeholders

Promoting the new organization and spreading awareness of what it offers can garner 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;
• Use feedback to improve the organization;
• Respond promptly to any concerns raised; and
• Identify champions or advocates within the community who will speak on behalf of the organization.

As mentioned, it is advisable to be aware that some people or organizations that are working in similar areas may have competing interests and for that reason may not want to support the organization or may even act in ways to undermine the organization’s goals and objectives. Reasons for this may include:

• Some mental health and related practitioners or government officials may not understand the need for or importance of the organization. They may also fear its objectives and be reluctant to any changes that might require a shift in paradigms for example, moving from medical models of care in mental health and related services towards recovery and human rights oriented models of care.
• The stigma associated with being a person with a psychosocial, intellectual or cognitive disability, who is leading the organization may lead others to being pessimistic or sceptical about the usefulness and viability of the organization.
• Other organizations or health services may see the organization as ‘competition’ and therefore be unwilling to promote or endorse the organization among its members and networks for fear that this will result in decreased resources, support, or success.

Organizational structure

It will be important to consider how the organization should be structured, as agreeing on these structural elements will allow 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 organizational structure include:

• What size will it be? Initially, the organization may be an informal gathering of people who have heard about meetings 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’ 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, as long as they have a structure that aligns with their vision and objectives.

- **Will it be open or closed?** In an open organization, members generally attend and stop attending according to their own needs. Generally, though not exclusively, membership to an open group is open to everyone. However, in a closed group, members may have more rigid rules and expectations in regard to mandated attendance and participation. In closed groups there may also be criteria that one has to meet before being eligible to join.

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**Scenario: Mariposa, setting up organizational structure in a civil society organization** (20)

Mariposa is the name of an organization of volunteers working for the social inclusion of people with psychosocial disabilities that have received care from the “San Giovanni de Dio” Hospital in Cagliari.

The organization consists of a group of workers from the hospital. Initially it was a small group of 6 volunteers who began to share ideas about putting people who use services at the center of care. The organization was then formed and it was decided:

- Not to formalize a leader but instead have two people coordinate meetings and then after a year initiate two new coordinators; and
- To prove the effectiveness of the organization by attaining some practical objectives before growing.

One of the first objectives was to establish a library for all the patients of the hospital and family members to use. This project involved recruiting and training people who used outpatient services into the role of librarians. The idea was to enable people with psychosocial disabilities to be at the center of a social service which was useful for the community—a hospital library—and useful to break down stigma.

The unit selected 10 people who used services and could benefit from a rehabilitation program as "workers of the library." Five psychiatric rehabilitation students supported the project in terms of rehabilitation. Volunteers helped people using the mental health outpatient services to apply for a small salary provided through a law of the region of Sardinia and took care of the practical activities needed to open and operate a library (e.g., finding book donations, finding funding for a storage program, etc.).

Currently, the library is active and those working in the library are quite satisfied with their work. Mariposa has grown as the number of components has increased, but it has decided to retain the friendly and informal nature of the organization by having two different coordinators each year. Mariposa is planning its future programs to involve librarians:
• In reading books to hospital patients with chronic medical illness who are not able to get up from their bed; and
• Showcasing to visitors how the hospital galleries were used to attend to ill patients during the bombing of World War II.

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 formally set up an organization is expensive or complex. However, it is also possible that having formal legal status may facilitate the work of the organization— for example, by opening up funding possibilities, and through establishing credibility and standing as an official organization.

The following questions can help decisions whether or not to set the organization up as a legal entity:

• What laws and regulations does the organization have to follow 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 example, 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 liability issues? How will people be covered in the event of incidents that 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 therefore covered/bound under those 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 funding? 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 individuals who can advise on legal issues to ensure that the organization operates in accordance with the law.
Policies and procedures

Sound governance of the organization is important and to achieve this, clear policies, procedures, and guiding documents need to be defined. A foundational document is the code of ethics which lists principles based on the organization's core values and the standards to which the organization’s activities and members are held accountable. When appropriate, the organization should review and adapt organizational policies and procedures from other similar groups and organizations according to the local context and purpose of the organization.

Some day-to-day operations that may require additional written policies and procedures include (21):

- Volunteer procedures and support
- Occupational health and safety regulations
- How to manage critical incidents
- Logistical procedures, such as running meetings
- Budget and cash handling
- Conflict of interest

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

Financial issues, including budget and funding

A pressing issue for new civil society organizations is around procuring and managing funds for activities and other operations. 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 these often takes a degree of creativity. For example, 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. Drawing upon and utilizing existing resources in the community can enable organizations with limited resources to grow and develop.

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 group. The organization needs to be transparent about its financial management and to share financial issues 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 (21):

- Set-up costs
- Administrative needs (e.g., computers, software, phones and phone 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 on an annual basis and used as a 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 of funding sources can impact how and what activities are carried out and need to be noted. For example, funding received from a donor with vested interests in certain activities will shape how the organization can use the funds received.

In contrast, funding from donors without vested interests can allow for more flexibility in working procedures and activities. It is advisable to ensure transparency when accepting and acknowledging funding sources and ensure that there are no conflicts of interest, as this can diminish an organization’s integrity and credibility. (22)

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. Below are some potential sources of funding:

- **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:** Using the internet, in particular 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.(23)

- **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. Often this is difficult when the organization is first forming, 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 fund 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 (24):
  - Bilateral organizations or governmental 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 UN 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 agreement that 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 but its funding and operating procedures most closely resemble those of bilateral organizations.
  - Global public-private partnerships, such as the Global Fund for AIDS, TB and Malaria.
  - Private foundations (international and national) such as the Bill & Melinda Gates Foundation and others 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 example, a government may have prioritised the issue of championing the legal rights of people with psychosocial disabilities. If the organization is providing this as a service and has achieved good results, the government may contract the organization to act as the implementing body for its official business in that area.(25)

- **Charitable and religious organizations:** Either of these types of organizations is generally amenable to helping and supporting marginalised groups. 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 such as, providing equipment, technical, management or legal support and publicity. Sponsors can also offer grants or in-kind donations for things like snacks, social outings, and excursions. A civil society organization may receive support from a sponsor, but it is advisable that the organization continue to function autonomously to avoid potential conflicts of interest.

- **Businesses and industry:** Often, resources from the private sector can 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 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. (26)

- **Other fundraising activities**: These will vary based on the resources available to the organization, cultural context, and target audience. Some common activities include music or theatre shows; auctioning off services such as dance lessons, sewing classes, or sport instruction; “cooking-for-a-cause” or raffle evenings with fees for participation; and more.

If the organization needs to complete a formal application for additional funding, the group will need to justify it by showing 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, consider referencing 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 and cognitive disabilities lead advocacy actions (27) and advise government on the direction and evaluation of mental health and related 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.
**Scenario 1: 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 shades of trees or on verandas. Often rain storms 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 space on a desk of a staff member who spent most of his time is the field. This was in the same building of 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), 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 be seated in the office.

Finally, we agreed that the volunteer should be the one seated in the in the office, since he was the one in charge of planning. The volunteer was located in the office and used half of the desk space 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.

**Scenario 2: Heartsounds Uganda gets creative with managing its start-up needs (29)**

Heartsounds was founded in 2008 through a collaboration of 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 programs and projects aim to minimize the negative social, cultural and economic effects on people with psychosocial disabilities.

Here, Heartsounds founder Joseph Atukunda relays the process of finding help to initially set up the organization.

**Joseph Atukunda on starting Heartsounds Uganda (30)**

I first opened up my home to be the resource centre of the organization and all our initial meetings were done there at no cost. I then called upon my old schoolmates from Kings College Budo with whom we held discussions on a Yahoo! group of Old Budinians called the “Kafunda” to help. Those who were interested supported me morally and financially. Most are professionals in various fields and they gave advice. Additionally, some donated computers for our internet cafe, and others donated books for our library and money for operational 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 office equipment like staplers, hole-punching machines, office trays, etc. These donated items helped us a great deal. Meanwhile our friends in East 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.
Day-to-day operations of the organization

Once a civil society group has been established, a new set of considerations enter into play and need to be addressed in order to effectively manage the organization’s day to day operations, including leadership, member responsibilities, running meetings, communication within the organization, and effective promotion to build and strengthen the organization and its activities.

Leadership

Effective leaders contribute to the organization’s goal and consistently put the organization’s interests ahead of their own—although in many instances those interests are often aligned. Leadership should be sensitive to relevant cultural and gender issues as appropriate for the local context – for example, some organizations may implement activities appropriate for only women (or may even be comprised only of women), or have branches that are targeted specifically toward youth.

Leadership of the organization is an important issue to discuss with all members, and it is important for all members to understand the leadership structure- for example, whether it is formal or informal and the types of rules and procedures governing the organization and its activities. When the organization is in its initial stages of formation, someone may already be acting in the role of group leader. It 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 role among different group members, or to elect one member as the leader. Even if all members are seen as equal within the group and there is no official leader, one or several people may take on more responsibilities than others—for example, when organizing meetings or activities. Regardless if it 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 as the group is setting up the organization (see section 3 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 operation 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
- Minutes taking - 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 bookkeeping responsibilities

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

It can also be helpful to develop a membership handbook which provides an overview of the organization, including its vision and values, structure, and areas of focus in addition to primary activities so that all members have a clear understanding of the organization and its purpose.

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 responsibility a responsible person or team for communication of information, and identify the different means through which communication should take place- for example, some organizations may prefer communicating via text messaging, while others may prefer phone communication; however some may prefer to avoid communicating via phone altogether, either due to lack of access or preference. 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 carefully decide the best means of communicating with one another.

Below are some comments on email and phone use, two of the more popular communication methods (31):

• **E-mail**: Some people find participation via electronic communication a more convenient form of participation in comparison to face-to-face meetings; however, if people’s access to email or the internet is restricted they will in effect not receive important information about activities and will be excluded from the opportunity to join debates and discussions. If the group does set up an email account for the organization, it is not advisable to use anyone’s personal email address. Instead, the group can set up a shared account which is free.

• **Phone**: Some organizations give out the mobile phone number(s) of leaders or members. Although the choice to do so should be a personal one, it can come with challenges. For example, the financial stress on the person charged with responding to inquiries can become burdensome. Personal boundaries can be violated if people are calling that person too much or at inappropriate times of the day. Sometimes, people simply do not have a mobile phone. If phone is the preferred method of communication, expectations concerning cell phone use should be discussed during meetings. Group text messaging is also an option and can allow
members to share important information with members relatively easily and cheaply. Furthermore, applications such as WhatsApp allow for international text messaging at no cost once connected to the internet.

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 about the meeting, its time and place, and share the agenda prior to the meeting in order to encourage attendance.

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 activities and events. Below are some important considerations when running meetings.

Meeting preparation

Adequate planning ensures that meetings are well organized and efficient. The following are some helpful ideas when preparing for meetings (32):

- **Agenda:** It can be helpful to prepare an agenda for each meeting. When the format of the meeting is planned and those attending know how it will proceed, things can run more smoothly. Encourage members to offer their input to the agenda if they wish to contribute.
- **Place to meet:** The setting for meetings is very important. Some aspects to consider when identifying a meeting place include providing a comfortable atmosphere, having access to toilets, and general accessibility. Other factors to consider are the proximity to members’ residences or places of work, and to public transportation and parking.
- **Date and time:** The day and time of meetings should be convenient and allow for the participation of as many members as possible; therefore, the availability and preference of members should be taken into account when scheduling meetings.
- **Supplies:** Items such as flip charts, markers, pens/pencils and paper are helpful for brainstorming and recording discussion points, and contact details of people attending. Also, consider providing nametags.
- **Refreshments:** Food and drinks are a way to create an inviting atmosphere. It is worth exploring whether members can contribute some of these items or whether they can be donated.

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

In general, meetings offer the opportunity 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 specific and relevant to the work being carried out. While some organizations may find it appropriate to share and disseminate important information relative 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 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 e-mail lists and contact details private. Members or participants in 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 group. It should be emphasized that their contribution to the organization is valued and that they have much to offer to help the organization succeed in meeting its goal(s) and objectives. Sending a welcome letter and a certificate of membership can be a welcoming 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; therefore, 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, skills, and strengths that they bring, as well as 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 example, 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, while members with strong organizational skills may be a good fit to manage community events or activities.
Promoting the organization

Promoting the organization is an important component of 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.

Official launch or information session

An official launch can be a helpful means to promote the organization. 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. Similar to 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 for them to come (e.g. a high-profile guest speaker or food and drinks provided)?
- 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 formation of the organization to the public can help make the launch more successful. For example, often launches will 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 Human Rights Day (held on December 10th), World Health Day (April 7th), World Mental Health Day (October 10th), and World Alzheimer’s Day (September 21st), International Day of Persons with Disabilities (December 3).

Scenario: National Organization of Users and Survivors of psychiatry (NOUSPR), Rwanda – launch on World Mental Health Day October 10 (28)

Launching of NOUSPR’s took place on World Mental Health Day on October 10. 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 valued with trust and dignity.”
Other activities can also be put in place to promote the group on an ongoing basis. These 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 or finding out more about the group. (31) “Membership forms,” on the other hand, are applications to become a member of the organization. These forms can take on different formats depending on the organization. Additionally, some organizations may have one or the other, while others may have both. 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 pace for:

- People’s names;
- Preferred methods of communication (phone, email, or mail);
- Preferred methods of participation; and
- 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, or group that the organization is trying to engage. Consider the use of pictures and graphic representations for contexts with low literacy rates and consider accessibility, for example by using braille.
- How should the brochure or flyer look? – For example, glossy, flashy, professional, simple, welcoming, etc.? Who will design it?
- How will the organization get the flyer or brochure printed? How much will it cost? What quantity 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.

Similar to 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— for example, in community and mental health and related service venues visited by target groups, such as clinics, community recreational centers, churches, and social service agencies.

Newsletters

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

Content of the newsletter can include:

• Reports of events and meetings;
• 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.; and
• Members’ poetry, jokes, essays, thoughts, ideas, descriptions of personal experiences, art, etc.

The tasks of writing the newsletter can be rotated among members, though it may be necessary to set up clear editorial rules. Some examples include:

• Nobody will be identified without their consent.
• No member will be criticised.
• Statements that could put the group at risk of legal action will be avoided.
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. The organization should decide which option or options are most user-friendly and practical for the group, taking into account the benefits and barriers of the different platforms.

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

Using social media platforms has a number of benefits including being low cost (sometimes even free), having the ability to deliver instantaneous messaging to target audiences, and providing the opportunity to monitor an organization’s activities and their effectiveness (e.g., via online polls 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 organization’s goals and the social media platform. For example, newer platforms such as Twitter are more likely to target a younger audience in comparison to older platforms, such as Facebook.

There are some general strategies to keep in mind when using social media, which include (34):

- Selecting specific platforms which will not only be most effective, but also manageable in terms of time and effort.
- Only posting 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).
Scenario: Autism Speaks uses e-advocacy to advance its mission (35)

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the lifespan, for the needs of individuals with autism and their families through advocacy and support; increasing understanding and acceptance of autism spectrum disorder; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

Autism Speaks uses a variety of social media platforms including Facebook, Instagram, Twitter, and YouTube to advance their mission and goals, advocate, fundraise, promote events, and disseminate important information and resources.

To learn more visit: https://www.autismspeaks.org/
Monitoring and evaluation

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 it anticipated. Both will also help to identify factors that are facilitating or acting as barriers to achieving the organization’s goal(s) and objectives.

The following are different ways to monitor and evaluate the organization’s impact.

**Overall functioning of the organization, its programs and activities**

It is useful to understand the overall functioning of the organization. For example, whether:

- The planned activities have been completed;
- The time frames that were originally planned have been met; and
- 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 or others, 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 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 example, by recording group activities and obtaining internal and external evaluations on these activities (e.g., what worked versus didn’t work, what went well versus did not go well, etc.). Evaluation methods can take many different forms including surveys, focus groups and individual structured interviews. The evaluation method selected should depend on the objectives of the actions, activities, services, or programs implemented and the feasibility of collecting and analysing this data.

It should be emphasized that in general organizational activities are expected to produce changes in knowledge, attitude, and behaviour and/or an improvement in wellbeing, quality of life or empowerment at the individual level or changes in policy and legislation at systemic levels;
Therefore, careful evaluation of each of the organization’s activities is required to ensure that the group is having its desired and intended impact. For example, if an organization conducts advocacy actions to reduce stigma surrounding psychosocial, intellectual or cognitive disabilities, for each service, program or action that the organization has initiated, it is helpful to understand 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 implemented on the well-being of the target group (i.e., did it benefit them in the intended way).

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 programs or services that are in place. For example, 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 6 Reporting).

Reflection – “Taking a moment”

Reflection is a process whereby organizations set aside some time to consider how they are faring in terms of process and progress. Reflective practice is a form of qualitative evaluation and is generally worth adopting as a way of evaluating the impact of specific actions or events (e.g. after a guest speaker visits the organization or an advocacy action has been carried out). Members could be, for example, encouraged to share how they felt about the event, action, or its outcome, and ideas or suggestions for future activities.

Criticism or complaints do not mean that the organization and its activities as a whole are not valuable, but rather present opportunities for improvement. If many members agree that changes need to be implemented it is unwise not to listen and respond to these concerns. Decisions to alter the activities of the organization should be discussed with the all members, so that this process is inclusive. All members should be made to feel comfortable in offering their opinion and suggestions. Organizing regular meetings to discuss the usefulness of activities may be a helpful way to obtain ongoing feedback and new ideas. This will help ensure that the organization remains relevant and continues to provide a beneficial service to its members.

Reporting (36)

Having started a new organization, it is useful to keep stakeholders informed of its progress. Reporting to funders, partners, and other people 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 specific 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 the:

- Achievement of agreed milestones in budget expenditure;
- Number of people engaged within a pre-determined timeframe; and/or
- Recruitment of new members or volunteers.
It is essential that all reports are completed as required. Failure to complete reports in a timely manner could jeopardize the organization’s ongoing funding or endorsement. In these situations, it is critical to inform funding bodies as early as possible of any potential setbacks or challenges with regard to reporting in a timely, accurate fashion.

**Examples of reports**


**Sustainability**

An organization that manages to operate over the long-term is more likely to have important impacts. 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 only remain involved 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
- Getting positive feedback about or celebrating the work being done

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 (36):

- 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 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
- Making sure that members can rely on competent persons
Celebrating achievements

Organizations may have big ambitions; 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 set smaller, achievable objectives— even if this means that goals may take longer 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 encourage them to remain involved. Publicizing successes will also build support from others who will appreciate the good work being carried out by the organization.
Annex 1: UN human rights instruments and corresponding treaty bodies

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<tr>
<th>UN human rights instruments</th>
<th>UN Treaty monitoring body</th>
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<tbody>
<tr>
<td>International Covenant on Civil and Political Rights (ICCPR)</td>
<td>Human Rights Committee (HRC)</td>
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<tr>
<td>International Covenant on Economic, Social and Cultural Rights (ICESCR)</td>
<td>Committee on Economic, Social and Cultural Rights (CESCR)</td>
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<tr>
<td>International Convention on the Rights of Persons with Disabilities (CRPD)</td>
<td>Committee on the Rights of Persons with Disabilities (CRPD)</td>
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<td>International Convention against Torture and Other Cruel, Inhuman or Degrading Treatment (CAT)</td>
<td>Committee Against Torture (CAT)</td>
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<td>Convention on the Rights of the Child (CRC)</td>
<td>Committee on the Rights of the Child (CRC)</td>
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<tr>
<td>International Convention on the Elimination of All Forms of Racial Discrimination</td>
<td>Committee on the on the Elimination of All Forms of Racial Discrimination (CERD)</td>
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<tr>
<td>International Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)</td>
<td>Committee on the Elimination of All Forms of Discrimination against Women (CEDAW)</td>
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For more information see:

- **Office of the High Commissioner for Human Rights- General Information about the UN human rights treaty system:**

- **International Disability Alliance (IDA)- Guidance Document on Parallel Reports:**
References


