QualityRights

Advocacy actions to promote human rights in mental health and related areas

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

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

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What is the WHO QualityRights initiative?

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

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

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

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

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

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

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

WHO QualityRights - Guidance and training tools

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

Service assessment and improvement tools

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

Training tools

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

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

Guidance tools

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

About this guidance

This document has been developed to provide guidance to individuals and organizations planning to design and run an advocacy campaign to promote a human rights approach in mental health and related areas.

Who is this guidance for?

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

Preliminary note on language

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

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

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

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

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

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

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

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

1   Introduction

All over the world, people with psychosocial, intellectual and cognitive disabilities experience a wide range of human rights violations, stigma and discrimination. For example(1),

- They are subjected to high levels of stigma and discrimination, due to widely held misconceptions about the causes and nature of mental health conditions.
- They experience high levels of physical and sexual abuse. This can occur in a range of settings, including prisons and hospitals.
- They often encounter restrictions in the exercise of their political and civil rights, such as the right to vote, to marry, to found a family. This is largely due to the incorrect assumption that people with psychosocial, intellectual and cognitive disabilities are not able to carry their responsibilities, manage their own affairs and make decisions about their lives.
- People with psychosocial, intellectual and cognitive disabilities are not able to participate fully in their societies by taking part in public affairs, such as policy decision-making processes.
- In many countries, they are not able to access essential health and social care. Many people with psychosocial, intellectual and cognitive disabilities fail to receive treatment and care for physical illnesses.
- They also face significant barriers in attending school and finding employment. The exclusion of children with mental and psychosocial, intellectual and cognitive disabilities from education leads to their further marginalization. Poor educational outcomes also lead to poor employment opportunities. Specifically, people with psychosocial disabilities experience the highest rates of unemployment of people with disabilities.

A human rights approach to mental health and related areas recognises that disability is caused by many barriers that prevent persons with psychosocial, intellectual and cognitive disabilities from participating in society on an equal basis with others. This approach also emphasizes that diversity and difference are part of humanity and should be valued, not rejected.

Therefore, persons with psychosocial, cognitive and intellectual disabilities are entitled to equal rights and equal opportunities to participate in society as all other persons. Barriers that prevent people with psychosocial, intellectual and cognitive disabilities from participating fully in society and from enjoying their rights are discriminatory and must be removed so that people can claim their rights.

> *For more information on human rights see **Annex 1: Understanding and promoting the rights of people with psychosocial, intellectual and cognitive disabilities, including dementia***

This module describes the process of designing and running an advocacy campaign and actions to promote the human rights of people with psychosocial, intellectual and cognitive disabilities. The

module provides guidance on developing campaign goals, objectives, and activities, identifying key stakeholders and target groups, taking action, and finally, monitoring and evaluating the advocacy campaign's effectiveness. There is also a discussion on the challenges that may arise as a campaign is being developed and put into action.

This module focuses on advocacy actions designed to promote the rights of people with psychosocial, intellectual and cognitive disabilities and their families and care partners. These actions need to be dynamic, fluid, and multifaceted and involve many different stakeholders, ideas, agendas, and politics (2) in order to raise awareness and achieve positive outcomes including:

- The prioritization of the rights of persons with psychosocial disabilities, intellectual and cognitive disabilities on government agendas.
- The alignment of policies, plans, and laws with international human rights standards.
- Ensuring that human rights and quality issues are at the core of mental health and related services.

Scenario: Pan African Network of People with Psychosocial Disabilities (PANUSP) advocates for the rights of people with psychosocial disabilities (3)

PANUSP is a regional organization of people with psychosocial disabilities in Africa that is a collective voice to promote and protect the rights and dignity of people with psychosocial disabilities. The organization aims to increase continental solidarity amongst organizations that promote and protect the rights of people with psychosocial disabilities. PANSUP aims to:

- Ensure that member organizations work towards improving the quality of life of people with psychosocial disabilities in Africa so that they may reclaim their dignity and achieve equal rights and opportunities;

- Function as an advocacy mechanism that is dedicated to social justice, human rights, empowerment, social development and full participation and inclusion of all people with psychosocial disabilities in Africa;

- Promote the establishment of national organizations and to support and promote their work and that of existing member organizations;

- Network and build relationships with other civil society organizations, intergovernmental organizations, regional bodies, governments and other relevant institutions and individuals to further its mission; and

- Be an African forum and network for the exchange of knowledge, raising awareness and the promotion of research regarding psychosocial disability.

For more information visit: http://www.panusp.org/advocacy/

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2   Running an Advocacy Campaign

> *The steps below outline how to run an advocacy campaign. A useful form to help guide this process is provided in **Annex 2: Template for planning an advocacy campaign***

Define the advocacy issue

The first step in the advocacy process is to identify the issue. The campaign's priority issue should be specific and concrete. To begin this process it is useful to list all the possible issues (or challenges) identified and expressed by advocacy group members. Members don't need to agree on all of the issues, outcomes and solutions at once.

Next, the group's ideas should be narrowed down to a single issue that campaign members would like to tackle. There might be many things the group would like to address, but by trying to do them all at once the campaign is likely to be less effective.

Strategies for identifying and prioritizing the issues can be found below.

Brainstorming (4)

Brainstorming as part of a group can be a helpful way to identify many of the issues the campaign may want to address. By definition brainstorming is a process of quickly generating as many ideas as possible related to a specific topic within a defined timeframe. Brainstorming may highlight a series of facts related to a particular situation, a list of challenges, or a range of solutions to address a specific issue. In most cases, these ideas need to be substantiated by further research and analysis. The advantages of brainstorming include:

- Quick generation of many ideas or facts related to a particular issue.
- Allowance of ideas and facts to be mentioned without discrimination, even if they are conflicting.
- Bringing people's ideas and opinions together without exclusion, thus building consensus.
- Sustaining focus and using time efficiently, as brainstorming is generally a short time limited exercise.

Prioritisation will also be required in order to identify the key issue that will form the focus of the campaign. One way this can be done is through preference ranking.

Preference Ranking

Preference ranking is a quick method to prioritise different options. It can be used to build consensus on different options leading, for instance, to the identification of common priorities for action. Preference ranking can help people better understand priorities or perceptions about a particular situation or event and it can help the group facilitate a discussion on the reasons for a particular choice or preference. For example, if a group is trying to select the most important advocacy issue to address, a preference ranking would generate a list of options of issues and subsequently have group members rank them according to how important they think each is. Finally the votes can be tallied and a discussion on reasons behind people's preferences can take place in

order to decide which priority issue will be addressed through the campaign.(4)

Examples of priority issues

The advocacy issue should be context-specific. This means that it is related to the specific country and community context. Below are some examples of advocacy issues.

• Lack of human rights protection for people with psychosocial, intellectual and cognitive disabilities in national policies, strategies and laws.

• Poor quality of care and respect for human rights in mental health and related services.

• The need to end institutionalisation and to develop community-based alternatives that are in line with the CRPD.

• Lack of access to community-based services and supports that are compliant with international human rights standards, including the Convention on the Rights of Persons with Disabilities (CRPD).

• Lack of participation of people with psychosocial, intellectual and cognitive disabilities in decision making processes on issues affecting them.

• Discrimination and lack of opportunities for people with psychosocial, intellectual and cognitive disabilities in employment/income generating opportunities, education, housing, etc.

• The need to overcome stigma, myths, and misconceptions about people with psychosocial, intellectual and cognitive disabilities.

• The need to end violence and abuse in mental health and related services.

• Implementing strategies to end the use of seclusion and restraint and other coercive practices in mental health and related services.

• The need to promote informed consent and the right of people with psychosocial, intellectual and cognitive disabilities to make decisions for themselves on issues affecting them.

• Promoting a recovery approach through mental health and related services.

• Ending guardianship for people with psychosocial, intellectual and cognitive disabilities and replacing this with a supported decision making model.

• Ensuring that all decisions about treatment and life choices are based on the will and preference of the individual.

For information on each of these topics, refer to the QualityRights guidance and training materials.

Form partnerships and alliances (5)

Building relationships and partnerships with other people and groups requires an investment of time and effort but is critical to the success of a campaign. Many advocacy groups believe this aspect of their work to be the most difficult, but also the most satisfying.

The development of alliances and partnerships should begin at the early stages of a campaign in order to agree on both the strategy and objectives of the campaign. So at this early point in planning it is useful to hold a meeting of stakeholders in order to build consensus and to develop the advocacy plan.

Specific types of alliances are outlined below:

Networks

A network is a group of people or organizations willing to collaborate and to work with each other. Because networks are informal and fluid, they can be fairly easy to create and maintain. The relationship with each person in the network can be tailored depending on their and the group's working style.

Coalitions (4)

A coalition is a group of organizations that share common interests and work together to achieve a common goal and can be another option for advocacy efforts. Coalitions require far more work than networks, as they are more formal than networks; however, because members of organizations (rather than individuals) are coming together to advocate on an issue the results can be more impactful. Coalition-building should augment, not replace, relationships with existing networks.

Tips for building successful relationships include:

- Offer to help with causes or issues about which stakeholders care (and which do not conflict with the advocacy group's interests);
- Find out how the advocacy group can help stakeholders accomplish their job;
- Be a trustworthy, credible and reliable source of information;
- Be sociable and develop friendships where possible and appropriate; and
- Keep in regular contact and be patient. It takes time to create lasting relationships.

> *Tools for forming partnerships and alliances can be found in Annex 3, Section 3.2: Helpful tools for developing an advocacy campaign: Forming partnerships and alliances*

Conduct a situational analysis on the priority issue

A situational analysis is an assessment of the current situation relative to the priority issue and is fundamental to designing and effectively carrying out advocacy campaigns. The results of a situational analysis help to better understand the internal and external environments impacting the target issue, including, but not limited to the context, target audience, barriers and enablers, and potential solutions. To gather the information needed to complete this analysis, a wide range of activities can be conducted. Some examples include:

- **Observation:** Talk to people, attend meetings, and be familiar with news items in the media.
- **Surveys/Polls:** A series of questions asked in a systematic way to large groups of people. These can be conducted either by the advocacy group or another organization.
- **Focus Groups:** Focus groups provide an in-depth perspective on what people think and why. This method is particularly useful in testing policy messages (To learn more about policy messages see *Develop key messages*).
- **Interviews:** Conduct individual interviews with key representatives if there are not sufficient resources available to conduct a large survey, poll, or focus group. Limit the number of questions to an essential few and be sure that the people being interviewed are truly representative of the target audience.
- **Documentation review:** Read local and international policies, plans, research and program information on the priority issue and/or past advocacy strategies that have been successful (or unsuccessful) in order to gain a better understanding of the issue.

Stakeholders

It is important that a situational analysis includes an analysis of the stakeholders, or those individuals or groups who have an interest in the campaign. This interest may be positive (they support the campaign as it makes their life better or aligns with their own priorities) or negative (they do not support the campaign or it conflicts with their priorities). It is important to gain a good understanding of stakeholders in order to determine who already might have a vested interest in the priority issue and therefore whose participation and support may be crucial to the campaign's success. On the other hand, it is important to identify those stakeholders whose interests and priorities may conflict or even jeopardize the campaign's success in order to prepare for challenges that this may create.

Some examples of types of stakeholders include (4):

- **Audiences**: This refers to the people or group the campaign 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 advocacy issue.
  - *Secondary audiences* are those people who exert pressure on primary audiences to make a decision.
- **Beneficiaries:** Those people who will benefit from the advocacy campaign.
- **Potential partners:** Other advocates who may be able to assist in the campaign.

Often the primary targets will be the policymakers, officials, or others that have the power to make the change a campaign is advocating for. When primary targets cannot be influenced, choose to influence secondary targets. A secondary target is the person/group/etc. that can be influenced and who can then, in turn, influence the primary target. The targets must be specific (e.g., a person, newspaper, department, committee) —"the public" or "the government" are too general and, therefore, not good targets. (5)

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Examples of types of audiences, beneficiaries, and/or partners (2)**:**

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

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Barriers and Enablers

Conducting a thorough situational analysis also includes identifying the immediate opportunities (i.e., enablers) and obstacles (i.e., barriers) which can be key to developing an informed implementation strategy to carry out advocacy actions. Activities that are chosen to overcome barriers identified early on will be more successful than those that have not taken these potential challenges into account. Issues to consider include:

- The overall environment, including potential opportunities and barriers, and levels of public understanding and support for change.
- Current policies or actions in place that support the advocacy actions or that need to be changed in order to support the actions.

- What has been tried before? What has worked and what has failed? Research other advocacy campaigns with similar or related goals to determine what has been successful and/ or unsuccessful. The more informed the campaign is the more success it is likely to have.

Once opportunities and obstacles have been identified a strategy should be set up to address them. For example, if an advocacy group is finding it difficult to interest people in a particular issue, members may want to consider making influential individuals or groups aware of the cause, so they can send out the same message, lobby, and reach a wider audience.(6)

Barriers

Sometimes advocacy groups may find that some specific factors conflict with their campaign's message. In these cases it will be important to develop a strategy for addressing such conflicts. For example, an outdated law may restrict the legal capacity of people with psychosocial, intellectual and cognitive disabilities and can be detrimental to the goals of the campaign. As a result the advocacy campaign may incorporate specific messages and actions to change the existing law. Specific actions or "activities" that advocates may consider carrying out to overcome barriers will be explained later in, *Determine the activities and timeframes*.

Enablers

Whenever possible, advocates should seek to draw upon policies, laws, and/or evidence that help support the implementation of their campaign. For example, some international and regional human rights treaties/instruments impose legal obligations on governments. At the international level these include the UN Convention on the Rights of Persons with Disabilities (CRPD), the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, The Universal Declaration of Human Rights, the UN Convention on the Rights of the Child, and the UN Convention on the Elimination of All Forms of Discrimination against Women.

Specifically, the CRPD reaffirms the key rights that should be afforded to people with psychosocial, intellectual and cognitive disabilities and works to ensure that countries recognize that people with disabilities must be provided the opportunities to live life to their fullest potential, on an equal basis with all other people. The Convention is a legally binding instrument. This means that by ratifying the CRPD, countries are under the obligation to take a full range of measures to ensure that people with disabilities have the same rights as everyone, are treated fairly and equally and are not discriminated against. In regard to the CRPD and other Conventions, advocacy groups can take a number of actions, including urging states to adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in these Convention and modifying or abolishing existing laws, regulations, customs and practices that discriminate against persons with disabilities. To learn more about using international human right instruments in advocacy see later section, *Using international human rights instruments*.

> *For more information on human rights see **Annex 1: Understanding and promoting the rights of people with psychosocial, intellectual and cognitive disabilities, including dementia***

Scenario: Situational analysis of the implementation of the CRPD in the Caribbean Subregion (7)

Background

In a 2009 study published by the Economic Commission for Latin America and the Caribbean (ECLAC) Subregional Headquarters for the Caribbean a strong recommendation was made to conduct a follow-up study to "collect information on the availability of statistical information on persons with disabilities and on the implementation of legislation and policies in order to measure the commitment of governments in the Caribbean region towards the CRPD."

The Situational Analysis

In response, the ECLAC Subregional Headquarters for the Caribbean conducted two surveys in order to assess the current situation of the rights of persons with disabilities in the Caribbean subregion. The first was with government ministries responsible for policies regarding persons living with disabilities and the second was with people with disabilities and directly administered by Disabled Persons Organizations (DPOs), in line with the principle of 'nothing about us, without us'.

The study aimed to provide an understanding of where the Caribbean subregion was in relation to the implementation of the CRPD in order to check compliance and identify discrepancies. Additionally, the study highlighted the specific policies, programmes and other measures related to the rights of persons living with disabilities that were available, as well as access and adaptation issues for persons with disabilities in relation to public facilities and basic services.

Conclusions

The responses from the survey of government and NGOs showed that some progress had been made in certain areas of disability in the Caribbean subregion; however, there were still some areas for where significant improvement was needed.

Several steps to improve the situation for persons with disabilities were identified, including (i) support to several countries to ratify, implement and monitor the implementation of the CRPD, (ii) support in the design of laws that were compliant with the CRPD; (iii) conduct of further data collection and research on the epidemiology of the situation to guide the development and implementation of national and regional policies promoting and protecting the rights of people with disabilities as well as (iv) a range of specific actions regarding education, employment, sexual and reproductive health, and accessibility standards for public facilities for people with disabilities.

To see the full report visit: http://www.addc.org.au/content/resources/20101228-situation-analysis-of-crpd-in-the-caribbean/836/

Formulate the advocacy goal and objectives

Once the situational analysis has been completed and there is more clarity concerning the focus issue, a logical next step is to develop the campaign's specific goal and objectives. It may be helpful to first have group members discuss the different things they would like to change or improve through the advocacy campaign. The group should agree on the broadest change that members want to achieve.(8) Once in agreement the goal can be written down in a clear, one-sentence statement. Keep in mind that most advocacy campaigns aim to produce changes in knowledge, attitudes and/or behaviour (8) or a policy or legislative change. For example, a goal could be "To decrease the stigma experienced by people with psychosocial, intellectual and cognitive disabilities in the community."

From the goal, it is possible to determine the campaign's objectives. Objectives are what need to be met in order to achieve the goal—that is, they must be fulfilled in order for the overall goal to be fulfilled. Objectives should be SMART and thus be (6):

- **S**pecific- the objective is defined, focused, and targeted.
- **M**easurable- the objective has the ability to be monitored and evaluated.
- **A**chievable- the objective is attainable.
- **R**ealistic- the objective can be achieved given the resources available.
- **T**ime-bound- the objective indicates when it will be achieved and ensures that the time to carry out the objective is feasible and manageable.

Note that a campaign's objectives should be realistic and not overly ambitious. The following table provides some examples of objectives for the goal "To decrease the stigma experienced by people with psychosocial, intellectual, and cognitive disabilities in the community."

GOAL: *To decrease the stigma experienced by people with psychosocial, intellectual, and cognitive disabilities in the community.*			
Objective	**Type of change**	**Does it lead to the goal?**	**Is it SMART?**
In one year, increase by 50% the number of health providers and families who believe that people with psychosocial, intellectual, and cognitive disabilities should have the same opportunities to exercise their legal capacity as everyone.	Attitude (from one of exclusivity to one of inclusivity)	Yes—having more people believe in the right to legal capacity for people with psychosocial, cognitive, and intellectual disabilities reduces their categorisation as "other," thereby reducing stigma	**Specific**: Yes **Measurable**: Yes, via surveys **Achievable**: Yes; should be based on community context **Realistic**: Yes; should be realistic based on community context **Time-bound**: Yes (one year)
Increase the number of advocacy groups lobbying to government for a change in legislation within one year.	Structure (from one group to 15 groups)	Yes—the engagement of more advocacy groups on this issue will lead to more awareness and actions to reduce stigmatisation within the community	**Specific:** Yes **Measurable:** Yes **Achievable:** Yes; should be achievable based on community context **Realistic:** Yes; should be realistic based on community context **Time-bound:** Yes (one year)
Increase contact between people with psychosocial, intellectual, and cognitive disabilities and people without by 50% within three months.	Process (from no interaction to interaction that brings people together)	Yes—contact has been proven to reduce stigma	**Specific:** Yes **Measurable:** Yes, via surveys **Achievable:** Yes; should be achievable based on community context **Realistic:** Yes; should be realistic based on community context **Time-bound:** Yes (three months)

Identify targets and indicators

What gets measured is more likely to be implemented. Therefore, once the goal and objectives have been determined, they should be broken down into specific targets and indicators to later assess whether the advocacy campaign has been effective or not.

Targets are what the campaign aims to achieve.

Indicators help assess whether the campaign has achieved its target.

The targets and indicators must be realistic and appropriate. The figure below illustrates how targets and indicators flow from the goal and objectives.
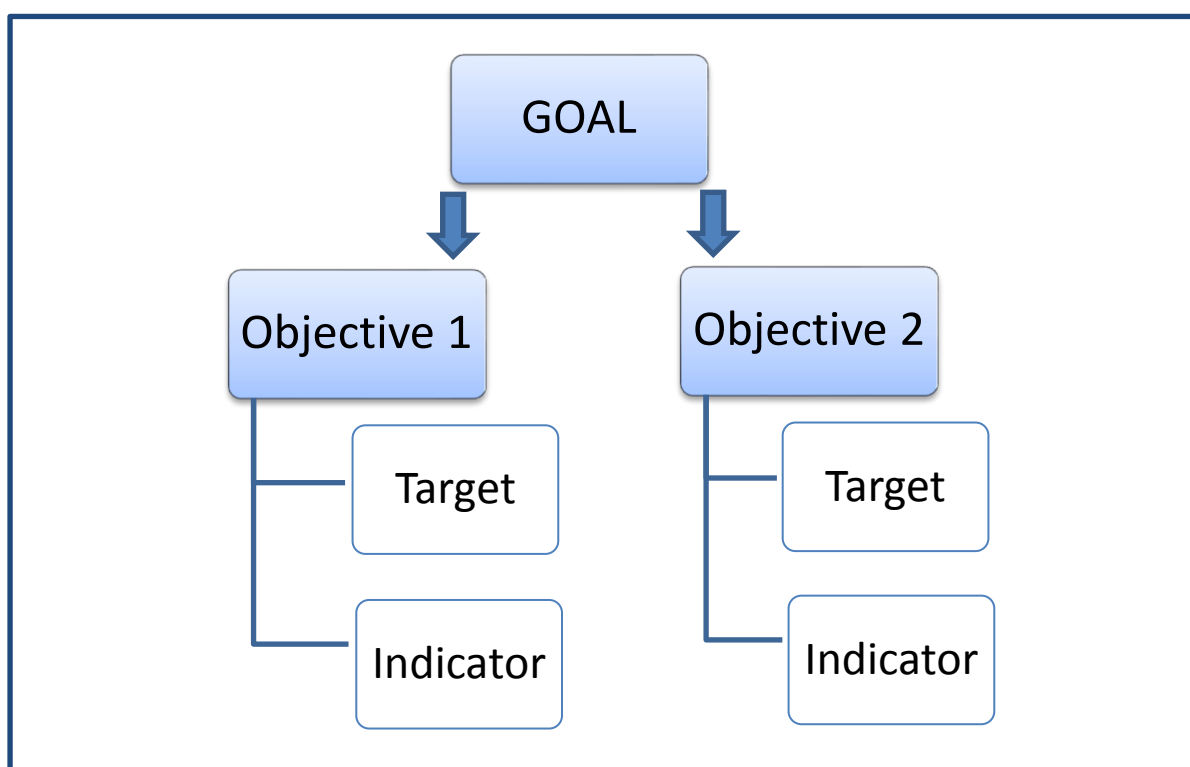
An example of a target and indicator is provided below.

> **Scenario: Mental Health Act, identifying targets and indicators**
>
> *Goal:* *To end the use of seclusion and restraint in mental health and related services.*
>
> *Objective:* To advocate for the revision of the Mental Health Act that currently allows for the use of seclusion and restraint.
>
> *Target*: The Mental Health Act will be revised so that the use of seclusion and restraint is forbidden by January 2017
>
> *Indicator*: Adoption of the revised Mental Health Act by parliament (Yes/ No).

> *A useful form for developing the campaign's goal, objectives, targets, and indicators is provided in **Annex 4: Template for developing the advocacy goal and objectives***

Determine the activities and timeframes (5)

Once the indicators and targets have been identified, it is time to define the specific activities that will be carried out as part of the advocacy campaign.

Activities should be designed to help achieve individual objectives, hence, moving the campaign towards its overall goal. Often it is important to use a combination of different types of activities to create a comprehensive and effective campaign targeting different audiences.

Some key questions to ask when planning activities are:

- What activities are necessary to achieve the campaign's goal and objectives?
- Who will be responsible for each activity?
- Which activities should be done simultaneously and which can only follow the completion of another?
- How long will each activity take?

It is important that for each activity there is also a defined timeframe. Some activities will be continuous, while others will only operate for a limited period. In addition, some advocacy activities might be more impactful if they are timed to occur just before or in conjunction with certain events or announcements related to the campaign's priority issue. Therefore, when carrying out campaign activities it is strategic to think about what events (e.g., conferences, forums, etc.) or important dates (e.g., World Health Day, Human Rights Day, etc.) might be useful to centre these activities around.

Activities will fall into a number of different categories. Below are general types of activities advocacy groups may conduct, and some examples of ways to conduct these. It should be noted that activities may fall into more than one category. Furthermore, the list is meant to serve as a guide rather than a list of prescriptive actions to be followed.

Categories of activities can include, but are not limited to:

- Lobbying governments and politicians
- Creating and generating debate within communities
- Working with the media
- Using the courts
- Using international human rights mechanisms

These categories and some specific examples of activities that frequently fall within each category are described below.

Lobbying governments and politicians

Lobbying governments and politicians is often done by advocacy groups when their goal is to change legislation or policy or to persuade governments to invest more funding into mental health and related services. First it is important to identify the level of government which holds responsibility for the priority issue and the proposed solutions. Each level of government has its own policy development and legislative process; therefore, it is worth considering talking to everyone in the government that may be useful to the campaign. For example, someone who has very little power today may be much more influential (and thus have the ability to help advance the campaign) in the future (9). Public health and human rights issues frequently cross many sectors, so it may be relevant to raise issues with all the appropriate sectors and describe how their activities impact the health and wellbeing of the community.

Relevant tools for lobbying governments and politicians include:

- Writing letters or submissions to politicians
- Petitioning politicians
- Face-to-face meetings with politicians (or with ministers or their staff) and/or policymakers
- Arranging a site visit or study tour
- Providing technical information and recommendations to policymakers (e.g. policy briefs)

These specific tools are discussed in further detail below.

Writing submissions

The aim of a submission is to influence policymakers in order to secure a favourable outcome on the advocacy issue. For example, a group may want to put forward a submission in response to a new or proposed government policy/law and may want to provide recommendations to improve the policy/law. Writing a submission allows advocates to express their ideas to the government, so that people can better understand how the new or proposed policy/law affects the community.

When writing a submission consider including (10):

- An short description of the advocacy group;

- Arguments and opinions on the law or policy;

- Facts and examples; and

- Recommendations – that include solutions to the identified problems.

> ✗ *Tools for writing a submission can be found in Annex 3, Section 3.4: Helpful tools for developing an advocacy campaign: Writing a submission*

Letters to politicians

Writing letters to policymakers can sometimes influence government policy. If all members of a network write to members of parliament at the same time, it can have an even greater impact. **(9)** Keep the following points mind when writing letters to politicians (11):

- Make it clear in the opening that the advocacy group has some knowledge of the individual being contacted.
- Keep letters as concise as possible in order to increase the likelihood that they will be read. One page or less is usually preferred.
- If possible, make letters as personal as possible. Avoid letters that are too "scripted".
- Cover only one issue per letter, as letters that address multiple issues may be less effective.
- Ask the individual being contacted to reply and directly ask if they will support the campaign's position.

> ✖ *Tools for writing letters to politicians can be found in Annex 3, Section 3.5: Helpful tools for developing an advocacy campaign: Letters to politicians*

Writing petitions (4)

A petition targets someone in power, such as a government minister. The petition is signed by as many individuals as possible in order to show support for a specific issue. Petitions can be handwritten or electronic and distributed via the internet.

When submitting a petition, keep in mind that a government official or entity is more likely to respond if the issue is:

- Supported by their constituents (particularly when addressing an elected official);
- Related to pending legislation or a topic of interest to that official; and
- Connected to them in a personal way.

> ✖ *Tools for writing petitions can be found in Annex 3, Section 3.6: Helpful tools for developing an advocacy campaign: Writing a petition*

Face-to-face meetings (9)

Meeting with a policymaker face-to-face can be one of the most effective ways to influence their position on a particular issue. However, be aware that these meetings can be difficult to arrange and may require a great deal of time and effort to organize. If given the opportunity to meet face-to-face with a policymaker there are a few points to keep in mind:

- Schedule the visit in advance;
- Ensure that attending members are well prepared for the meeting and are knowledgeable about the issue and also the individual policymaker;
- Ensure that the meeting is focused and organized (e.g., introduce self, the organization being representing, and the topic to be discussed);
- Listen, gather information, and do not become angry if the policymaker does not provide the desired response; and
- Express thanks and follow up as needed.

Arranging site visits

Arranging site visits can be an effective way to increase the awareness of policy makers, government officials, and other persons of influence of the importance of the priority issue. Site visits can serve a variety of functions depending on the advocacy group's goal and objectives. For example, site visits to several mental health and related services will provide an opportunity for policy makers to see first-hand the urgent need to improve the conditions of services - a situation that may otherwise go overlooked. These visits also create the opportunity for policymakers and officials to develop more personal, emotional connections with the priority issue, hence, opening up opportunities for increased support and possible funding. Site visits can also be used to showcase to government officials projects being carried out in the local community and their impact.

Writing policy briefs (12)

A policy brief is a short summary of a particular issue (or challenge) that includes not only the existing policy options surrounding the issue, but most importantly, recommendations for changes in the policy to best address the target issue. As their name implies policy briefs are generally used to facilitate policy making. Policy briefs are typically informed by current research and follow a prescribed format.

The format generally includes the following 4 main components:

- **Executive summary**- includes a description of the issue and why the existing policy (or approach) should be changed or modified, together with specific recommendations for change
- **Problem importance and context**- includes a summary of the evidence clarifying the extent and nature of the problem and why it is important to address.
- **Critique of the current policy** - includes an overview of the policy and an argument for why this approach is ineffective and what (if any) other policy alternatives exist that may more effectively address the issue.
- **Policy recommendation(s)**- includes recommendations for changing the current policy to make it more effective in addressing the target issue.

When writing policy briefs it is important to make sure that the document is concise and focused, professional, supported by evidence, easy to understand, and practical and feasible to implement. The ultimate outcome of a policy brief is one where the target audience pays attention to the priority issue and implements the recommended action(s) to effectively address the issue.

> ⚒ *Tools for writing a policy brief can be found in Annex 3, Section 3.7: Helpful tools for developing an advocacy campaign: Writing a policy brief*

Creating and generating debate within communities (9)

Creating and generating debate may be initiated for a wide range of advocacy issues. It can occur on a number of levels, including with the government and within the community. Often advocacy groups will use a mixture of activities in order to advocate on the same issue at different levels simultaneously in order to reach multiple sectors and capture the largest possible.

Relevant tools for creating and generating debate within communities include:

- Face-to-face communication and meetings with stakeholders
- Letters to the editor
- Serving on a committee
- Empowering community champions
- Holding events to increase public awareness (e.g., marches, walks, presentations)
- Holding public dialogues and forums (e.g., in churches, faith-based organizations, schools, council meetings)
- Mobilization of groups (community members, public interest groups, etc.) in support of policy change

These tools are discussed in further detail below.

Face-to-face communication and meetings with stakeholders

Face to face meetings with policymakers or other key people in the community can be an ideal opportunity to make the case for an advocacy issue. However, organising opportunities for face to face meetings often requires persistence and creativity since many senior representatives are difficult to reach and have limited time and availability. Some strategies that have proven successful include taking advantage of fortuitous situations, such as talking to a guest speaker after a public event or developing personal connections through networking.

Letters to the editor (9)

Writing a 'letter to the editor' in a newspaper is generally widely read and can provide a timely opportunity. Letters allow readers to respond to recently published articles to express a personal viewpoint or that of the advocacy group or organization. Editors may select letters written by 'ordinary citizens' over ones written by lobby groups; therefore there may be times where it is appropriate that individuals write under their own name as a concerned citizen and other times when showing credentials and the organization represented is necessary or more appropriate.

Scenario: A letter to the Editor of the Irish Times from CBM Ireland CEO Sarah O'Toole (13)

Sir,

It is welcome news to see Minister Fitzgerald at Ireland's recent UPR review committing the government to ratifying the UN Convention on the Rights of Persons with Disabilities (CRPD) by the end of this year. Ireland has signed the convention, and it is now the last remaining EU Member State to ratify it.

The CRPD promotes, protects and ensures the equal rights of people with disabilities, and obliges States to treat people with disabilities as 'subjects' with full legal capacity as distinct from 'objects' to be managed and cared for. In addition to protecting the rights of people with disabilities here in Ireland, the Convention requires the Irish government to ensure that the development aid it spends overseas is inclusive of people with disabilities.

In practical terms, this means that Irish funded overseas development programmes in areas such as health, education and emergency response must ensure that people with disabilities are included and benefit from such programmes.

This year marks the tenth anniversary of the adoption of the CRPD by the UN. By ratifying the Convention, the Irish government is signalling its commitment to a disability inclusive society and to upholding the rights of people with disabilities both at home and in Ireland's overseas development work.

Yours, etc.

Sarah O'Toole

CEO, CBM Ireland

Monaghan

🛠️ *Tools for writing letters to the editor can be found in Annex 3, Section 3.8: Helpful tools to develop an advocacy campaign: Letters to the editor*

Serving on committees

People with psychosocial, intellectual and cognitive disabilities and their families/care partners and other advocates can serve as members on many different types of committees at local and national levels. Examples of committees include: quality improvement committees in hospitals, mental health policy review committees, committees set up to monitor the implementation of the UN Convention on the Rights of Persons with Disabilities, and committees for assessing human rights and quality conditions in mental health and related services. Offering to be a committee member can be a good opportunity to influence decision making and to expand networking opportunities with people who may be able to assist with campaign activities.

Community champions (9)

It may be useful to recognise and showcase individual 'champions' when dealing with a specific issue. Champions can be celebrities, politicians, or well-regarded community members. The role of champions is to inspire and motivate others to join in a group's advocacy efforts. Community champions can be utilized in a variety of ways, including arranging an event or forum where they can publicly support the campaign issue or by profiling their story and campaign support on a website or other social media platform.

Events to increase public awareness

A variety of events can be held in the community to increase the public's awareness of the advocacy campaign's goal. These events can include marches, walks, presentations, rallies, and/or fundraisers. Often, the event will receive more attention and therefore reach a wider audience if it is paired with important calendar dates, events, or announcements related to the priority issue. 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), and International Day of People with Disability (December 3).

Join in celebrating International Day of People with Disability (14)

International Day of People with Disability (IDPwD) is a United Nations sanctioned day that is celebrated internationally. It aims to increase public awareness, understanding and acceptance of people with disability and celebrate the achievements and contributions of people with disability.

The best way to celebrate is for individuals and groups to hold events in their community, organization or business. Celebrating is a collaborative effort between schools, organizations, community groups, businesses and individuals to help break down disability barriers and celebrate abilities. These events create an opportunity to promote human rights for people with disability.

Information on how individuals, groups, and organizations can get involved in the day and break down barriers (both structural and attitudinal) for people with disability can be found at the link below, which includes event ideas, planning tips, and ways to register and promote the event.

To learn more visit: http://www.idpwd.com.au/

Public dialogues and forums (15)

Holding public dialogues and forums is a great way to create a space for the public to not only learn more about the advocacy campaign and its priority issue and activities, but to engage in open discussions surrounding the issue at hand. Forums can be open, such that all community members have the opportunity to share their ideas, thoughts, and opinions or they can be more structured to include keynote speakers and/or a guest panel. Public forums in particular can offer the unique

opportunity to introduce the community to individuals who are highly knowledgeable or passionate about the issue or who may have relevant personal experience (e.g., an individual sharing their lived experience with a psychosocial, intellectual or cognitive disability or a family member and/or care partner).

Some questions to consider when holding a public forum or dialogue include:

- Where will the forum take place?
- What will be the format? Will it be open, semi-structured, or structured?
- What are the forum's main goals and objectives (e.g., to disseminate information, create dialogue, etc.)?
- Will there be a keynote speaker and if so, who will this be and why?
- Who will be responsible for ensuring that the forum runs effectively?

Mobilization of groups (16)

The mobilization of various groups (e.g., community members, public interest groups, coalitions, etc.) can be an effective tool to support policy change. Group mobilization allows a campaign to not only reach various sectors of a community, but encourages these different sectors to come together to address the priority issue. By mobilizing different stakeholders from the start, various groups and sectors of a community are encouraged to take action to facilitate the desired change, which can be a very empowering process. Groups should be mobilized on a continuous basis in order to build and sustain momentum over time. Group mobilization has the potential to garner resources, provide important information to community members, and foster partnerships among various sectors of the community.

Working with the Media (9)

Advocacy groups can use many different types of media to disseminate key messages and generate support- for example, campaigns can use paid media (e.g. advertising via radio and television) or unpaid media (e.g., through editorials, letters to the editor and social media platforms). Success in using unpaid media will depend on the strength of the group's relationship with journalists and producers, and how they have tailored their messages. Journalists and producers often count on receiving good stories that are likely to have wide public appeal so it is crucial to frame key messages in a media friendly way to achieve this. To learn more about developing key messages see section, *Develop key messages.*

Examples of using the media

Scenario 1: *Time to Change* **uses the media to combat stigma** (17)

Time to Change is a programme in England aimed at challenging mental health stigma and discrimination. Below is a picture of their E-campaign.

For more information visit: http://www.time-to-change.org.uk/
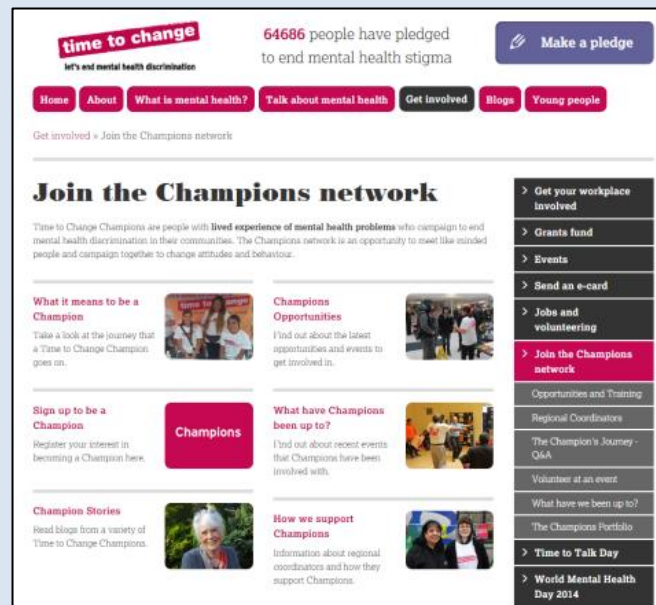
Scenario 2: *I Got Better* **campaign promotes hope in mental health through the media** (18),(19)

MindFreedom International's *I Got Better* campaign aims to challenge the dominant narrative of hopelessness in mental health care by making stories of hope and mental wellness widely available through a variety of media.

The campaign collects personal videos, written stories, and data to support its mission. With this collection of stories and evidence the *I Got Better* campaign intends to spark a new dialogue in society about mental and emotional distress, moving from hopelessness and chronic illness to themes of resiliency, recovery, wellness, and HOPE!

To learn more about MindFreedom visit: http://www.mindfreedom.org/

To learn more about the *I Got Better* campaign visit: http://igotbetter.org/

> ⚒ *Tools on working with the media can be found in Annex 3, Section 3.9: Helpful tools for developing an advocacy campaign: Working with the media*

Relevant tools for working with the media include, but are not limited to:

- Press/ media release

- Interviews

- E-Advocacy via social media (e.g., Facebook, Twitter, Instagram, YouTube, blogs, etc.)

These specific tools are discussed in further detail below.

Press/media release

A press release is a short, catchy story that captures the key points of the advocacy issue in a way that will interest the media and build awareness of and support for the campaign. As mentioned, media coverage of an issue is a useful tool to extend the reach of key messages and gain the attention necessary to increase public awareness of an issue. Specifically, sending a media release to media organizations is an effective way of getting information in the media and provides the opportunity to build good relationships with journalists and other media professionals.

When writing a media release it is recommended to keep the following points in mind (9):

- Be clear and concise (use short paragraphs and keep the press release under one page if possible);
- Ensure that the first paragraph of the release will catch the attention of the target audience;
- Position the most important points near the beginning of the release (e.g., explain who, what, when, where, and why);
- Use clear, easy to understand language;
- Stick to the facts, but give context to the story; and
- Make the release as attention grabbing as possible

Examples of press/media releases

Scenario 1: WHO urges development programmes to INCLUDE People with psychosocial disabilities (20)

People with psychosocial disabilities are among the most marginalized groups in developing countries. Even though development actors have pledged to focus their work on the most vulnerable in a community, many programmes continue to ignore and exclude this vulnerable group.

This is the message of a new World Health Organization (WHO) report on mental health and development - *Targeting people with psychosocial disabilities as a vulnerable group* - which is being launched today at the United Nations in New York.

According to the report, the majority of development and poverty alleviation programmes do not reach persons with psychosocial disabilities. For example, between 75% and 85% do not have access to any form of mental health treatment. Psychosocial disabilities are associated with rates of unemployment as high as 90%. Furthermore people are not provided with educational and vocational opportunities to meet their full potential.

"A greater attention from the development community is needed to reverse this situation", says Dr Ala Alwan, Assistant Director-General for Non-Communicable Diseases and Mental Health at WHO. "The lack of visibility, voice and power of people with mental and psychosocial disabilities means that an extra effort needs to be made to reach out to and involve them more directly in development programmes."

The challenge is enormous. An estimated one in four people globally will experience a mental health condition in their lifetime. Mental health conditions are responsible for a great deal of mortality and disability, accounting for 8.8% and 16.6% of the total burden of disease due to health conditions in low- and middle-income countries, respectively. Depression will be the second highest cause of disease burden in middle-income countries and the third highest in low income countries by 2030.

The report calls for development actors to address the needs of people with psychosocial disabilities in development work by:

- Recognizing the vulnerability of this group and including them in all development initiatives.
- Including people with psychosocial disabilities in income generating programmes and providing social and disability benefits.
- Involving people with psychosocial disabilities in the design of development programmes and projects.
- Incorporating human rights protections in national policies and laws.
- Improving social services for people with psychosocial disabilities.

WHO is working jointly with the UN Department of Economic and Social Affairs (UNDESA) in order to integrate mental health into the development agenda and programmes at national level.

"We need to break down the barriers that continue to exclude persons with mental or psychosocial disabilities" says Mr Sha Zukang, Under-Secretary General of UNDESA. "In order for them to have access to better opportunities and to benefit from the fruits of development, they

must also be involved in the design of policies and programmes related to development."

The WHO report stresses that by investing in people with psychosocial disabilities, development outcomes can be improved.

Scenario 2: Kenyan government must recognise autonomy of people with mental disabilities (21)

"I felt like an animal going to a slaughter and I had no choice."

Yusuf, a man with a psycho-social (mental health) disability from Nairobi.

Tomorrow MDAC will launch a major report in Nairobi shining a light on systemic legal and social barriers to people with mental disabilities being full members of society. Despite Kenya's ratification of the United Nations Convention on the Rights of Persons with Disabilities, the 120-page report "The Right to Legal Capacity in Kenya" sets out widespread stigma and prejudice against those who society regards as "mad" or "of unsound mind".

Atieno, a woman with an intellectual disability from a rural community, described to MDAC how she was sterilised without her consent:

"I will tell you something, you see here (lifts up her blouse and reveals a scar on her abdomen), here I was made an operation. This is contraceptive. All of us had been done like this, we cannot get children. They should have asked me, because I love children."

Ndungu, a man with an intellectual disability living in rural Kenya told MDAC:

"I don't have an ID because of my head. My uncles say it and even I hear it from my grandmother sometimes when she is talking to people."

Launching the report, Oliver Lewis, MDAC Executive Director will say:

"Our report documents human rights violations, including forced sterilisation of women with disabilities, denial of the opportunity to education or employment, forced psychiatric treatment without any due process safeguards, and life-long social isolation. For the first time anywhere in Africa, this report gives voice to the life stories of people with intellectual disabilities and people with psycho-social (mental disabilities)."

In her Foreword to the report, Florence Simbiri Jaoko, former Chairperson of the Kenya National Commission on Human Rights said:

"This report significantly expands the focus of the previous work of the Kenya National Commission on Human Rights by bringing in the perspectives of those directly affected, including carers. In our communities the responsibility for caring for people with disabilities is often entirely on family members, As a result, these dealings are based on private and socially acceptable norms that have no direct reference to legal or human rights standards. It is unsurprising, therefore, that family members – often the carers/providers of basic necessities – believe they should make

decisions for those they care for. As communities and individuals we have collectively hindered the space and opportunities for people with disabilities, through our judgmental and intolerant attitudes."

Key findings of the report are:

1. People with mental disabilities are stripped of their decision-making rights, arbitrarily making them subject to the decisions of officials, family members and healthcare providers.

2. Many experience highly restricted lives due to stigma and negative perceptions. This occurs within families and communities. It means that people are denied access to education and employment. In rural areas where superstitious beliefs are prevalent, the impact on people's lives is more pronounced.

3. Several women with mental disabilities reported that they are victims of sexual abuse. In many cases, authorities failed to take any action.

4. There is no comprehensive national data about the numbers of people with mental disabilities in the country, their socio-economic situation, and about those who require access to support. This means that it is impossible for the Kenyan government to plan actions to improve their lives in a way which respects their dignity and human rights.

The report's recommendations to the Kenyan government include:

1. Abolishing discriminatory laws which strip people with mental disabilities of their rights, including removal of prejudicial language including 'unsound mind', 'mental infirmity' and 'mental incapacity' in conformity with the principle of non-discrimination enshrined in the Kenyan constitution.

2. Combatting informal substituted decision-making by families and communities, and instead, to embrace the latent potential of communities to provide supports.

3. Undertaking public awareness campaigns to tackle social stigma. Campaigns must be designed to broaden knowledge of the human rights of people with mental disabilities, and target negative stereotypes associated with them.

4. Providing national identity documents to all people with mental disabilities, ensuring that none are left undocumented and without the opportunity to exercise their civil and political rights.

5. Protecting people with mental disabilities from all forms of abuse, exploitation and violence.

✂ *Tools for generating a press/media release can be found in Annex 3, Section 3.10: Helpful tools for developing an advocacy campaign: Press/media release*

Interviews (9)

Journalists from radio, television, or newspapers may want to conduct an interview with a member or members of an advocacy group in order to learn more about the advocacy campaign. There are three common types of interviews that advocates often encounter, which include:

- On-the-spot, live requests for comments over the phone or TV.
- A live-to-air radio or television interview in which the broadcast will include everything that is said.
- A pre-recorded radio or television interview which can be edited.

For interviews it is important to be prepared, know the campaign's key messages, and have good knowledge of the research supporting the priority issue and key messages.

> ✖ *Tools for effective interviewing can be found in Annex 3, Section 3.11: Helpful tools for developing an advocacy campaign: Interviews*

E-advocacy and social media

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 campaign activities, such as a press release or letter to a local member or minister on the issue.(9)

E-advocacy via various social media platforms can also assist the campaign by reaching more of the target audience. Social media platforms include, but are not limited to: Facebook, Twitter, Instagram, YouTube, blogs, and others. These platforms can be used to contact, inform, and mobilize a group of people around a particular issue. This strategy has a number of benefits including being low cost (sometimes even free), having the ability to deliver instantaneous messaging to a target audience, and providing the opportunity to monitor a campaign and its effectiveness (including receiving feedback from the target group- for example, through polling or soliciting comments and/or reactions on the target issue).

Different social media platforms will target different audiences, so research into the demographics of platform users can help identify the best fit between campaign activities 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 (22):

- 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).

Examples of using e-advocacy

Scenario 1: Inclusion International's Global Campaign on the *Right to Decide* (23)

Inclusion International is a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities worldwide. Inclusion International envisions a world "where people with intellectual disabilities and their families can equally participate and be valued in all aspects of community life".

As a part of this vision Inclusion International works to develop strategies to raise awareness of key issues affecting the lives of people with intellectual disabilities and their families. Through campaigns and global reports Inclusion International has enabled the voices of people with intellectual disabilities and their families to be heard on issues such as poverty, education, and community inclusion.

Inclusion International launched a Global Campaign on the Right to Decide, which has been an important tool for advancing policy change and awareness at the national and global level on the Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD that asserts that with support all people with intellectual disabilities are able to make decisions and have control in their lives.

As part of this Global Campaign on the Right to Decide, Inclusion International created a video supporting the campaign on YouTube to raise awareness of the campaign's goals and priority issues for promoting the human rights of people with intellectual disabilities.

To view the video visit: http://inclusion-international.org/global-campaign-the-right-to-decide/

Scenario 2: *Breaking the Chains,* e-advocacy efforts to end abuse of people with psychosocial disabilities (24)

Breaking the Chains is an ethnographic photo/film-documentary project about human rights violations against people with mentally illness. *Breaking the Chains* depicts the use of physical restraint and confinement of people with mental illness in Indonesia, a practice known as *pasung* in this country but widespread also in other low-middle income countries.

This campaign contributes to an understanding of *pasung*, the reasons behind its practice, the issues that must be overcome and the social and political activism needed to eradicate this form of

human rights abuse in countries all over the world. Until recently *Pasung* has remained largely undocumented by the international media. The *Breaking the Chains* is a first of its kind documentary which situates *pasung* in the socio-cultural-political situation of Indonesia and gives voice to people with psychosocial disabilities in Indonesia and throughout the world.

The Breaking the Chains campaign also aims to increase awareness and stimulate action and advocacy for human rights on a global level. In addition to photo essays and movie documentaries *Breaking the Chains* uses multiple social media platforms, including Facebook and Twitter to advance their campaign efforts.

To learn more visit: https://movie-ment.org/breaking-the-chains/

Tools for e-advocacy and social media can be found in Annex 3, Section 3.12: Helpful tools for developing an advocacy campaign: E-advocacy and social media

Using the Courts (25)

Strategic litigation (taking cases to court) is one means of advocacy to ensure that human rights in mental health and related areas are legally enforced. Often this is a means to obtaining justice for an individual whose rights have been violated; however its potential impact extends to changes in law, practice, and public awareness. When engaging in strategic litigation in the realm of advocacy, the case should be chosen carefully and thoughtfully, so that it is representative of many other similar cases and can therefore be used to maximum impact. This is important as a favourable ruling on one case will influence the court's decision on subsequent cases both nationally and internationally.

Successful outcomes of strategic litigation can include creating a legal system that promotes and respects human rights for people with disabilities, reforming law that is not in compliance with international human rights standards, ensuring that laws are appropriately understood and enforced, and ensuring that people with psychosocial, intellectual, and cognitive disabilities who have experienced rights violations obtain justice and are not further victimized.

Using the courts is often an overlooked method of advocacy; however, cost and available expertise should be considered before embarking on such a campaign.

Examples of using strategic litigation

Scenario 1: Mental Disability Advocacy Center uses litigation to achieve social change for people with disabilities (25)

The Mental Disability Advocacy Center (MDAC) is an international organization that uses strategic litigation to promote human rights for people with psychosocial and intellectual disabilities.

MDAC works in partnership with organizations (mainly disabled people's organizations and human rights organizations) and lawyers in various countries to develop and litigate cases. These relationships enable MDAC to tap into local expertise, to work with lawyers who maintain contact with clients, and to work with organizations who can use judgments to change and implement laws.

MDAC's research and monitoring programme furthers their strategic litigation by identifying specific rights violations which serves as the basis for reports to which government responses may provide direct evidence. MDAC uses advocacy tactically to make it more likely for judges to decide in applicants' favour, and as a follow-through from successful (and unsuccessful) court judgments. MDAC's capacity-building program supports strategic litigation by strengthening the lawyering skills and specific legal knowledge of attorneys and advocates in order to improve strategic litigation strategies.

For example, the European Court of Human Rights held Russia in violation of numerous human rights of a young man with mental health disabilities. MDAC was responsible for bringing the case before the court.(26)

For more information visit: http://www.mdac.org/en/content/europes-highest-human-rights-court-holds-russia-violated-rights-man-mental-health-disabiliti

Scenario 2: Disability Rights International (27)

The Inter-American Commission on Human Rights of the Organization of American States (OAS) announced its ruling in 2012, on an emergency "precautionary measures petition" filed by Disability Rights International (DRI) and the Office of Human Rights of the Archdiocese of Guatemala City (ODHAG). This petition was filed on behalf of more than 300 children and adults residing at the Federico Mora Hospital in Guatemala City's – a psychiatric facility comprised of a dilapidated collection of buildings adjacent to a large penitentiary facility at the edge of the city. The Inter-American Commission called on the Guatemalan government to take "[i]mmediate preventive measures aimed at protecting all patients, particularly women and children, from physical, psychological and sexual violence by other inmates, guards and hospital staff."

For more information visit: http://www.disabilityrightsintl.org/2012/11/28/inter-american-commission-on-human-rights-orders-guatemala-to-protect-children-and-adults-from-abuses-in-psychiatric-facility/

Using international human rights instruments

A number of international standards, Treaties, and Conventions have been put in place to ensure that the rights of pall people, including persons with psychosocial, intellectual and cognitive disabilities are upheld and respected. Advocacy groups can play a vital role in promoting human rights by engaging directly with the international human rights system and the work of the 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. For example, the UN Convention on the Rights of Persons with Disabilities (CRPD) sets out a wide range of rights for people with psychosocial, intellectual and cognitive disabilities, which include, but are not limited to civil and political rights, the right to live in the community, and the right to education, health, employment and social protection.

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, advocacy groups 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 advocacy group, 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 advocacy groups 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 government 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;
- Work in coalition with other organizations with similar focuses and concerns.

Advocacy groups 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.

Scenario: Using human rights instruments for advocacy- Shadow report on the implementation of the UN CRPD (28)

In 2012, lead disability NGOs in Australia partnered to draft a shadow report on the implementation of the Convention. The first CRPD shadow report was the result of a three year process and of a wide consultation of people with disabilities and of their representative organizations.

Individuals were able to contribute directly to the report by providing information on practical difficulties encountered when exercising their Convention's rights. The report was used by the Committee on the rights of persons with disabilities when issuing comments and recommendations regarding Australia.

For more information visit: http://www.globaldisabilityrightsnow.org/

Tools for implementing activities can be found in Annex 3, Section 3.14: Helpful tools for developing an advocacy campaign: Implementing activities

Develop key messages

Once activities, targets and indicators have been identified it is time to develop the key messages that will be contained within a campaign's activities. The International NGO Training and Research Centre (2008) (29) define an advocacy message as "a concise and persuasive statement about your advocacy objective that captures:

- What you want to achieve;
- Why you want to achieve it – (including the positive or negative consequences of no action);
- How you proposes to achieve it; and
- What action you want taken by the audience**."**

Keep in mind that key messages may be different for different audiences and may be delivered in a variety of forms according to the needs of that specific target audience (e.g., written, verbal, visual, auditory, and other mediums).

Examples of key messages

Scenario 1: CBM uses CRPD and SDG infographic (30)

In February 2016 CBM launched an infographic linking the Agenda 2030 and the Sustainable Development Goals (SDGs) to the UN. The infographic serves to promote the key message of linking disability, human rights, and SDGs. Specifically, the message outlines the important relationship between the SDG Goals and the CRPD and highlights that SDG implementation must be underpinned by ensuring the human rights of all people with psychosocial, intellectual and cognitive disabilities.

To learn more visit: http://www.cbm.org/New-resources-on-Agenda-2030-and-the-CRPD-501728.php
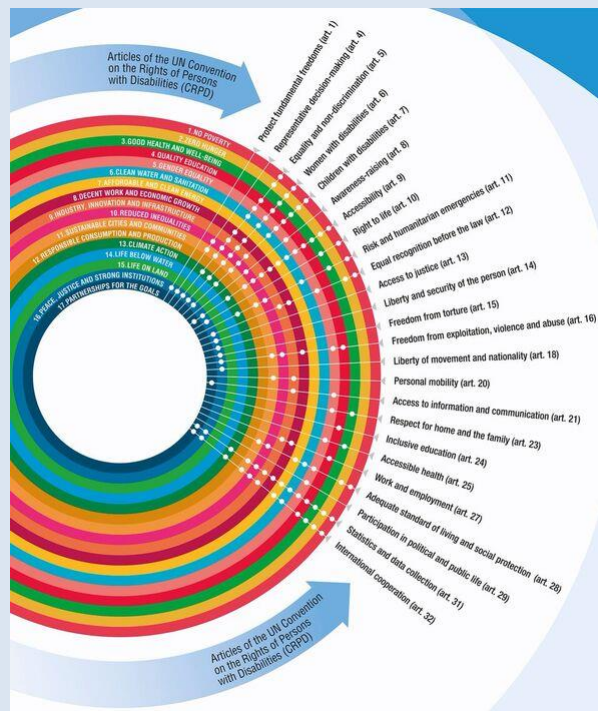
Example 2: QualityRights Gujarat (31)

QualityRights Gujarat aimed to improve the quality of care and human rights of people with psychosocial disabilities throughout the state of Gujarat in western India, through helping mental health services develop a supportive and respectful recovery environment for the people using the service.

In July 2015 the project helped organize an awareness walk and "Flash Quiz" for World Schizophrenia Day, encouraging individuals to spread awareness and carry forward the conversation about the rights of people with psychosocial disabilities. Thanks to the campaign, citizens of Gujarat are being called upon to act, unite and empower for mental health.

To learn more visit: http://www.who.int/mental_health/policy/quality_rights/en

Personal Stories

It should be noted that a powerful component of any message can be the telling of personal stories, as these can be an effective way of making the public aware of the challenges encountered by people with psychosocial, intellectual and cognitive disabilities and/or their families and care partners. Personal stories, therefore, can be incorporated into different forums and can be a particularly powerful component of any campaign activity. For example, personal stories can be written down, published in the media or on websites, or filmed; hence, can be shared through organized talks or panels, readings, or movie screenings. Finding creative ways to incorporate personal stories into key messages of advocacy campaigns is a powerful tool for capturing the attention of target audiences.

When including personal stories it is important to make sure that:

- The person has given consent to tell the story.
- People's names are kept anonymous and non-identifiable where applicable.
- The key message or theme of the story is clear and obvious.

Examples of personal stories

Scenario 1: Dementia: My New World (32)

Below is a personal story from Kate Swaffer, a co-founder and Board member of Dementia Alliance International. Although Kate does not feel desperate now and has gone on to find ways to live well with dementia, through self advocacy and empowerment, she shares her personal feelings after being first diagnosed with younger onset dementia.

"Dementia is an uninvited visitor to my world, an unwelcome early 50th birthday present, one where the old me seems to be rapidly moving away to a new me. I am being dragged along on this journey with no way to get back home as it races along like an express train without brakes. I read then I forget; I read, I take notes, and then I forget; I read, I highlight and take notes, and I still forget. That photographic memory I once had is gone, dead and fully buried. My high functioning mind has slipped away, sometimes showing itself like a ghost, teasing me into believing it will be okay, but just outside of my reach. Words now have no meaning and whole patches of my memory are disappearing.

The mountain I am climbing is finite, but even if I get to the top there will be no grand planting of my flag nor will I have remembered the climb, and when I come down, I won't remember having been there. Some of my friends inform me I am not aphasic, that I am not remembering any less well than they do, that their world is the same as mine. They say I am getting old and this is what it is like, so get used to it. I ask myself, 'What would they know?' They are wrong. It is different...

It is insidiously depriving me of a normal existence, and is very humiliating and awkward to live with, stealing my soul, and threatening my very existence. It makes me nervous to go out. Every day now feels like a brand new one, except that my body feels very old and tired. I realise that writing about my dementia is not an option and that no matter how long it takes to make it legible and worthwhile to read, it is important to the management of this disease. It is possibly the only form of therapy that will ease my stress and tears.

Most days are now an effort not to just sit in a corner and cry, not to just give up or to give in to it. It requires a great amount of emotional effort to live a 'normal' existence and is truly the most demeaning and frightening experience I have had, with a feeling of wretchedness I have not felt before.

This new place is full of hidden and impending madness, full of people already whispering behind closed doors away from my ears, trying to plan for my demise and how I and they will cope. They provide words of comfort and gentle pats on my back, meaning well but never realising it usually makes me feel as like a leper, as if I am to be pitied. They are the ones who will eventually have the challenges of coping, as I will be lost in a world of inhibition and supposed joyfulness, locked out of the reality of the world and its occupants. And so, I keep asking myself am I to be the lucky one in this strange place called dementia. Perhaps so."

Scenario 2: The Right to Legal Capacity in Kenya: Atieno's Story (33)

In early April 2014 MDAC released "The Right to Legal Capacity in Kenya". The report highlights the voices of people with psychosocial disabilities themselves for the first time, outlining the need for substantial legal and social reform, and provides comprehensive recommendations to bring Kenya in line with international law, and specifically right to legal capacity guaranteed by Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD). The report exposes deeply-rooted oppression of people with intellectual and psycho-social disabilities, urging the Kenyan government to take practical actions to address widespread social stigma which restrict the daily lives of people with mental disabilities. A number of key documents were included in this report including personal stories one of which was from Atieno, a women with an intellectual disability living in Kenya.

Scenario 3: MindFreedom Personal Story Project: Beate's Story (34)

The MindFreedom Personal Story Project collects histories from psychiatric survivors and mental health consumers about their experiences of survival, resistance, recovery and self-determination in the mental health system. Below Beate Braun shares her personal story.

"I've spent about ten years of my life in and out of psychiatric hospitals. I've been out for two years now, and I feel strongly that the hospital did me more harm than good. When I was first labeled with chronic schizophrenia, I felt down, down, and once more down. The worst part of being in the hospital was probably the forced drugs. Two or three times a day the hospital staff would

come with the needle and give me shots of strong drugs. The drugs were so strong that I would bite my lips and fall to the ground. The forced drugs caused me to have these awful convulsions. When I would complain, the doctor told me that I was lying, I didn't have convulsions, and wouldn't do anything to help me. I felt so helpless. If you are diagnosed with schizophrenia, they talk with you like you are not there. They talk about you but not with you, but you have to hear it. But if you really want to talk, the doctors and nurses in the hospital don't have time for a conversation. One of the sad things is, they couldn't have done what they did to me without the state's approval. They had to get approval from a judge to force these drugs on me. Right now, my dose of Risperdal is not too much. I take care of myself by taking a tour with my bicycle for 20 kilometers a day. I take a walk with my dog, to hold the drugs as low as possible. I don't drink or smoke, or take other drugs anymore either, which helps. One thing that really helped me was never believing I was ill. I'm just a human being like everybody else. As I get older, I'm becoming more interested in spirituality books and things, and having more fun at life. I paint oil pictures on canvas about mystic themes and I read about other artists.   I feel my social activism is just beginning. I now read two books a month about organizing, etc. It's good for my soul."

Identify resources and funding

Once each activity has been outlined and developed, it is then necessary to cost them to ensure that appropriate funding to cover the implementation of these activities is available.

First, the resources needed to carry out desired activities need to be determined. These may include:

- Activity costs (e.g., video, printing, design, website, use of media, meetings)
- Administration costs (e.g., photocopying, email, computer)
- Travel costs (e.g., airfares, accommodation,, transportation to and from meetings)
- Physical space (e.g.,)
- Dissemination costs(e.g., email, mail, phone)
- Refreshments

Next, each resource and/or activity should be costed to come up with the overall cost of the campaign. Finally, the way in which the required resources will be financed needs to be considered, including an understanding of what existing financing is already available, and what realistic options exist for finding additional resources.

Examples of potential funding sources include:

- Donor agencies and philanthropic organizations(e.g., providing grants)
- Local NGOs and health services (e.g., providing office space or meeting rooms for free)
- Local businesses (e.g., donating services or items, such as refreshments or prizes)

If the overall cost to implement campaign activities is not sufficient, , it may be necessary to come up with new, more cost-effective activities or at least prioritize those activities which are most important to carry out and which will have the largest impact.

3   Take action: Implement, monitor, and evaluate

It is important to review of all of the previous steps before putting the campaign into action.

Additionally, unexpected circumstances can arise when implementing a campaign (both good and bad), which might mean going back and revising the plan accordingly. This will require a thorough review of all of the campaign components previously mentioned. For this review process asking the following questions may prove helpful:

- Is there sufficient funding to carry out campaign activities?
- Are the objectives realistic? Timely?
- Is there sufficient support to carry out the campaign?
- Have strong partnership and alliances been developed?
- Are the campaign activities directly related to the goal and objectives?

Changes that might be required include scaling down activities or just focusing on one activity initially, and the other later. For example, a group may have devised a comprehensive e-advocacy campaign, but later learn that they do not have enough volunteers to regularly monitor and update all of their chosen social media platforms (website, Facebook, and Twitter). Once realized, they may decide to scale down their e-advocacy efforts by only using a Facebook page which they can update on a regular basis. Additionally, an advocacy group may have decided to visit all senior government officials, but later learn they do not have sufficient funding to cover travel costs. As a result, they decide to conduct a fundraising initiative in order to secure necessary funding to cover travel costs.

Remember that running an effective advocacy campaigns is not easy and even with a great deal of motivation, good planning and organization, success is not guaranteed.

Some examples of challenges for implementation that may arise include:

- *Credibility issue*: Despite being someone with a psychosocial, intellectual and cognitive disability or a family/care partner, and thus holding key expertise on issues related to mental health and human rights, in many cases mental health and related practitioners may fail to appreciate this expertise and continue to judge themselves as experts on the needs of people with psychosocial, intellectual and cognitive disabilities and families/care partners. Don't be discouraged; however, as creditability will build over time, from the small wins and through relationships developed with others.
- *Lack of support*: Some advocacy campaigns are not effective because they are not supported by enough stakeholders. Sustainability of advocacy activities is increased through organizational support. Advocacy campaigns are more effective when the cause is a collective one and when individuals are supported by a strong organization.

- **Resistance to change**: For many people, acceptance of change is challenging and this includes the many issues that people with psychosocial, intellectual and cognitive disabilities face or those that families and care partners may be advocating for. It is important to not lose sight of the small incremental changes that can occur over time. Eventually, these can add up to produce larger, more visible improvements.
- **Stigma and discrimination**: There is still a lot of stigma and discrimination in the community towards people with psychosocial, intellectual, and cognitive disabilities. Information and education will contribute to reducing prejudice but competing pressures will lessen their impact. Only over time will community attitudes move positively towards non-discrimination. Advocacy activities need to match and address both the tendencies of people to discriminate and the prevailing community views held about social justice.
- **Political support**: Sometimes, a good cause is undermined by the lack of political will. A good idea can be just too challenging for the time or situation. With this in mind the issue to be addressed needs to be carefully selected and paired with key events and opportunities to promote key messages.
- **Continuity:** Advocacy requires long term efforts and motivation. Over time, people may lose interest in a cause. That is why advocates need to be in it for the long haul.

Monitor and evaluate

As mentioned earlier, advocacy campaigns are expected to produce changes in knowledge, attitudes and behaviour or changes at the level of policy and law. Monitoring and evaluation become crucial to understand whether the campaign has had its intended impact. This includes, but is not limited to, measuring whether identified targets have been reached according to the indicators defined in the campaign plan (see section, *Identify targets and indicators*).

The following questions should be considered when conducting the evaluation.(2)

- Did message(s) reach the target audiences?
- How did the audience respond to the key message(s)?
- Were the partnerships/members/coalitions successful in gaining attention to the issue and building support for the advocacy objective?
- Were the targets met according to the predefined indicators?
- What was the impact and outcome of the campaign?
- Have the objectives been achieved?

Scenario: Evaluation of 'see me' -the national Scottish campaign against mental health stigma and discrimination (2)

To address the negative attitudes and behaviors which systematically disadvantage people with psychosocial disabilities and those close to them, the 'see me' campaign was launched in October 2002 in Scotland, with the purpose of tackling the stigma and discrimination experienced by people with psychosocial disabilities.

The 'see me' campaign had five core objectives:

- To tackle stigma and discrimination by raising public awareness of how both affect individuals with psychosocial disabilities, and by improving public understanding of mental health.
- To challenge individual incidents of stigma and discrimination.
- To involve people in anti-stigma activities across Scotland at national and local levels and across sectors and communities of interest.
- To ensure that the voices and experiences of people with psychosocial disabilities and their families/ care partners are heard.
- To promote a culture of learning and evaluation through all its work, so that effectiveness can be demonstrated.

The campaign evaluation had five objectives:

- To examine how the campaign was established, funded, and developed- including how activities were chosen and what factors affected the ongoing development and focus of activities over time.
- To assess the effectiveness of the campaign in its ability to reach the target audience, raise awareness about stigma and discrimination, and change attitudes towards people with psychosocial disabilities.
- To assess whether and how the practice of media professionals had changed in relation to the reporting of mental health issues since the launch of the 'see me' campaign.
- To explore the experiences of 'see me' media volunteers in relation to their involvement in the campaign.
- To identify and consider ways in which anti-stigma and discrimination work could be taken forward in Scotland, including what the key objectives and activities should be and where such work might be carried out, through consultation with key stakeholders.

To meet these aims and objectives, the evaluation used a combination of primarily qualitative methods. These included documentary analysis, face-to-face and telephone interviews, workshops and surveys. The participants represented a broad range of actual or potential stakeholders, including people with psychosocial disabilities and their families and/ or care partners, government stakeholders, media professionals, voluntary organizations and other organizations and agencies with a role in helping to tackle the stigma and discrimination experienced by people with psychosocial disabilities. To learn more visit: https://www.seemescotland.org/

Annexes

Annex 1: Understanding and promoting the rights of people with psychosocial, intellectual and cognitive disabilities, including dementia

A number of international standards, treaties, and conventions have been put in place to ensure that the rights of persons with psychosocial, intellectual and cognitive disabilities are upheld and respected.

The international human rights framework

The international (United Nations) and regional human rights frameworks represent an important means of promoting and protecting the rights of people with psychosocial, intellectual and cognitive disabilities. Human rights are afforded to *all* people on the basis of their humanity and consequently people with psychosocial disabilities, intellectual and cognitive disabilities are also entitled to the enjoyment of the same human rights on an equal basis with others.

Key UN and regional human rights treaties	
United Nations treaties	**Regional treaties**
❖ Convention on the Rights of Persons with Disabilities (CRPD) http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx ❖ Universal Declaration of Human Rights http://www.un.org/en/documents/udhr/ ❖ International Covenant on Economic, Social and Cultural Rights (ICESCR) http://www.ohchr.org/en/professionalinterest/pages/cescr.aspx ❖ International Covenant on Civil and Political Rights (ICCPR) http://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx ❖ Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or	❖ African Charter on Human and Peoples' Rights http://www.achpr.org/instruments/achpr/ ❖ American Convention on Human Rights http://www.oas.org/juridico/english/treaties/b-32.html ❖ Additional protocol to the American Convention on Human Rights in the area of Economic, Social and Cultural Rights http://www.oas.org/juridico/english/treaties/a-52.html ❖ Inter-American Convention on all Forms of Discrimination Against Persons with Disabilities http://www.oas.org/juridico/english/treaties/a-65.html ❖ Inter-American Convention to Prevent and

Punishment (CAT) http://www.ohchr.org/EN/ProfessionalInterest/Pages/CAT.aspx	Punish Torture http://www.oas.org/juridico/english/treaties/a-51.html
❖ Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) http://www.un.org/womenwatch/daw/cedaw/cedaw.htm	❖ European Convention for the Protection of Human Rights and Fundamental Freedoms http://conventions.coe.int/treaty/en/treaties/html/005.htm
❖ Convention on the Rights of the Child (CRC) http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx	❖ European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment http://www.cpt.coe.int/en/documents/ecpt.htm

International human rights law place duties on governments to a) respect human rights, that is, refrain from infringing on rights; b) Protect human rights, that is, states have a duty to take action to prevent violations by third parties; and c) fulfil human rights, which requires states to adopt appropriate legislative, administrative budgetary, judicial and other measures to promote human rights.

The major international human rights instruments within the UN system, known collectively as the International Bill of Rights, are: the Universal Declaration of Human Rights (**UDHR**) adopted in 1948; the International Covenant on Economic, Social and Cultural Rights (**ICESCR**) and the International Covenant on Civil and Political Rights (**ICCPR**) both adopted in 1966.

The Universal Declaration of Human Rights: The UDHR states that all humans are "born free and equal in dignity and rights." Among the rights enshrined under the UDHR are several that are of particular relevance to people with psychosocial, intellectual and cognitive disabilities. These include the rights to equality before the law; to freedom from torture and cruel, inhuman or degrading treatment; the right to employment and to remuneration ensuring "an existence worthy of human dignity" and the right to education. Many of these most basic rights are routinely denied to people with mental disabilities. The two International Covenants (the ICESCR and the ICCPR) address many of the same rights found in the UDHR but in some instances expand them significantly.

The International Covenant on Economic, Social and Cultural Rights: The ICESCR elaborates on a number of economic, social and cultural rights. For instance, Article 12 requires governments to recognize and take steps to respect, protect and fulfil the right of everyone to the highest attainable level of physical and mental health. In recognition that economic and social rights, including the right to health, are more likely to require the investment of resources and to require government planning and reform (e.g. to reform laws, policies and practices) the ICESCR creates a requirement of progressive realization - this creates *immediate* obligations on governments to take deliberate,

concrete and targeted steps to bring about the full enforcement of the rights recognized under the ICESCR. However, there are aspects of the ICESCR which also create immediate obligations on States Parties to the convention (for example, the principle of non-discrimination has immediate effect).

The International Covenant on Civil and Political Rights: The ICCPR also contains important rights relevant to people with psychosocial, intellectual and cognitive disabilities. These include the right to freedom from torture and cruel, inhuman or degrading treatment or punishment, the right to liberty and security of person, the right to recognition as a person before the law, right to privacy, the right to take part in the conduct of public affairs, vote and stand for election, the right to marry and found a family, as well as freedom of thought, conscience and religion among others.

Governments that ratify human rights instruments have a legal obligation to take actions that protect the fundamental human rights of people with mental disabilities and the International Bill of Rights contain important norms and principles which need to be considered in the design of mental health laws, policies, services and strategies. The vast majority of countries around the world have ratified one or both of the Covenants.

In addition to the ICCPR and the ICESCR, the UN human rights system includes five other important legally binding human rights treaties: The Convention on the Elimination of All Forms of Racial Discrimination (1963); the Convention on the Elimination of All Forms of Discrimination Against Women (1979); the Convention on the Rights of the Child (1989); the Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (1984); and the UN Convention on the Rights of Persons with Disabilities (2006) (discussed in detail below). Each of the legally binding UN treaties has its own monitoring body established to oversee Member State compliance with the instrument.

The UN Convention on the Rights of Persons with Disabilities

In 2008 the UN Convention on the Rights of Persons with Disabilities (CRPD) (35) came into force. The Convention sets out a wide range of rights including, among others, civil and political rights, the right to live in the community, participation and inclusion, education, health, employment and social protection. It's coming into force marks a major milestone in efforts to promote, protect and ensure the full and equal enjoyment of all human rights of persons with disabilities.

The CRPD does not create new rights, rather it specifies measures to ensure that people with psychosocial, intellectual and cognitive disabilities can equally access all of the fundamental rights already stated in previous international conventions.

Key rights within the CRPD include:

- ***The right to live independently and be included in the community (Article 19)***
  Article 19 states that people with disabilities have the right to live in the community and that governments must take effective, appropriate measures to facilitate their full inclusion and participation in society. It further states that people have the right to decide where and with whom they live; they must not be obliged to live in a particular living arrangement. Article 19 also states that people must be given access to a range of in-home, residential and other community support services, including the personal assistance necessary to support living

and inclusion in the community, and to prevent isolation or segregation from the community. The concepts of inclusion and participation outlined in Article 19 are further articulated in other articles of the Convention, including those on the rights to education, to work and employment and to participation in political, public and cultural life and in recreation, leisure and sport.

- ***The Right to Equal Recognition before the (Articles 12).***
  Article 12 of the CRPD states that people with disabilities have the right to recognition everywhere as persons before the law. It also re-asserts the rights of people with disabilities to exercise their legal capacity on an equal basis with others in all aspects of life. They must therefore remain central to all decisions that affect them, including about their treatment, where they live and their personal and financial matters. Article 12 also states that, when needed, people should be given support in exercising their legal capacity. This means that they should have access to a trusted person or group of people, who can explain issues related to their rights, treatment and other relevant matters and who can help them to interpret and communicate their choices and preferences.

- ***The right to personal liberty and the security of person (Article 14).***
  Article 14 of the CRPD states that people with disabilities must not be deprived of their liberty unlawfully or arbitrarily, that any deprivation of liberty must be in conformity with the law and that the existence of a disability shall in no case justify deprivation of liberty.

- ***Freedom from torture or cruel, inhuman or degrading treatment or punishment (Article 15)***
  Article 15 requires that all appropriate measures be taken to prevent people with disabilities from being subjected to torture or cruel, inhuman or degrading treatment or punishment. This Article also states that no one must be subjected to medical or scientific experimentation without his or her free consent.

- ***Freedom from exploitation, violence and abuse (Articles 16)***
  Article 16 requires that all measures be taken to protect people against and prevent all forms of exploitation, violence and abuse. This Article also requires that all appropriate measures be taken to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of people with disabilities who become victims of any form of exploitation, violence or abuse, including by the provision of protection services. In addition, recovery and reintegration must take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs. Importantly also, Article 16 requires that all facilities and programmes designed to serve people with disabilities be effectively monitored by independent authorities.

To see the full range of rights covered by the CRPD go to:
http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx

Annex 2: Template for planning an advocacy campaign (36)

This template will help advocates plan an advocacy campaign. This template covers all the steps outlined in this module.

Priority Issue

The advocacy issue should be specific and concrete. It should clearly reflect the policy change that the advocacy group aims to achieve (i.e., the issue should be directly linked to the goal).
What is the priority issue?

Partnerships & Alliances

Forming strong partnerships with other groups/organizations is essential to a successful advocacy campaign. It is important to identify partners who will bring helpful, unique skills and contributions to the campaign effort. Make sure that potential partners are in agreement about the issue and its potential solutions. A stakeholder forum is a good way to build consensus.

Identify 5–10 potential partners and what they can contribute to the advocacy initiative. Also include the advocacy group's representative organization and its resources in this list.

Potential partner	Contributions (human resources, funding, political and media connections, advocacy, communications, technical expertise, etc.)

Situational Analysis

A situational analysis helps advocates to understand the situation, problem, context, target audience, barriers, enablers and potential solutions. Consider the following when conducting a situational analysis:

Situational Analysis	Description	Purpose and/or relevance to the campaign
Activities		
Observation		
Surveys/polls		
Focus groups		
Interviews		
Documentation review		
Stakeholders		
Barriers		
Enablers		
Tools*:		
WHO QualityRights tool kit		
Problem & Solution tree		
Gap analysis		
Duty Bearers analysis		
SWOT analysis		
Other		

* For information on these tools see Annex 3, Section 3.3: *Tools for developing an advocacy campaign: Carrying out situational analyses*.

Goal

The advocacy goal builds on the priority issue and should be a clear, concise one-sentence statement. Remember that most goals aim to produce changes in knowledge, attitudes and/or behaviour. Be sure to set a goal that is attainable and realistic.
What is the campaign goal?

Objectives

The goal can be broken down into a few shorter-term objectives that will directly contribute to achieving the goal. Objectives are the smaller steps that must be completed in order to reach the overall goal. Objectives should be clear and focused, and should include: the change advocates desire to see, who (e.g., person, institution, office) will make the change, and when it will be achieved. Note: If the objective is likely to take longer to achieve than the goal, it is not a good objective.
What are the objectives?
Objective 1
Objective 2
Objective 3
Other Objectives

Audience

Identify the primary audience for each objective. Then fill in the audience's position on the issue based on 2 criteria: supportive/neutral/opposed, and informed/uninformed. Next, note which organization/partners have the connections needed to influence each primary target. If the connections needed to influence the primary target do not exist, choose a secondary target (who can influence the primary) and fill in same the information in the Secondary Audience table.

Objective 1

Primary audience name	Position on priority issue	Partner with connections to influence target

Objective 2

Primary audience name	Position on priority issue	Partner with connections to influence target

Objective 3

Primary audience name	Position on priority issue	Partner with connections to influence target

Secondary audience

Objective #	Name	Secondary audience it can influence	Position on priority issue	Partner with connections to influence audience

Date(s) of key opportunities

Advocacy activities should be timed to occur just before key decisions are made or before an important event. *What upcoming events, significant dates, or government decisions might be important mobilization and communication opportunities?*

List of Key Events and/or Opportunities:

Activities

Advocacy activities should be designed to help achieve individual objectives, moving the campaign toward its goal.

Fill out the chart below to determine which activities will be carried out to meet the objectives. For each activity, determine the approximate timing. Timing will depend on each activity's priority. Do not try to do everything at the same time. Identify the cost of the activity and the person/organization primarily responsible for leading it, along with partners who will support them.

Be as detailed as possible regarding specific plans and tactics, including how they will reach the targets. For example, do not just write "public awareness campaign"—include the topic of the campaign, who it target, what forms of media will be used, etc.

Objective 1:

Target:

Indicator:

Activity	Lead person/organization	Partner(s)	Timing	Cost

Objective 2:

Target:

Indicator:

Activity	Lead person/organization	Partner(s)	Timing	Cost

Objective 3:

Target:

Indicator:

Activity	Lead person/organization	Partner(s)	Timing	Cost

Key Messages

What are the key messages for the target audience(s)?

Target Audience(s)	Key Message

Resources

What resources are needed for each of the identified activities?

Activities	Resources Needed

Annex 3: Helpful tools for developing an advocacy campaign

This annex lists a number of tools that can be used when developing an advocacy campaign.

3.1 Defining the advocacy priority issue

-> To learn more about how to define advocacy priority issues see the *Self Advocacy Tool Kit for Mental Health Services Users* (4) at
http://www.cbm.org/article/downloads/54741/The_Self_Advocacy_Toolkit_-_For_Mental_Health_Service_Users.pdf

3.2 Forming partnerships and alliances

-> For an overall toolkit on guidance for creating a partnership among different organizations to address a common goal, including networking and coalition-building, see the *Community Tool Box* (37) at http://ctb.ku.edu/en/creating-and-maintaining-partnerships.

-> For guidance on increasing participation and engaging stakeholders in change efforts visit (4) http://ctb.ku.edu/en/increasing-participation-and-membership. This page includes information on discerning why increased participation is needed, identifying stakeholders who may be interested in joining the campaign, and addressing unmet or underrepresented needs of the campaign.

-> An **Allies and Opponents Map** is a tool that identifies who among a group's stakeholders promotes or threatens their plans or activities. It is useful to understand perceptions within the group about what each partner brings to the advocacy campaign, as well as people, groups or organizations that may be threats to the success of the campaign. For more information on allies and opponents maps visit page 54 (4):
http://www.cbm.org/article/downloads/54741/The_Self_Advocacy_Toolkit_-_For_Mental_Health_Service_Users.pdf

3.3 Carrying out a situational analysis

-> The **WHO QualityRights assessment tool kit** (38) can be used to provide a situational assessment of the quality of care and human rights conditions in mental health and related services.
It provides practical guidance for:

- Preparing for and conducting a comprehensive assessment of services; and
- Reporting findings and making appropriate recommendations on the basis of the assessment.

The tool kit can be used by many different stakeholders, including advocacy groups, assessment committees, NGOs, national human rights institutions, and others to monitor the implementation of

human rights standards and promote and uphold the rights of people with psychosocial, cognitive and intellectual disabilities.

For more information visit:
http://www.who.int/mental_health/publications/QualityRights_toolkit/en/

-> Developing a **problem and solution tree** can be a useful tool when carrying out a situational analysis. A problem and solution tree provides a comprehensive picture of all the known causes and effect to an identified problem and can be a helpful tool when developing a visual structure of the solutions and how these can impact change. To learn more visit page 19 (39):
http://www.unicef.org/evaluation/files/Advocacy_Toolkit.pdf

-> A **gap analysis** is a tool is used to identify current gaps (issues) and steps to improving the situation. This is a good pre-planning tool for developing a future action plan. To learn more see page 75 of the *The Self Advocacy Tool Kit for Mental Health Services Users* (4):
http://www.cbm.org/article/downloads/54741/The_Self_Advocacy_Toolkit_-_For_Mental_Health_Service_Users.pdf

-> A **Duty Bearers Analysis** is a tool that helps advocacy groups analyse influential people, their institution, their roles and responsibilities, their capacity and available resources, the type of power they hold, and their potential help for the campaign's advocacy initiative. This exercise is beneficial for identifying the needs to be accessed and why. For more details see page 48 of *The Self Advocacy Tool Kit for Mental Health Services Users* (4):
http://www.cbm.org/article/downloads/54741/The_Self_Advocacy_Toolkit_-_For_Mental_Health_Service_Users.pdf

-> A **SWOT analysis** is a tool used to identify areas where improvements can be made. It looks at both the internal and external environment. SWOT stands for strengths, weaknesses, opportunities and threats. It is presented in a square with four quadrants. For more information visit page 8 of the *People's Peace-making Perspectives Project: Advocacy Capacity Building: A training Toolkit* (40) available at: http://www.c-r.org/sites/default/files/AdvocacyCapacityBuildigToolkit_201110.pdf

3.4 Writing a submission

-> To learn about the steps in writing a submission to government read the information sheet by the Mental Health Legal Centre Inc. that can be accessed at (41):

https://www.google.ch/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CB0QFjAA&url=http%3A%2F%2Fwww.ourcommunity.com.au%2Ffiles%2FOCP%2FTipsForMakingASubmi

ssion.doc&ei=D6tHVOeXHJDLaMargJAN&usg=AFQjCNHdc8NhdC-eaw329cWoZ-ZYycwp4A&bvm=bv.77880786,d.bGQ

3.5 Letters to politicians

-> To learn more about the structure of writing a letter to a politician see page 56 of the *Advocacy in Action: A toolkit for Public Health Professionals* (9) at: http://www.phaiwa.org.au/wordpress/wp-content/uploads/2015/08/PHAIWA-Advocacy-in-Action-Toolkit-3rd-Edition.pdf

3.6 Writing a petition

->For details on how to write a petition visit the Self Advocacy Tool Kit for Mental Health Services Users (page 68) (4) at: http://www.cbm.org/article/downloads/54741/The_Self_Advocacy_Toolkit_-_For_Mental_Health_Service_Users.pdf

3.7 Writing a policy brief

-> For detailed information on how to write an effective policy brief see (12): https://www.pep-net.org/sites/pep-net.org/files/typo3doc/pdf/CBMS_country_proj_profiles/Philippines/CBMS_forms/Guidelines_for_Writing_a_Policy_Brief.pdf

3.8 Letters to the editor

-> To learn more about the structure of writing a letter to the editor visit page 64 of the *Advocacy in Action: A toolkit for Public Health Professionals (*page 62) (9) at: http://www.phaiwa.org.au/wordpress/wp-content/uploads/2015/08/PHAIWA-Advocacy-in-Action-Toolkit-3rd-

3.9 Working with the media

-> For more information on media relations see page 71 of the *Self Advocacy Tool Kit for Mental Health Services Users* (4) that can be found at: http://www.cbm.org/article/downloads/54741/The_Self_Advocacy_Toolkit_-_For_Mental_Health_Service_Users.pdf

3.10 Press/media release

-> To find useful hints and tips on writing a successful press release visit page 50 of the *Public Health Advocacy Toolkit 2007* (42) available at: http://www.cieh nireland.org/uploadedFiles/core/policy/public_health_advocacy_toolkit_07.pdf

-> For additional information on media releases see page 49 of the *Advocacy in Action: A toolkit for Public Health Professionals* (42) that can be found at: http://www.phaa.net.au/documents/100114PHAIAdvocacyToolkit%202ndedition.pdf

3.11 Interviews

-> To learn more about the structure of interviews visit page 60 of the *Advocacy in Action: A toolkit for Public Health Professionals* (9) at: http://www.phaiwa.org.au/wordpress/wp-content/uploads/2015/08/PHAIWA-Advocacy-in-Action-Toolkit-3rd-Edition.pdf

3.12 E-advocacy and social media

-> For more information on using social media for e-advocacy visit The Community Tool Box's *Using Social Media for Digital Advocacy (37)* at: http://ctb.ku.edu/en/table-of-contents/advocacy/direct-action/electronic-advocacy/main

3.13 Strategic litigation

-> The Global Initiative for Economic, Social and Cultural Rights website (43) provides additional information on strategic litigation and legal advocacy. To learn more visit: *http://globalinitiative-escr.org/strategic-priorities/strategic-litigation-and-legal-advocacy/*

3.14 Implementing activities (37)

-> To learn more on implementing campaign activities visit the *Community Tool Box: Developing an Intervention* at http://ctb.ku.edu/en/developing-intervention and *Conducting a Direct Action Campaign* at http://ctb.ku.edu/en/table-of-contents/advocacy/direct-action

Annex 4: Template for developing the advocacy goal and objectives

Below is a blank template that provides guidance in developing and organising a campaign's priority issue, goal, objectives, targets, and indicators.

PRIORITY ISSUE:	
GOAL:	
OBJECTIVE 1:	
	Target:
	Indicator:
OBJECTIVE 2:	
	Target:
	Indicator:
OBJECTIVE 3:	
	Target:
	Indicator:

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