Advocacy for mental health, disability and human rights

WHO QualityRights guidance module

QualityRights

World Health Organization

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

Advocacy for mental health, disability and human rights. WHO QualityRights guidance module

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The accompanying slides are available here: https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools

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Foreword

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

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

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

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

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

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

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

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

Dr Tedros Adhanom Ghebreyesus
Director-General
World Health Organization

Supporting statements

Dévora Kestel, Director, Department of Mental Health and Substance Use, World Health Organization, Geneva

Around the world, there is increasing awareness of the importance of mental health and providing services and supports that are person-centred and promote a recovery oriented and human rights-based approach. This awareness comes alongside a recognition that mental health systems in high, middle and low-income countries are failing many individuals and communities due to limited access, poor quality services and human rights violations.

It is unacceptable that people using mental health services can be exposed to inhuman living conditions, harmful treatment practices, violence, neglect and abuse. There are many reports of services not responding to people's needs or failing to support them to live the independent lives in their community - instead their interactions with services often leaves them feeling hopeless and disempowered.

In the wider community context, people with mental health conditions, psychosocial, intellectual or cognitive disabilities are subjected to stigma, discrimination and extensive inequalities that permeate all aspects of their lives. They are denied opportunities to live where they choose, marry, have families, attend school, seek employment and enjoy leisure activities.

Adopting recovery and human rights approaches is essential if we are going to change this situation. A recovery approach ensures that services place people themselves at the centre of care. It focuses on supporting people to define what recovery looks like and means for them. This approach is about helping people to regain control of their identity and life, have hope for the future, and to live a life that has meaning for them, whether that be through work, relationships, community engagement, spirituality or some or all of these.

Recovery and human rights approaches are very much aligned. Both approaches promote key rights such as equality, non-discrimination, legal capacity, informed consent and community inclusion (all enshrined in the Convention on the Rights of Persons with Disabilities). However, the human rights approach imposes obligations on countries to promote these rights.

Through these training and guidance modules developed as part of the QualityRights initiative, the World Health Organization has taken decisive action to address these challenges and to support countries to meet their international human rights obligations. These tools enable several key actions to be realized around: promoting participation and community inclusion for people with lived experience; capacity building in order to end stigma and discrimination and promote rights and recovery; and strengthening peer support and civil society organisations to create mutually supportive relationships and empower people to advocate for a human rights and person-centred approach in mental health and social services.

I look forward to seeing these World Health Organization tools used in countries to provide a comprehensive response to the challenges faced by people with mental health conditions, psychosocial, intellectual or cognitive disabilities.

Dainius Puras, Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest attainable Standard of Physical and Mental Health.

QualityRights offers a new approach to mental health care which is rights-based and recovery-oriented.

This initiative of the World Health Organization is very timely. There is increasing understanding that mental health care policies and services worldwide need to change. Too often services for people with psychosocial disabilities and other mental health conditions are reliant on coercion, overmedicalization and institutionalization. This status quo is not acceptable, as it may continue to reinforce stigma and helplessness among both users and providers of mental health services.

All stakeholders – including policy-makers, mental health professionals and people using mental health services – need to be equipped with knowledge and skills in effective ways to manage change and to develop sustainable rights-based mental health services.

The QualityRights initiative, through specific well-designed modules, provides the necessary knowledge and skills, convincingly demonstrating that change is possible and that this change will lead to a win-win situation. Firstly, persons with disabilities and other mental health conditions, who may need mental health services, will be motivated to use services that empower them and respect their views. Secondly, providers of services will be competent and confident in applying measures that prevent coercion. As a result, power asymmetries will be reduced, and mutual trust and therapeutic alliance will be strengthened.

To abandon the legacy of outdated approaches in mental health care – based on power asymmetries, coercion and discrimination – may not be an easy direction to take. But there is growing understanding that the change towards rights-based and evidence-based mental health services is needed around the globe – in high-, middle- and low-income countries. WHO's QualityRights initiative and its training and guidance materials are extremely useful tools that will support and empower all stakeholders willing to go in this direction. I strongly recommend all countries to take QualityRights on board.

Catalina Devandas Aguilar, Special Rapporteur on the Rights of Persons with Disabilities

Persons with disabilities, particularly those with psychosocial and intellectual disabilities, often experience human rights violations in the context of mental health services. In most countries, mental health legislation allows involuntary hospitalization and treatment of persons with disabilities on grounds of their actual or perceived impairment, plus factors such as "medical necessity" and "dangerousness". Seclusion and restraints are regularly used during emotional crisis and severe distress in many mental health services, but also as form of punishment. Women and girls with psychosocial and intellectual disabilities are regularly exposed to violence and harmful practices in mental health settings, including forced contraception, forced abortion and forced sterilization.

Against this background, the WHO QualityRights initiative can provide essential guidance on the implementation of mental health services and on community-based responses from a human rights perspective, offering a path towards ending institutionalization and involuntary hospitalization and treatment of persons with disabilities. This initiative calls for training health-care professionals to provide health care and psychosocial support to persons with disabilities in a way that is respectful of their rights. By promoting compliance with the CRPD and the 2030 Agenda frameworks, the WHO QualityRights modules bring us closer to realizing the rights of persons with disabilities.

Julian Eaton Director, Mental Health, CBM International

The increase in interest in mental health as a development priority offers the opportunity to close the huge gap in care and support, enabling people to realize their right to good health care where this has previously been lacking. Historically, mental health services have often been of very poor quality and have ignored the priorities and perspectives of people who were using them.

The WHO QualityRights programme has been instrumental in putting in place the means for measuring mental health services according to the standards of the Convention on the Rights of Persons with Disabilities. This often marks a paradigm shift from the way that services have historically worked. The new training and guidance modules are an excellent resource, facilitating better practice in supporting people with mental conditions and psychosocial disabilities, enabling their voices to be heard, and promoting healthier environments that foster recovery. There is a long way to go, but QualityRights is a crucial resource for service providers and users, guiding practical reform for services that value dignity and respect, wherever they may be in the world.

Charlene Sunkel, CEO, Global Mental Health Peer Network

The World Health Organization's QualityRights training and guidance package promotes a strong participatory approach. It recognizes and values the importance of the lived experience of people with psychosocial, intellectual or cognitive disabilities in promoting recovery, undertaking advocacy, conducting research and reducing stigma and discrimination. The QualityRights tools ensure compliance with human rights standards, implementing strategies to end coercive practices. They show how persons with lived experience can provide peer support and can also contribute to the development, design, implementation, monitoring and evaluation of mental health and social services. Lived experience is much more than just knowledge and skills. Expertise emanates from people's in-depth understanding of the social and human rights impact of living with a psychosocial, intellectual or cognitive disability and the adversities of being shunned, segregated and discriminated against. It emanates from having to struggle to navigate a mental health system that often fails to provide services or support that would be beneficial to the person as an unique individual and that speaks to their specific recovery needs.

The mental health system is not the only societal system that presents barriers through which the person must navigate; access to other life opportunities such as education, employment, housing and overall health and well-being can be equally challenging. The unique and in-depth perspectives of people with lived experience can be the catalyst for change and transformation of all societal systems in order to protect human rights, encourage inclusion in the community, improve quality of life, and promote empowerment – all of which can contribute towards improved mental health and well-being.

Kate Swaffer, Chair, CEO Dementia International Alliance

It has been an honour and pleasure for Dementia Alliance International (DAI) to work with the WHO QualityRights initiative and its collaborators on this very important project. Human rights have generally been ignored in practice for people with dementia. However, these modules introduce a new approach to mental health, and also to dementia which is a neurodegenerative condition that causes cognitive disabilities. In contrast to the current post-diagnostic pathway for dementia, which is a pathway focused only on deficits and leading only to disability and dependence, this new approach and these unique and enabling modules promote rights and encourage and support people with dementia to live more positively.

By promoting the need for clear access to rights, the modules are practical tools that can be used by everyone, regardless of who they are. The modules, which take key human rights principles and make them actionable in practice, are as applicable and effective for health professionals as they are for people with dementia and their family members. For example, highlighting the need and benefits of peer-to-peer support – which is a free service DAI has been offering people with dementia since 2013, even before it was officially launched – and focusing on the issue of legal capacity and its relevance in terms of Article 12 of the CRPD provide tangible ways to better inform professionals and families to ensure that the rights of people with dementia will no longer be denied. I personally have every confidence that these modules will support all people experiencing mental health problems and psychosocial, intellectual or cognitive disabilities to live with a better quality of life.

Ana Lucia Arellano, Chair, International Disability Alliance

The United Nations Convention on the Rights of Persons with Disabilities, or CRPD, is the groundbreaking human rights treaty that promotes the paradigm shift from considering persons with disabilities as objects of charity or medical treatment to fully recognizing them as subjects of rights. This paradigm shift is particularly significant for persons with intellectual, psychosocial and multiple disabilities, or for persons with more intense support needs. Article 12 of the CRPD is key in promoting this shift in that it recognizes that persons with disabilities can exercise full legal capacity. This is the core human right that establishes the foundation on which all the others can be exercised.

QualityRights is a superb tool for enabling professionals and health practitioners to better understand and embrace the CRPD. The tool creates a bridge between persons with psychosocial disabilities, users and survivors of psychiatry and mental health services and the health sector, respecting the principles and values of the CRPD. The QualityRights modules have been developed in close consultation with users and survivors of mental health services, linking their voices to messages conveyed to States Parties of the CRPD. The International Disability Alliance (IDA) and its member organizations offer congratulations for the work developed under the QualityRights initiative. We strongly encourage WHO to continue efforts to transform mental health laws, policies and systems until they are CRPD-compliant, echoing the strong voices that call out for “Nothing about us, without us!”

Connie Laurin-Bowie, Executive Director, Inclusion International

WHO QualityRights aims to empower individuals and Disabled Persons Organizations to know their human rights and to advocate for change to enable people to live independently in the community and receive appropriate supports. Inclusion International welcomes this initiative which seeks to promote rights that are often denied to people with intellectual disabilities – namely the right to access appropriate mental health services in the community, the right to choose, the right to have a family life, the right to live in the community, and the right to be active citizens. QualityRights is a valuable contribution to our collective efforts to shape and influence policies and practice which enable everyone to be included in their communities.

Alan Rosen, Professor, Illawarra Institute of Mental Health, University of Wollongong, and Brain & Mind Centre, University of Sydney, Australia.

Freedom is therapeutic. Facilitating human rights in our mental health services can bring healing. It can ensure that, whenever possible, the person who is living with a mental health condition: a) retains choice and control over the assistance and care provided and b) is offered good-quality clinical and home support, if needed, to live in the community without disruption and "on their own turf and terms".

Following a long history of human rights advocacy in psychiatry, these modules show how the right to adequate care and all human rights and fundamental freedoms can be met without contradiction. Coercion in care – such as restraints, seclusion, forced medications, locked inpatient units, being cooped up in restrictive spaces, and institutional warehousing – must be curtailed. The optimal attainment of liberty in care entails immense change. This includes the widespread systematizing of practical evidence-based alternatives to avoid coercion – i.e. open doors, open respite facilities, open and free access, open communities, open minds, open conversations between equals, supported community living, enhancement of individual and family communication, problem-solving skills and support, advance directives, training in soothing and de-escalation, supported decision-making, the recovery orientation of all services and peer workers, and the co-production of policy with all stakeholders.

The WHO QualityRights programme, based on the United Nations CRPD, has been transformed here into a highly practical set of modules. For our professions, these modules offer a trajectory and a horizon to work towards rather than a finite answer or deadline. As well as optimizing clinical and support services, our political, legal and social actions with service users and their families have to be combined with our own emancipation as professionals from institutional thinking and from being yoked to habitual practices in mental health care. Only then and together can we vastly improve the prospects for an empowered, purposeful, contributing life, with full citizenship and full rights, for persons living with severe, persistent or recurrent mental health problems.

Victor Limaza, Activist and facilitator of Justice for People with Disabilities, Documenta AC (Mexico)

Dignity and well-being are closely related concepts. Nowadays, those criteria by which we judge psychological suffering only in terms of neurochemical imbalances are being questioned, as is the view that certain manifestations of human diversity are pathologies that must be attacked to protect the person and society from supposed dangers, even though the interventions used may violate rights and cause irreversible damage. The interdisciplinary and holistic outlook in which subjective discomfort is addressed without undermining the dignity and ability of the person to make decisions, even in critical situations, should be the foundation on which the new mental health care models are constructed, respecting the principles of the CRPD. Understanding the experience of a person facing a critical state in their mental health is possible thanks to the bond generated through empathy, listening, open dialogue, accompaniment (especially among peers), support in decision-making, life in the community and the advance directives under strict safeguards. People with psychosocial disabilities are experts from experience and must be involved in developing the instruments that seek to lead to recovery. The QualityRights initiative of WHO is a good example of this paradigm shift providing tools and strategies for mental health care with the highest standards of respect for human rights. Undoubtedly, the full and equitable enjoyment of all human rights by every person promotes mental health.

Peter Yaro, Executive director, Basic Needs Ghana

The WHO package of training and guidance documents is a rich collection of material that aims to enhance work in mental health and rights-based inclusive development. The materials provide a significant step towards effective programming and mainstreaming of disabilities – especially psychosocial, intellectual and developmental disabilities – in interventions to address individuals' needs and rights as provided for in the CRPD. The QualityRights package marks a giant stride towards the longstanding recommendation that persons with lived experience be part and parcel of the conceptualization and implementation of interventions, together with the monitoring and evaluation of the project's achievements. With this guidance, the sustainability of initiatives can be assured and, for this reason, practitioners, service users, caregivers and all stakeholders are encouraged to utilize

the documents. In the approach presented here, there is no place for perpetrating violence and abuse on already vulnerable persons.

Michael Njenga, Chairperson of the Pan African Network of Persons with Psychosocial Disability, Executive Council Member, Africa Disability Forum and C.E.O. Users and Survivors of Psychiatry, Kenya

There is paradigm shift in the way we need to address mental health globally. The impetus for this shift has been created by the Convention on the Rights of Persons with Disabilities (CRPD) and by the adoption of the Sustainable Development Goals (SDGs) and the 2030 Agenda for Sustainable Development.

WHO's QualityRights tools and materials for training and guidance build on this key international human right as well as on international development instruments. The QualityRights initiative adopts a human rights-based approach to ensure that mental health services are provided within a human rights framework and are responsive to the needs of persons with psychosocial disabilities and mental health conditions. These materials also lay emphasis on the need to provide services as close as possible to where people live.

The QualityRights approach recognizes the importance of respecting each individual's inherent dignity and ensuring that all persons with psychosocial disabilities and mental health conditions have a voice, power and choice while accessing mental health services. This is an integral element in reforming mental health systems and services both globally and at local and national levels. It is essential, therefore, to make sure that these training tools and guidance materials are widely used so that they result in tangible outcomes at all levels for people with lived experience, their families, communities and entire societies.

What is the WHO QualityRights initiative?

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

1. Build capacity to combat stigma and discrimination, and to promote human rights and recovery.
2. Improve the quality of care and human rights conditions in mental health and social services.
3. Create community-based and recovery-oriented services that respect and promote human rights.
4. Support the development of a civil society movement to conduct advocacy and influence policy-making.
5. Reform national policies and legislation in line with the Convention on the Rights of Persons with Disabilities and other international human rights standards.

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

WHO QualityRights – Training and guidance tools

The following training and guidance modules and accompanying slide presentations available as part of the WHO QualityRights initiative, can be accessed at the following link: https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools

Service transformation toolkit

- **The WHO QualityRights assessment toolkit**
- **Transforming services and promoting human rights**

Training tools

Core modules

- **Human rights**
- **Mental health, disability and human rights**
- **Recovery and the right to health**
- **Legal capacity and the right to decide**
- **Freedom from coercion, violence and abuse**

Specialized modules

- **Supported decision-making and advance planning**
- **Strategies to end seclusion and restraint**
- **Recovery practices for mental health and well-being**

Evaluation tools

- **Evaluation of the WHO QualityRights training on mental health, human rights and recovery: pre-training questionnaire**
- **Evaluation of the WHO QualityRights training on mental health, human rights and recovery: post-training questionnaire**

Guidance tools

- **One-to-one peer support by and for people with lived experience**
- **Peer support groups by and for people with lived experience**
- **Civil society organizations to promote human rights in mental health and related areas**
- **Advocacy for mental health, disability and human rights**

Self-help tools

- **Person-centred recovery planning for mental health and well-being – self-help tool**

About this training and guidance

The QualityRights training and guidance modules have been developed to enhance knowledge, skills and understanding among key stakeholders on how to promote the rights of persons with psychosocial, intellectual or cognitive disabilities and improve the quality of services and supports being provided in mental health and related areas, in line with international human rights standards, and in particular the United Nations Convention on the Rights of Persons with Disabilities and the recovery approach.

Who is this training and guidance for?

- **People with psychosocial disabilities**
- **People with intellectual disabilities**
- **People with cognitive disabilities, including dementia**
- **People who are using or who have previously used mental health and social services**
- **Managers of general health, mental health and social services**
- **Mental health and other practitioners** (e.g. doctors, nurses, psychiatrists, psychiatric and geriatric nurses, neurologists, geriatricians, psychologists, occupational therapists, social workers, community support workers, personal assistants, peer supporters and volunteers)
- **Other staff working in or delivering mental health and social services, including community and home-based services** (e.g. attendants, cleaning, cooking, maintenance staff, administrators)
- **Nongovernmental organizations (NGOs), associations and faith-based organizations working in the areas of mental health, human rights or other relevant areas** (e.g. organizations of persons with disabilities (DPOs); organizations of users/survivors of psychiatry, advocacy organizations)
- **Families, support persons and other care partners**
- **Relevant ministries (Health, Social Affairs, Education, etc.) and policymakers**
- **Relevant government institutions and services** (e.g. the police, the judiciary, prison staff, bodies that monitor or inspect places of detention including mental and social services, law reform commissions, disability councils and national human rights institutions)
- **Other relevant organizations and stakeholders** (e.g. advocates, lawyers and legal aid organizations, academics, university students, community or spiritual leaders, and traditional healers if appropriate)

Who should deliver the training?

Training should be designed and delivered by a multidisciplinary team, including people with lived experience, members of disabled persons' organizations (DPOs), professionals working in mental health, disability and related fields, families and others.

If the training is about addressing the rights of people with psychosocial disabilities specifically, it is important to have representatives from that group as leaders for the training. Likewise, if the purpose is to build capacity on the rights of persons with intellectual or cognitive disabilities, the leaders of the training should also be from these groups.

In order to liven up discussions, different options can be considered. For instance, facilitators with specific knowledge of a particular part of the training can be brought in for specific aspects of the training. Another option may be to have a panel of trainers for specific parts of the training.
Ideally, facilitators should be familiar with the culture and context of the location where the training is taking place. It may be necessary to conduct train-the-trainer sessions in order to build up a pool of people who are able to carry out the training within a particular culture or context. These train-the-

trainer sessions should include persons with psychosocial, intellectual or cognitive disabilities. They should also include other relevant local stakeholders who contribute to improving the quality of mental health and social services and the human rights of people with psychosocial, intellectual or cognitive disabilities.

How should the training be delivered?

Ideally, all the QualityRights training modules should be delivered, starting with the five core foundational modules. This can be followed by more in-depth training using the specialized modules (see above).

The whole training can be conducted through multiple workshops taking place over the course of several months. Each separate training module does not necessarily have to be completed in one day. It can be divided into topics and can be conducted over the course of several days, as required.

Since the training materials are quite comprehensive and time and resources may be limited, it may be useful to adapt the training according to the existing knowledge and background of the group, as well as the desired outcomes of the training.

Thus, the way these training materials are used and delivered can be adapted according to the context and requirements.

- For example, if participants do not yet have any expertise in the areas of mental health, human rights and recovery, it would be important to conduct a 4–5-day workshop using the five core training modules. A 5 day sample agenda available at the following link: https://qualityrights.org/wp-content/uploads/Sample-program-QR-training.pdf

- If participants already have a basic understanding of the human rights of people with psychosocial, intellectual and cognitive disabilities but require more advanced knowledge about how specifically to promote the right to legal capacity in practice, then a workshop could be organized to focus on the module *Legal capacity and the right to decide* on day 1 and on the specialized module on *Supported decision-making and advance planning* (or selected parts of that module) on days 2, 3 and 4.

When adapting the training materials according to specific training requirements it is also important, prior to the training, to go through all the modules to be covered in order to get rid of unnecessary repetition.

- For example, if a training is planned, covering all the core modules, then it will not be necessary to cover topic 5 (zooming in on article 12) or topic 6 (zooming in on article 16) since these issues will be covered in much greater depth in the subsequent modules (module on *Legal capacity and the right to decide* and on *Freedom from coercion, violence and abuse* respectively).

- However if an introductory training is planned based solely on module 2, then it is essential to cover topics 5 and 6 of this module, since this will be the only exposure that the participants will receive on these issues and articles.

These are examples of the different and varied ways in which the training materials can be used. Other variations and permutations are also possible on the basis of the needs and requirements of the training in a particular context.

Preliminary note on language

We acknowledge that language and terminology reflects the evolving conceptualization of disability and that different terms will be used by different people across different contexts over time. People must be able to decide on the vocabulary, idioms and descriptions of their experience, situation or distress. For example, in relation to the field of mental health, some people use terms such as "people with a psychiatric diagnosis", "people with mental disorders" or "mental illnesses", "people with mental health conditions", "consumers", "service users" or "psychiatric survivors". Others find some or all these terms stigmatizing or use different expressions to refer to their emotions, experiences or distress. Similarly, intellectual disability is referred to using different terms in different contexts including, for example, "learning disabilities" or "disorders of intellectual development" or "learning difficulties".

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

The use of the term "disability" is important in this context because it highlights the significant barriers that hinder the full and effective participation in society of people with *actual* or *perceived* impairments and the fact that they are protected under the CRPD. The use of the term "disability" in this context does not imply that people have an impairment or a disorder.

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

In addition, the use of the term "mental health and social services" in these modules refers to a wide range of services currently being provided by countries including, for example, community mental health centres, primary care clinics, outpatient services, psychiatric hospitals, psychiatric wards in general hospitals, rehabilitation centres, traditional healers, day care centres, homes for older people, and other "group" homes, as well as home-based services and services and supports offering alternatives to traditional mental health or social services, provided by a wide range of health and social care providers within public, private and nongovernmental sectors.

The terminology adopted in this document has been selected for the sake of inclusiveness. It is an individual choice to self-identify with certain expressions or concepts, but human rights still apply to everyone, everywhere. Above all, a diagnosis or disability should never define a person. We are all individuals, with a unique social context, personality, autonomy, dreams, goals and aspirations and relationships with others.

1. Introduction

All over the world, people with psychosocial, intellectual or cognitive disabilities experience a wide range of human rights violations *(1)*:

- They are subjected to high levels of discrimination due to widely held misconceptions and prejudices. Stigma and discrimination related to persons with disabilities can intersect with discrimination across other factors, including "race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status," according to the preamble to the Convention on the Rights of Persons with Disabilities ((CRPD) (2).
- They experience high levels of physical, emotional and sexual violence and abuse. This can occur in a range of settings, including prisons, mental health and social services, and in the community.
- They are denied the right to exercise their legal capacity and make choices about their own lives. Mental health, guardianship and related laws allow people to be detained in mental health services against their will and treated without their informed consent. The prevailing model of **substitute decision-making** that exists in most countries means that many people are also denied the right to make decisions on many personal, financial and other matters affecting them.
- They often encounter restrictions in the exercise of their political and civil rights, such as the right to vote, to marry and to have a family.
- People with psychosocial, intellectual or cognitive disabilities are often prevented from participating fully in their communities or taking part in public or political affairs, such as policy-making processes.
- In many countries, they are denied access to essential health and social care or they receive care and services of a lesser quality. Many people with psychosocial, intellectual or cognitive disabilities fail to receive treatment and care for physical illnesses.
- They also face significant social and structural barriers in attending school and finding employment. The exclusion of children with psychosocial, intellectual or 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 among people with disabilities.

A human rights-based approach recognizes that disability is caused by many barriers which – in interaction with physical, mental, intellectual or sensory impairments – prevent people 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.

Persons with disabilities are entitled to equal rights and equal opportunities to participate in society as are all other persons. Barriers that prevent people with disabilities, including people with psychosocial, intellectual or 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 or cognitive disabilities**

This module describes the process of designing and running an advocacy campaign to promote the human rights of people with psychosocial, intellectual or cognitive disabilities. It provides guidance on

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

There are many different approaches to advocacy. Some organizations may try to build alliances and consensus among different people with psychosocial, intellectual or cognitive disabilities and their allies while others may keep a very strong line of advocacy and not seek consensus at all. Both approaches can be highly effective in achieving change. Furthermore, some advocacy organizations, including grassroots organizations, may not do advocacy in a linear and structured manner as described in this module. Advocacy can be developed as a fluid and flexible process, responding and advocating on issues and needs as they arise. This may be equally effective. Positive outcomes that can be achieved through advocacy include:

- The prioritization of the rights of persons with psychosocial, intellectual or 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 social services.

Scenario 1: Pan African Network of People with Psychosocial Disabilities (PANPPD) advocates for the rights of people with psychosocial disabilities *(3)*

PANPPD is a regional organization of people with psychosocial disabilities in Africa. It is a collective voice to promote and protect the rights and dignity of people with psychosocial disabilities. The organization aims to increase continental solidarity among organizations that promote and protect the rights of people with psychosocial disabilities. PANPPD 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.
- Be an African forum and network for the exchange of knowledge, raising awareness and the promotion of research regarding psychosocial disability.

For more information, see: https://www.facebook.com/PANPPD/.

Scenario 2: Perspectives and experiences of self-advocacy for inclusion of people with intellectual disabilities in different countries *(4)*

Inclusion International is an international network of people with intellectual disabilities and their families advocating for the human rights of people with intellectual disabilities worldwide. Taking into consideration that self-advocacy can have different meanings around the world, organizations and groups were asked about their understanding of, and actions relating to, self-advocacy. Here are some of the responses:

"We are fighting the negative stereotype about capabilities of people with intellectual disabilities as well as legislation to support their rights" (Jordan).

"Someone standing for himself, who has wishes, who speaks up, who makes a positive change also for the other citizens and the whole community" (Mauritius).

"Support persons can be trusted and reliable. No attitude of pity but empower self-advocates. Understanding of needs and desires" (South Africa).

"We fight to become self-advocates to defend our rights based on UN CRPD, mainly in article 12 on our legal capacity and article 19 on our right to live included in the community and not be institutionalized in dangerous places that threaten human rights. Also work with the government to comply with the convention to create services in the community and create reasonable adjustments for people with psychosocial disabilities." (Mexico).

"The view of society towards disability, the environment, the respect to identify that we are not less valuable than anyone else and we are able to respect, improve and love as anyone else" (Spain). "Closing institutions, to have people in my community think of me as a person, better housing, more support and help with employment" (Canada).

The following videos also explains what self-advocacy is from the perspective of people with disabilities:

Inclusion International, "Self-advocacy is…". https://youtu.be/mVIqkkqqd5U (7:23) (accessed 9 April 2019).

Inclusion International, "Why self advocacy is important" https://youtu.be/cE32AQU--3U (2.04) (accessed 9 April 2019).

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 priority issue

The first step in the advocacy process is to identify the priority 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. People do not need to agree on all the issues, outcomes and solutions at once.

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

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

Brainstorming *(5)*

Brainstorming can be a helpful way to identify many of the issues the campaign may want to address. By definition, brainstorming is a process of generating as many ideas as possible related to a specific topic within a defined time frame. 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.
- Ideas and facts can be mentioned without judgement, even if they are conflicting.
- People's ideas and opinions come together without exclusion, thus building consensus.
- Focus is sustained, using time efficiently, as brainstorming is generally a short time-limited exercise.

Prioritization 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 prioritize 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, when 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 *(5)*.

Examples of priority issues

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

- The lack of human rights protection for people with psychosocial, intellectual or cognitive disabilities in national policies, strategies and laws.
- Poor quality of care and respect for human rights in mental health and social services.
- The need to end institutionalization and to develop 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 or cognitive disabilities in decision-making processes on issues affecting them.
- Discrimination and lack of opportunities for people with psychosocial, intellectual or cognitive disabilities in employment/income-generating opportunities, education, housing, social benefits etc.
- The need to overcome discrimination and to dismantle myths and misconceptions about people with psychosocial, intellectual or cognitive disabilities.
- The need to end violence and abuse in mental health and social services and in the community.
- Implementing strategies to end the use of involuntary admission and treatment, seclusion and restraint and other coercive practices in mental health and social services.
- Promoting informed consent to treatment in mental health and social services and ensuring that all treatment and life choices are based on the will and preference of the individual.
- Promoting a recovery approach through mental health and social services.
- Ending guardianship for people with psychosocial, intellectual or cognitive disabilities and replacing this with a supported decision-making model.
- The need to reform mental health-related policy and legislation so that these align with the obligations set under the CRPD.

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

Tools for identifying priority advocacy issues can be found in Annex 3, Section 3.1: Helpful tools for developing an advocacy campaign: Forming partnerships and alliances

Forming partnerships and alliances (6)

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 is the most difficult but also the most satisfying.

The development of alliances and partnerships should begin in the early stages of a campaign in order to reach agreement on both the strategy and the objectives of the campaign. Consequently, 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. For the network to be successful and to be empowered, its members should share common ethical standards and values. 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 according to people's working styles.

Coalitions (5)

A coalition, which is a group of organizations that share common interests and work together to achieve a common goal, can be another option for advocacy efforts. Coalitions require far more work than networks, as they are more formal. However, because members of organizations (rather than individuals) are coming together to advocate on an issue, the results can have more impact. 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 to accomplish their job.
- Be a trustworthy, credible and reliable source of information.
- Be sociable and develop friendships where possible and appropriate.
- Keep in regular contact and be patient. It takes time to create lasting relationships.

Tools for identifying priority advocacy issues can be found in Annex 3, Section 3.1: 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 that have an impact on the priority issue, including 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. Surveys can be conducted either by the advocacy group or by another organization (e.g. a university).
- **Focus groups:** Focus groups provide an in-depth perspective on what people think and why. This method is particularly useful in testing policy messages. (For more information about policy messages, see *Develop key messages*).
- **Interviews:** Conduct individual interviews with key representatives if there are insufficient 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 programme 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 might already 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 *(5)*:

- **Audiences**: This refers to the people or group towards whom the campaign will be directed. 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 policy-makers, officials or others who have the power to make the change that a campaign is advocating for. When primary targets cannot be influenced, one must choose to influence secondary targets.

A secondary target is the person/group/organization 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); terms such as "the public" or "the government" are too general and therefore are not good targets *(6)*.

Examples of types of audiences, beneficiaries and/or partners *(7)*:

- People with psychosocial, intellectual or cognitive disabilities
- 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 (NGOs)
- Community groups
- Women's organizations
- Religious groups/churches/faith-based organizations
- Other professionals
- Media
- Civil society organizations.

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 (e.g. social contexts, institutions, structures), including potential opportunities and barriers, and levels of public understanding and support for or resistance to change.
- Current policies or actions 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, including in other countries, 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 instance, 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 that they can send out the same message, lobby for it and reach a wider audience *(8)*.

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, outdated laws may restrict the legal capacity of persons with psychosocial, intellectual or cognitive disabilities. This situation would undermine and be detrimental to any campaign that aims to promote the rights of persons with disabilities since legal capacity is fundamental to exercising all human rights. Thus, any campaign about promoting rights may initially need to centre on reforming outdated national legislation in this area. Specific actions or "activities" that advocates may consider carrying out to overcome barriers will be explained later in the section Determine the activities and time frames.

Enablers

Whenever possible, advocates should seek to draw upon policies, laws, and/or evidence that help support the implementation of their campaign. For instance, some international and regional human rights instruments impose legal obligations on governments. At the international level these include the United Nations Convention on the Rights of Persons with Disabilities (CRPD), the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of the Child, and the 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 or cognitive disabilities and aims to ensure that countries recognize that people with disabilities must be provided with the opportunities to live their lives to their fullest potential on an equal basis with all other people. The CRPD 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 else, that they are treated fairly and equally and are not discriminated against. Most countries have today ratified the CRPD.

Advocacy groups can take a number of actions in relation to these instruments, including urging states to adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the conventions and modify or abolish existing discriminatory laws, regulations and customs. To learn more about using international human rights instruments in advocacy, see the section on Using international human rights instruments.

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

Situational analysis of the implementation of the CRPD in the Caribbean subregion (9)

Background

In a 2009 study published by the Economic Commission for Latin America and the Caribbean (ECLAC) sub-regional 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".

Situational analysis

In response, the ECLAC subregional headquarters for the Caribbean conducted two surveys to assess the current situation of the rights of persons with disabilities in the Caribbean subregion. The first survey was with government ministries responsible for policies regarding persons living with disabilities and the second was with people with disabilities and was 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 that were available regarding the rights of persons living with disabilities, as well as pointing out access and adaptation concerns in relation to persons with disabilities using 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 which significant improvement was needed.

Several steps to improve the situation for persons with disabilities were identified. These included 1) support to several countries to ratify and monitor the implementation of the CRPD, 2) support for the design of laws that were compliant with the CRPD, 3) 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, and 4) a range of specific actions regarding education, employment, sexual and reproductive health, and accessibility standards of public facilities for people with disabilities.

The full report is available at:
https://repositorio.cepal.org/bitstream/handle/11362/5043/1/S2011963_en.pdf, accessed 11 February 2019.

Tools for identifying priority advocacy issues can be found in Annex 3, Section 3.3: Helpful tools for developing an advocacy campaign: Carrying out situational analyses

Formulate the advocacy goal and objectives

Once the situational analysis has been completed and there is more clarity concerning the focus, a logical next step is to develop the campaign's specific goal and objectives. These can be time-bound and can change depending on the political or legal context locally, nationally or internationally. It may be helpful to first have people discuss the different things they would like to change or improve through the advocacy campaign *(10)*. Once in agreement the goal can be written down in a clear, one-sentence statement.

it is important to keep in mind that most advocacy campaigns aim to produce changes in knowledge, attitudes and/or behaviour *(10)* or in policy or legislation. For example, a goal could be: "To end discrimination experienced by people with psychosocial, intellectual or cognitive disabilities in the community."

From the goal, it is possible to determine the campaign's objectives. Objectives need to be met in order to achieve the goal – i.e. they must be fulfilled in order for the overall goal to be fulfilled. Objectives should be SMART, as follows *(8)*:

- **S**pecific – the objective is defined, focused, and targeted.
- **M**easurable – the objective can 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 allocated 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 end discrimination experienced by people with psychosocial, intellectual or cognitive disabilities in the community."

GOAL: *To end discrimination experienced by people with psychosocial, intellectual or 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 or cognitive disabilities should have the same opportunities to exercise their legal capacity as everyone else.	Attitude (from one of exclusion to one of inclusion)	Yes. Having more people believe in the right to legal capacity for people with psychosocial, intellectual or cognitive disabilities reduces stigmatizing and discriminatory attitudes and promotes an understanding that people with disabilities must be able to exercise their rights on an equal basis with others.	**Specific**: Yes **Measurable**: Yes, via surveys **Achievable**: Yes; should be based on the community context **Realistic**: Yes; should be realistic, based on the community context **Time-bound**: Yes (1 year)
Increase the number of advocacy groups lobbying government for a change in legislation within one year.	Structure (from 1 group to 15 groups)	Yes. The engagement of more advocacy groups on this issue will lead to more awareness, actions and pressure to end discrimination within the community.	**Specific:** Yes **Measurable:** Yes **Achievable:** Yes; should be achievable based on the community context **Realistic:** Yes; should be realistic, based on the community context **Time-bound:** Yes (1 year)
Increase contact between people with psychosocial, intellectual or cognitive disabilities and people without by 50% within 3 months.	Process (from no interaction to interaction that brings people together)	Yes. Contact has been shown to reduce stigma and discrimination.	**Specific:** Yes **Measurable:** Yes, via surveys **Achievable:** Yes; should be achievable based on the community context **Realistic:** Yes; should be realistic based on community context **Time-bound:** Yes (3 months)

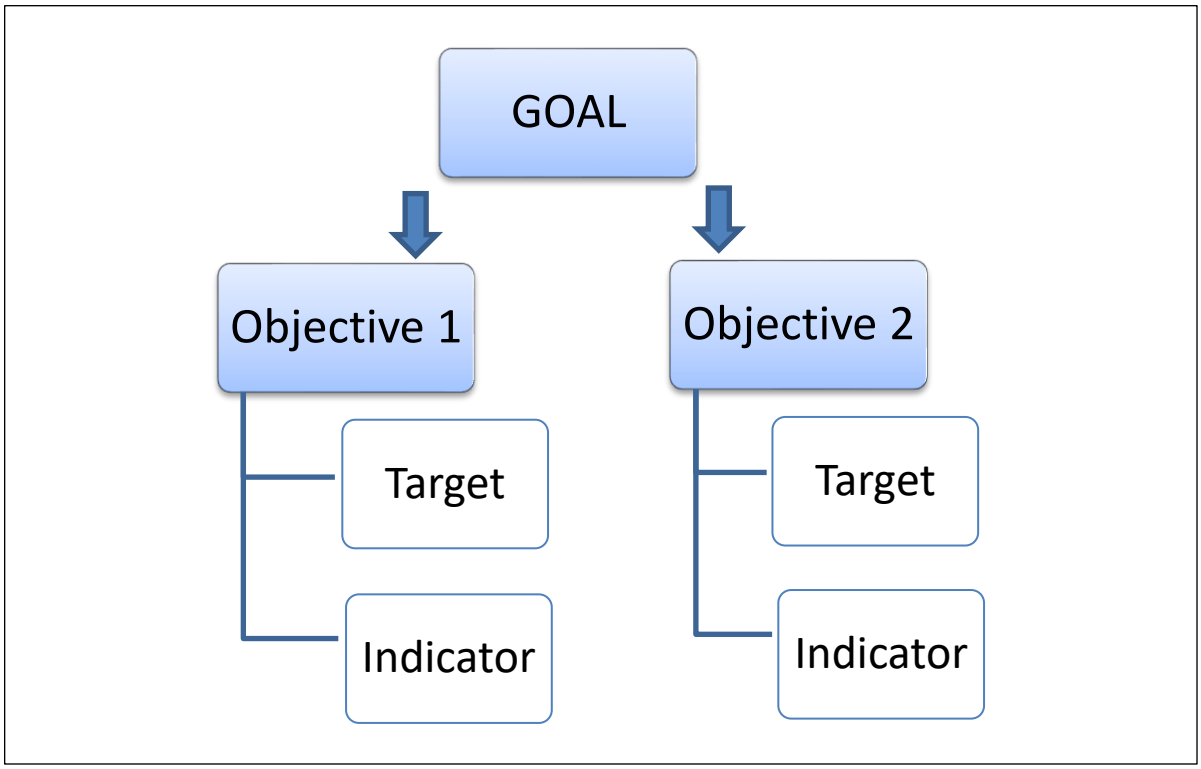
Identify targets and indicators

What gets measured is more likely to get 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 targets.

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.

Mental Health Act, identifying targets and indicators

Goal*: To end the use of seclusion and restraint in mental health and social 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 is revised so that the use of seclusion and restraint is prohibited by January 2020.

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 time frames (6)

Once the indicators and targets have been identified, the specific activities that will be carried out as part of the advocacy campaign need to be defined.

Activities should be designed to help achieve individual objectives, thus 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 carried out simultaneously and which must follow the completion of another?
- How long will each activity take?
- Would any cost be incurred?

It is important that there is a defined time frame for each activity. Some activities will be continuous, while others will operate only for a limited period. In addition, some advocacy activities might have more impact 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 consider events (e.g. conferences, forums etc.) or important dates (e.g. World Health Day, Human Rights Day etc.) that these activities could be linked with.

Examples of advocacy actions

1. Advocacy actions undertaken by a grassroots movement – the example of CHRUSP

The Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP) is a grass roots organization which is funded only through small individual donations. It aims to provide strategic leadership in human rights advocacy, implementation and monitoring relevant to people experiencing or labelled with madness, mental health problems or trauma.
Advocacy actions at the international level include:

- A CRPD course from the perspective of a survivor of psychiatry taught by Tina Minkowitz. The course has so far been offered free of charge to allow students to participate from all parts of the world; the majority have been survivors of abuse in psychiatry and others were allies in the legal profession, human rights and development community, and disability movement. For more information, see http://crpdcourse.org.

- Contribution to the Absolute Prohibition Campaign to abolish forced commitment and treatment. For more information see http://absoluteprohibition.org.
- Organization of a side event with the World Health Organization at the 10th CRPD Conference of States Parties in June 2017, in support of the abolition of forced treatment and the need for alternatives to existing practices both within and outside the mental health system. The side event was widely attended and well received. Materials from the side event and links to the videos can be found on the CHRUSP website: www.chrusp.org.
- Collaboration with colleagues in Asian countries to draft a model law of inclusion of persons with psychosocial disabilities.
- Attendance at public meetings of the Committee on the Rights of Persons with Disabilities and making a statement in the Opening Session.
- Participation in conferences in various countries.
- Participation in United Nations consultations through written submissions.

For more information, see: http://www.chrusp.org,

2. Advocacy action in Japan

In the following video, Mari Yamamoto talks about advocacy activity that she is conducting in Japan: https://youtu.be/UB2ZASt6jrc (6:11), accessed 9 April 2019.

Activities fall into several different categories. Below are general types of activities that advocacy groups carry out, with some examples of ways to conduct these. It should be noted that activities may fall into more than one category. The list below is meant to serve as a guide rather than as 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 is a form of advocacy intended to influence governments and politicians to change legislation or policy or to persuade governments to invest more funding in mental health and social 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 who may be useful to the campaign. For instance, someone who has very little political power or input today may be much more influential (and thus have the ability to help advance the campaign) in the future *(11)*. It is helpful to know the people that the group is seeking to approach in order to personalize the advocacy message and build relationships over time.

Useful ways to approach people can be:

- Attending meetings and spaces where relevant people can be met.
- Inviting decision-makers to events organized by the group.

Public health and human rights issues frequently affect many sectors, so it may be relevant to raise issues with all the appropriate sectors and describe how their activities have an impact on the health and well-being of the community. The group should find opportunities where interests may align with those of decision-makers; for instance, reducing suicides in the local area might be a way to bring attention to services and supports needed. When appropriate, it may be useful to acknowledge any good work being done by decision-makers.

The following video shows the first registered lobbyist with Down's syndrome in Washington (US) https://www.bbc.com/news/av/world-us-canada-44325048/first-washington-lobbyist-with-down-s-syndrome (2:28), accessed 9 April 2019.

Relevant tools for lobbying governments and politicians include:

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

These specific tools are discussed in further detail below.

Face-to-face meetings (11)

Meeting with a policy-maker in person 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 with a policy-maker in person, 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 both the issue and the policy-maker.
- Ensure that the meeting is focused and organized (e.g. introduce yourself, the organization being representing, and the topic to be discussed).
- Listen, gather information, and do not become angry if the policy-maker does not provide the desired response.
- Express thanks and follow up as needed.

Written submissions

The aim of a submission is to influence policy-makers in order to secure a favourable outcome on the advocacy issue. For instance, an advocacy group may want to put forward a submission in response to a new or proposed government policy or law and may want to provide recommendations to

improve that policy or 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 or law affects the community.

When writing a submission, consider including *(12)*:

- A short description of the advocacy group.
- Arguments and opinions on the issue at hand (e.g. the law or policy).
- Facts, examples and data.
- Recommendations that include solutions and proposals to address the problems identified.

Example of a written submission

People's Review of the Mental Health System, Aotearoa, New Zealand

The *People's Review of the Mental Health System* was an online crowdfunded and crowdsourced narrative-based inquiry into the public mental health system in Aotearoa, New Zealand. It gathered the written experiences of people involved with mental health services in New Zealand – from mental health professionals to those with direct or family experience – over a 3-month period before collating their accounts into the *People's Mental Health Report*. The Report advocated for the need for an independent review of the New Zealand mental health system, by highlighting the human stories of those within it and campaigning for a system based on fairness, justice, healing and hope.

The Report is publicly available to download at no cost and makes four key recommendations to the Government based on the recurring themes uncovered across more than 500 personal accounts. The recommendations form the foundation of an open letter to the Minister of Health calling for their implementation, which citizens are invited to sign.

The recommendations include:

- A national increase in funding for mental health services and supports, with a particular focus on access to community-based services and early intervention that address people's needs and preferences as well as supporting over-capacity service providers
- Enacting and upholding the CRPD obligation to have independent oversight of the mental health system through the creation of a Commission external to the system that promotes self-advocacy and incorporates roles for those with lived experience
- An urgent Royal Commission to examine the long-term systemic problems and ongoing independent inquiry into developing sufficient appropriate and accessible mental health services that uphold people's rights and promote recovery.
- The creation of a national mental health education programme to increase understanding of available services as well as promote the inclusion, dignity and empowerment of those with lived experience.

For more information visit: **https://www.peoplesmentalhealthreport.com/** *(13)*

Tools for writing a submission to governments 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 policy-makers 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 *(11).* Keep the following points mind when writing letters to politicians *(14)*:

- Make it clear in the opening that the advocacy group has some knowledge of the person being contacted.
- Keep letters as concise as possible in order to increase the likelihood that they will be read. No more than one page 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 person 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 *(5)*

A petition targets someone who holds a position of power within a system or institution, 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 can be 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.
- 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

Arranging site visits

Site visits can be an effective way to increase the awareness of policy-makers, government officials and other influential persons of the importance of the priority issue. Site visits can serve a variety of purposes depending on the advocacy group's goal and objectives. For example, site visits to several mental health and social 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 create the opportunity for policy-makers and officials to develop more personal and 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 (15)

A policy brief is a short summary of a particular issue (or challenge) that includes not only the existing policy options relating to the issue but, most importantly, recommendations for changes in the policy to best address the target issue. As the 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 four 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 it.
- **Critique of the current policy** – includes an overview of the policy and an argument for why the current 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. The expected impact of the policy should be stated.

When writing policy briefs, it is important to make sure that the document is concise and focused, professional, supported by evidence, easy to understand, 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 address the issue effectively.

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 *(11)*

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

Relevant tools for creating and generating debate within communities include:

- Face-to-face communication and meetings with stakeholders.
- Letters to the editor of a newspaper.
- 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 schools, council meetings, churches).
- Mobilization of groups (community members, public interest groups etc.) to take action 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 stakeholders, including with policy-makers or other key persons in the community, can be an ideal opportunity to make the case for an advocacy issue. However, organizing opportunities for face-to-face meetings often requires persistence and creativity since many stakeholders 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 of a newspaper (11)

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 for individuals to write under their own name as concerned citizens and other times when showing credentials and the organization represented is necessary or more appropriate.

Example of a letter to a newspaper

A letter to the Editor of the Irish Times from CBM Ireland CEO Sarah O'Toole *(16)*

Sir,

It is welcome news to see Minister Fitzgerald at Ireland's recent UPR [UN Universal Periodic Review] 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 for developing an advocacy campaign: Letters to the editor

Serving on committees

People with psychosocial, intellectual or cognitive disabilities (and, when appropriate, 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 CRPD, and committees for assessing human rights and quality conditions in mental health and social 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 (11)

It may be useful to recognize and showcase individual "champions" when dealing with a specific issue. Champions can include 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 by arranging an event or forum where they can publicly support the campaign issue or by profiling their story and support to the campaign on traditional media, websites or other social media platforms.

Example of a community champion (17)

Kit Harrington – Why I'm supporting Mencap

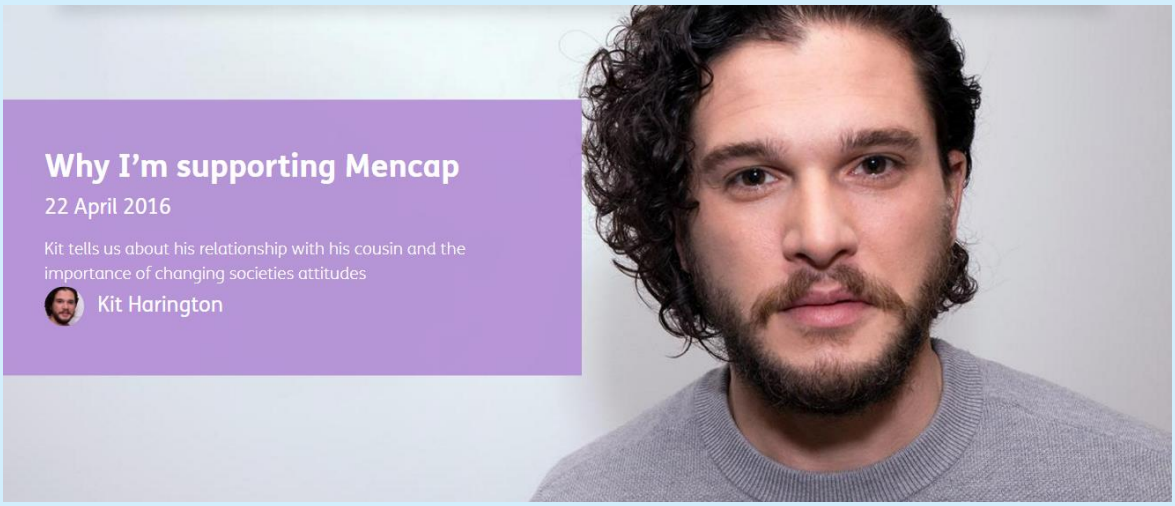
Game of Thrones star, Kit Harrington, has engaged to support Mencap, a United Kingdom charity providing support and advice to people with learning disabilities and their families.

My cousin Laurent is one of the 1.4 million people with a learning disability in the United Kingdom. Growing up with Laurent I know that people with a learning disability have the same hopes and dreams for their lives as all young people do.

However, others are sometimes awkward and afraid when it comes to engaging with someone with a learning disability and that means they are often ignored and overlooked.

We need to change this and stop ignoring the talents and contributions that people with a learning disability can bring to our society (…). Usually when you hear about learning disability in the media it's the horrific impact of abuse scandals or the effects of government social care cuts. That's important, but it's not everything - it's not how I think about learning disability, or how I feel when I'm hanging out with Laurent, who is an important, positive and really funny member of my family. The media has a role to reflect society and help give people with a learning disability a platform to be heard.

Let's show my cousin Laurent and Lloyd and Ciara and thousands of others that their lives are valued just as much as anyone else in society.



For more information, see: https://www.mencap.org.uk/blog/why-im-supporting-mencap, accessed 6 February 2019.

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 (10 December), World Health Day (7 April), World Mental Health Day (10 October), World Alzheimer's Day (21 September), International Day of People with Disability (3 December) and Mad Pride Day *(18)*. Mad Pride may be celebrated anytime but is most often observed in the month of July, usually on or around 14 July).

Example of an event for increasing public awareness (19)

Join in celebrating International Day of Persons with Disabilities

The International Day of People with Disabilities was proclaimed by the United Nations General Assembly in 1992. The day is celebrated both nationally and internationally.

Individuals and groups organize events in their community, organization, business or schools. The celebrations are usually a collaborative effort to help break down barriers, promote inclusion and celebrate the achievements and contributions of people with disabilities. These events create key opportunities to advocate for the rights of people with disabilities.

Public dialogues and forums (20)

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 on the issue at hand. Forums can be open, so that all community members have the opportunity to share their ideas, thoughts and opinions, or the forums can be more structured to include keynote speakers and/or a guest panel. Public forums can offer the unique opportunity to introduce the community to persons 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 diverse representation of the people and groups most affected by the issue or targeted by the campaign?
- 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 to take action *(21)*

The mobilization of various groups (e.g. community members, public interest groups, coalitions, umbrella organizations, other civil society groups etc.) can be an effective tool for supporting policy change. Group mobilization allows a campaign not only to 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 (e.g. people working within areas such as criminal justice, violence, substance use, public health etc.), 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 of people should be mobilized on a continuous basis in order to build and sustain momentum over time. Group mobilization has the potential to garner resources, break down practice and policy siloes, provide important information to community members, and foster partnerships among various sectors of the community.

Working with the media *(11)*

Advocacy groups can use many different types of media to disseminate key messages and generate support. For instance, 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 advocacy 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 the section *Develop key messages.*

Examples of working with the media

Example 1: Advocacy campaign for social participation of people with intellectual disabilities, Lebanon

The Lebanese Association for Self-Advocacy (LASA) is a family and self-advocacy organization in Lebanon that works to defend and promote the rights of people with disabilities. As part of an advocacy campaign, LASA produced a series of short films under the name *Media Serving Disability*. The films are based on the daily lives of people from the organization and were created to show civil society and organizations the need to promote social participation

For the video about living in community, see: https://youtu.be/d8ZVQfkYqOQ (accessed 9 April 2019).

Example 2: *I Got Better* campaign promotes hope in mental health through the media *(22),(23)*

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, see: http://www.mindfreedom.org/.
To learn more about the *I Got Better* campaign, see: http://igotbetter.org/.

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

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. 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 the 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 *(11)*:

- 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.
- Keep to the facts but give context to the story.
- Use data and information on "what's new".
- Make the release as attention-grabbing as possible.

Examples of press/media releases

Example 1: Extract from: WHO urges development programmes to INCLUDE people with psychosocial disabilities *(24)*

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 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 United Nations 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.

Example 2: Extract from: Kenyan government must recognize autonomy of people with mental disabilities (25)

"I felt like an animal going to a slaughter and I had no choice."
Yusuf, a man with a psychosocial (mental health) disability from Nairobi.

Tomorrow MDAC [now called Validity] 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 sterilized 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 sterilization of women with disabilities, denial of the opportunity to education or employment, forced psychiatric treatment without any due process safeguards, and lifelong 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 psychosocial (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 judgemental and intolerant attitudes."

Tools for writing letters to the editor can be found in Annex 3, Section 3.10: Helpful tools for developing an advocacy campaign: Press/media release

Interviews (11)

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 telephone or television.
- 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 writing letters to the editor 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 towards 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 concerns. This information can then become the basis of future campaign activities, such as a press release or letter to a local government representative or minister on the issue *(11)*.

E-advocacy via various social media platforms can also assist the campaign by reaching more of the target audience, enhancing public communication, building and strengthening relationships and encouraging involvement. 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 (e.g. 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. Some general strategies should be kept in mind when using social media, including *(26)*:

- Selecting specific platforms which will not only be the most effective but also manageable in terms of time and effort.
- Posting only relevant content and ensuring that this content comes from credible, reliable sources.

- Posting regularly; if an account is not updated regularly with new information it is likely that the audience will lose interest quickly. For example, the group can plan for a list of posts that can be updated on a regular schedule.
- 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).
- Checking and monitoring the content (e.g. spams, hate speech, rude language). As the use of social media platform and audience grow, it may be necessary to hire someone to moderate and manage these platforms.

Examples of using e-advocacy and social media

Example 1: Inclusion International's global campaign on the *Right to Decide (27)*

Inclusion International is the international network of people with intellectual disabilities and their families 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 levels on article 12 of the CRPD which asserts that – with support – all people with intellectual disabilities are able to make decisions and have control of their lives.

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

For more information, see: https://youtu.be/FdBwmE8dEhY

Example 2: *Breaking the Chains,* e-advocacy efforts to end abuse of people with psychosocial disabilities *(28)*

Breaking the Chains is an ethnographic photo/film documentary project about human rights violations against people with psychosocial disabilities. *Breaking the Chains* depicts the use of physical restraint and confinement of people with psychosocial disabilities 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. *Breaking the Chains* is a first of its kind documentary which situates *pasung* in the sociocultural-sociopolitical 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 the campaign efforts.

To learn more, see: https://youtu.be/T3eFlUwhGi0 .

Example 3: Mothers of children with Down's syndrome create a Carpool Karaoke video

Members of a Facebook group for children with Down's syndrome came up with the idea to create a video to celebrate World Down Syndrome Day. The families recorded clips in the style of Carpool Karaoke and then one father put it together. The singer Christina Perri, who performs the song A Thousand Years, which they sing along to, gave permission to use her song and supported the video. The video went viral on social media, with more than 4 million views on YouTube as of 2018.

To view the video, see: https://youtu.be/lbSBD-efKLA

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 *(29)*

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. This is often 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. Lawyers who are sympathetic to the cause that the advocacy group is defending should be approached.

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 in one case will influence the court's decision in subsequent cases both nationally and internationally.

Successful outcomes of strategic litigation can include bringing awareness to an issue, 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 or 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

Example 1: Validity, formerly the Mental Disability Advocacy Centre (MDAC), uses litigation to achieve social change for people with disabilities *(29)*

Validity, formerly the Mental Disability Advocacy Centre (MDAC), is an international organization that uses strategic litigation to promote human rights for people with psychosocial and intellectual disabilities.

Validity 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 Validity to tap into local expertise, to work with lawyers who maintain contact with clients, and to work with organizations who can use judgements to change and implement laws.

Validity'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. It uses advocacy tactically to make it more likely for judges to decide in the applicants' favour, and as a follow-through from successful (and unsuccessful) court judgements. The Organization's capacity-building programme 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. The organization was responsible for bringing the case before the court *(30)*.

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

Example 2: Disability Rights International *(31)*

The Inter-American Commission on Human Rights stated in a press statement that, after years of abuse, violence and exploitation in orphanages and psychiatric institutions, Guatemala must take urgent action to return children to their families and psychiatric detainees to the community.

The Inter-American Commission's statement results from legal action taken by Disability Rights International (DRI). Together with the Guatemalan Procuradoria de Derechos Humanos (PDH), DRI is representing hundreds of children who survived a fire at the Hogar Seguro Vírgen de la Asunción that killed 41 girls in March 2017 (see DRI's report "After the Fire" and the *Washington Post* op-ed). The girls who were killed had been protesting sexual abuse and forced prostitution at the orphanage. Instead of spending money on fixing up orphanages, DRI and the PDH are demanding that all children – including children with disabilities – be returned to their families and communities.

In collaboration with Guatemala's lead disability rights group, the Collectivo de Vida Independiente, DRI has also filed a collective complaint to represent the hundreds of people with disabilities detained at the Federico Mora psychiatric facility. That psychiatric facility has been called one of the most dangerous in the world, according to a BBC documentary done with DRI.

The United Nations Committee on the Rights of Persons with Disabilities has also responded to DRI's investigation by stating the orphanage placement in Guatemala should be brought to an end. DRI has asked the CRPD Committee to recognize this same principle for all children when it adopts a general comment on the right to community integration later this year.

For more information, see: https://www.driadvocacy.org/victory-guatemala-right-live-community/.

Tools for strategic litigation can be found in Annex 3, Section 3.13: Helpful tools for developing an advocacy campaign: Strategic litigation

Using international human rights instruments

A number of international standards, treaties and conventions have been put in place to ensure that the rights of all people – including persons with psychosocial, intellectual or 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 different treaty monitoring bodies which are responsible for overseeing the implementation of their respective conventions.

Each United Nations convention has a human rights treaty body that is responsible for overseeing the implementation of conventions and treaties. For example the Convention on the Rights of Persons with Disabilities is overseen by the Committee on the Rights of Persons with Disabilities. Given the importance of the convention in setting out rights and obligations related to persons with disabilities, it can be useful for advocacy groups to engage with the work of this committee.

Governments that have ratified conventions and treaties 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 or shadow reports) to the treaty monitoring body which will review these reports along with those submitted by a government.

On the basis of the reports submitted by both the state and the 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 seeing a full and accurate picture of the human rights situation in the country and not relying solely on reports by the government 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 United Nations system – the Human Rights Council. The council has its own state reporting mechanism known as the *Universal Periodic Review*, which allows for the involvement of NGOs, organizations of persons with disabilities and other bodies. Similar opportunities and mechanisms also exist within the regional human rights systems, including the African, Inter-American and European human rights mechanisms.

Examples of using human right mechanisms

Example 1: Using human rights instruments for advocacy – shadow report on the implementation of the CRPD *(32)*

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

Individuals were able to contribute directly to the report by providing information on practical difficulties encountered when exercising the human rights set out in the convention. The report was used by the Committee on the Rights of Persons with Disabilities when issuing comments and recommendations regarding Australia's obligations related to the convention.

For more information, see: http://www.globaldisabilityrightsnow.org/.

Example 2: International advocacy of a coalition of Haitian disabled persons' organizations to the CRPD Committee *(33)*

Haiti ratified the CRPD in 2009 and in 2017 undertook its first review by the CRPD committee on how the rights of the convention were being implemented in the country. At the time, a coalition of Haitian organizations of persons with disabilities developed a parallel report as part of the country review process. It was an opportunity for disability organizations, including those representing persons with psychosocial and intellectual disabilities, to express their concerns related to policies and programmes for persons with disabilities in Haiti. This example highlights how advocacy can be done at the international level and can influence the design of public policies at national level.

To check the alternative report on Haiti, see: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fICO%2fHTI%2f27387&Lang=en.

To check all State reports, see: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=1204&Lang=en.

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) (34) defines an advocacy message as "a concise and persuasive statement about your advocacy objective that captures:

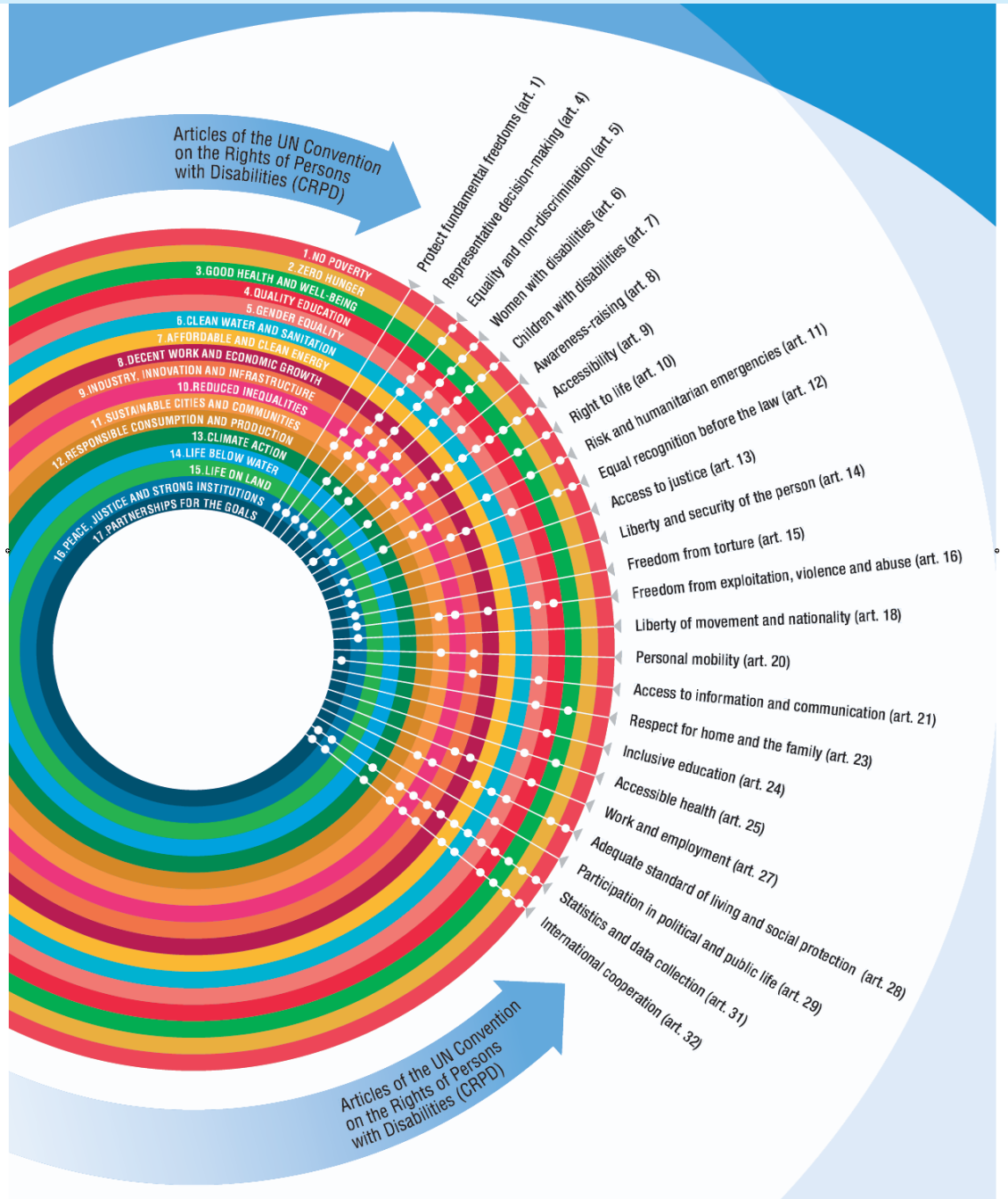
- what you want to achieve;
- why you want to achieve it (including the positive or negative consequences of no action);
- how you propose to achieve it; and
- what action you want taken by the audience."

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 media).

Examples of key messages

Example 1: CBM uses CRPD and Sustainable Development Goals infographic (35)

In February 2016 CBM launched an infographic linking disability, human rights and United Nations Sustainable Development Goals (SDGs). Specifically, the message outlines the important relationship between the SDGs and the CRPD and highlights that the rights of persons with disabilities must underpin all actions to implement the SDGs.



To learn more, see: http://www.cbm.org/New-resources-on-Agenda-2030-and-the-CRPD-501728.php.

Example 2: QualityRights Gujarat, India *(36)*

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 by helping mental health services to develop a supportive and respectful recovery-oriented environment for people using the services.

In July 2015 the project helped organize an awareness walk to promote mental health, encouraging persons 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, see: http://www.who.int/mental_health/policy/quality_rights/en and https://qualityrightsgujarat.wordpress.com/about/

Personal stories

A powerful component of any message can be the telling of personal stories. These can be an effective way of making the public aware of the challenges encountered by people with psychosocial, intellectual or cognitive disabilities and/or their families and care partners. Personal stories can be incorporated into different forums and can be an influential part of any campaign activity. For example, personal stories can be written down, published in the media or on websites, or filmed; hence, the stories 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 way to capture the attention of target audiences.

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

- The person who is the subject of the story has given consent for the story to be told.
- 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

Example 1: Dementia: My new world *(37)*

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, through self-advocacy and empowerment, has gone on to find ways to live well with dementia, she shares her personal feelings after first being 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 realize 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.

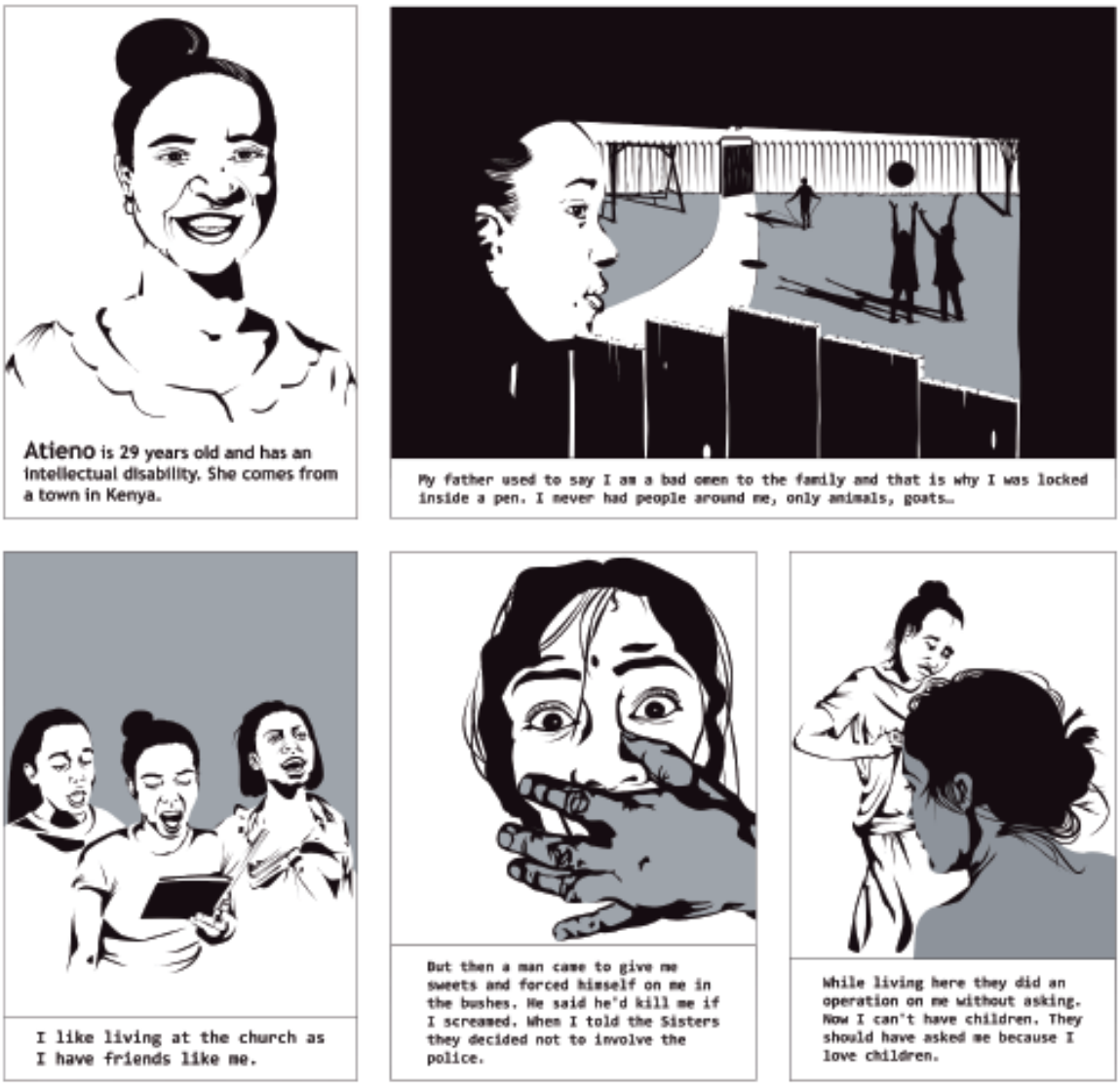
Most days are now an effort not to just sit in a corner and cry, not to just give up or to give in to it. It requires a great amount of emotional effort to live a 'normal' existence and is truly the most demeaning and frightening experience I have had, with a feeling of wretchedness I have not felt before.

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 realizing 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."

Example 2: The Right to Legal Capacity in Kenya: Atieno's Story *(38)*

In early April 2014, Validity, formerly the Mental Disability Advocacy Centre (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. It also provides comprehensive recommendations to bring Kenya in line with international law,

and specifically the right to legal capacity guaranteed by Article 12 of the Convention on the Rights of Persons with Disabilities, or CRPD. The report exposes deeply-rooted oppression of people with intellectual and psychosocial disabilities, urging the Kenyan government to take practical actions to address widespread social stigma which restricts 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 woman with an intellectual disability living in Kenya.



Example 3: MindFreedom Personal Story Project: Beate's story *(39)*

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. Beate Braun shares her personal story below.

"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 labelled 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 he 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 [medication] is not too much. I take care of myself by taking a tour with my bicycle for 20 kilometres 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 and so on. It's good for my soul."

Example 4: Dementia stigma, I'm still me and I have a lot to contribute, Ireland

The Alzheimer Society of Ireland released a video showing people diagnosed with dementia telling their stories.

Forget the stigma, https://youtu.be/euvfdJLlnAQ , The Alzheimer Society of Ireland (1:34), accessed 9 April 2019.

3. Identify resources and funding

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

First, the resources 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
- Subsistence costs (for those who may not be able to participate or contribute without financial assistance).

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 should 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 affordable activities or at least prioritize those activities which are most important to carry out and which will have the largest impact.

In some countries, registration as an NGO may be a prerequisite for receiving funding.

4. Take action: Implement, monitor and evaluate

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

Additionally, unexpected circumstances (both good and bad) may arise when implementing a campaign, which might mean going back and revising the plan accordingly. This will require a thorough review of all 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? Are they 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 others later. For instance, an advocacy group may have devised a comprehensive e-advocacy campaign, but later learn that they do not have enough volunteers to monitor and update regularly all of their chosen social media platforms (website, Facebook and Twitter). Once realized, they may decide to scale down their e-advocacy efforts by using only a Facebook page which they can update on regularly. 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. After reflection, they may decide to conduct a fundraising initiative in order to secure the necessary funding for the travel costs.

Remember that running an effective advocacy campaign is not easy. 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:

- ***Resistance*:** Advocacy groups may encounter resistance from policy-makers, practitioners and others who fail to acknowledge the expertise and experience that persons with psychosocial, intellectual or cognitive disabilities bring to decision-making processes. However, the CRPD requires that persons with disabilities participate in all processes on issues affecting them, and thus sustained lobbying may be needed to overcome this resistance and ensure that the slogan “nothing about us without us” becomes a reality.
- ***Lack of support*:** Some advocacy campaigns are not effective because they are not supported by enough stakeholders. Sustainability of advocacy activities is increased by

organizational support. Advocacy campaigns are more effective when the cause is a collective one and when individual advocates 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 or cognitive disabilities face or those that families and care partners may be advocating for. It is important not to lose sight of the small incremental changes that can occur over time. Eventually, these can add up to produce larger, more visible improvements.
- ***Discrimination*:** There is still a lot of discrimination in the community towards people with psychosocial, intellectual or cognitive disabilities. Information and education will contribute to reducing prejudice but competing pressures will lessen their impact. Time and self-reflection are required for community attitudes to move positively towards non-discrimination. Advocacy activities need to address both the tendencies of people to discriminate and the prevailing community views about social justice.
- ***Political support*:** A good cause may be undermined by the lack of political will. A good idea can be too challenging for the time or situation. With this in mind, the issue to be addressed should 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.

Scenario: Challenges concerning self-advocacy in Cambodia, Myanmar and Thailand *(40)*

Setting up an advocacy process can be challenging. Advocacy movements in each country face unique obstacles. Nevertheless, it is possible to identify common challenges. For instance, self-advocacy groups from Cambodia, Myanmar and Thailand participated in a workshop in 2010 and shared with each other the challenges they faced. Their challenges included limited financial and technical support, limited techniques for marketing projects, and limited ownership, among others.

Monitor and evaluate

As noted 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 for understanding whether the campaign has had its intended impact. This includes measuring whether identified targets have been reached according to the indicators defined in the campaign plan (see Identify targets and indicators). The result of the evaluation may be shared with partners (e.g. the media, donors etc.).

The following questions should be considered when conducting the evaluation (7):

- Did the message(s) reach the target audiences?
- How did the audiences respond to the key message(s)?
- Were the partnerships/members/coalitions successful in drawing attention to the issue and building support for the advocacy objective?
- Were the targets met as assessed against predefined indicators?
- What was the impact and outcome of the campaign?
- Was there a differential impact of the campaign on different populations? Why/why not?
- Have the objectives been achieved?

Example of monitoring and evaluation

Evaluation of "see me" – the national Scottish campaign against mental health stigma and discrimination *(7)*

To address the negative attitudes and behaviours which systematically disadvantage people with psychosocial disabilities and persons close to them, the "see me" campaign was launched in October 2002 in Scotland. Its purpose is to tackle the stigma and discrimination experienced by people with psychosocial disabilities.

The "see me" campaign has five core objectives:

- To tackle stigma and discrimination by raising public awareness of how they affect persons 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, through consultation with key stakeholders, the ways in which anti-stigma and anti-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.

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. For more information, see: https://www.seemescotland.org/ .

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Annexes

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

A number of international standards, treaties and conventions have been put in place to ensure that the rights of persons with psychosocial, intellectual or 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 or cognitive disabilities. Human rights are afforded to *all* people on the basis of their humanity and consequently people with psychosocial, intellectual or cognitive disabilities are also entitled to the enjoyment of the same human rights on an equal basis with others.

Key United Nations 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 http://www.ohchr.org/en/professionalinterest/pages/cescr.aspx • International Covenant on Civil and Political Rights http://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx • Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment http://www.ohchr.org/EN/ProfessionalInterest/Pages/CAT.aspx • Convention on the Elimination of All Forms of Discrimination Against Women http://www.un.org/womenwatch/daw/cedaw/cedaw.htm • Convention on the Rights of the Child http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx	• 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 Punish Torture http://www.oas.org/juridico/english/treaties/a-51.html • European Convention for the Protection of Human Rights and Fundamental Freedoms http://conventions.coe.int/treaty/en/treaties/html/005.htm • 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 places duties on governments to: 1) respect human rights (i.e. refrain from infringing these rights; 2) protect human rights (i.e. states have a duty to take action to prevent violations by third parties); and 3) 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 United Nations 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**) adopted in 1966; and the International Covenant on Civil and Political Rights (**ICCPR**) also 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 in the UDHR are several that are of particular relevance to people with psychosocial, intellectual or cognitive disabilities. These include the rights to equality before the law; the right 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 disabilities. The two International Covenants (the ICESCR and the ICCPR) address many of the same rights as are found in the UDHR but in some instances expand on 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. Other key rights in this convention are the right to employment, the right to social protection, the right to an adequate standard of living, the right to education and other rights. In recognition that economic and social rights 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 (e.g. 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 or 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; the 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 the rights to freedom of thought, conscience and religion among others.
In addition to the ICCPR and the ICESCR, the United Nations 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 Convention on the Rights of Persons with Disabilities (2006) (discussed in detail below). Each of the legally binding United Nations treaties has its own monitoring body established to oversee Member States' compliance with the instrument.

The Convention on the Rights of Persons with Disabilities

In 2008 the Convention on the Rights of Persons with Disabilities (CRPD)[1] came into force. The convention sets out a wide range of civil, cultural, economic, political and social rights that persons with disabilities must be able to enjoy on an equal basis with others. The convention's coming into force marked a major milestone in efforts to promote, protect and ensure the full and equal enjoyment of all human rights by persons with disabilities.

Some of the key rights of the CRPD include:

- **The Right to equal recognition before the law (article 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 drive 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 and wanted, people with disabilities 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. According to article 14, therefore, involuntary detention in mental health and social services is prohibited.

- **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 (article 16)**
  Article 16 requires that measures be taken to protect people against and prevent all forms of exploitation, violence and abuse, and 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-specific and age-specific needs. Importantly also, article 16 requires that all facilities and programmes designed to serve people with disabilities should be effectively monitored by independent authorities.

[1] Convention on the Rights of Persons with Disabilities (CRPD). United Nations (UN) General Assembly Resolution A/RES/61/106, 24 January 2007. New York (NY): United Nations; 2007. (https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html, accessed 20 November 2018).

- **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 and 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.

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

Annex 2: Template for planning an advocacy campaign[2]

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

Priority advocacy 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 and 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.)

[2] Straight to the point: mapping an advocacy strategy, pp. 3–9 [online publication]. Watertown (MA): Pathfinder International; 2011. (http://www.pathfinder.org/publications/straight-to-the-point-mapping-an-advocacy-strategy/, accessed 16 February 2017).

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 toolkit Problem and 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*.

Audience

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

audience (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 audience

Objective 2

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

Objective 3

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

Secondary audience

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

Advocacy 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 that 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

Targets and indicators

For each objective, specify the main targets that the campaign is trying to achieve and an indicator that can help you to assess whether the campaign has met its targets		
Objective	**Target**	**Indicator**
Objective 1		
Objective 2		
Objective 3		

Activities and time frames

Advocacy activities should be designed to help achieve individual objectives, moving the campaign towards 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 is targeting, the forms of media that 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

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 opportunities for mobilization and communication?
List of key events and/or opportunities:

Key messages

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

Target audience(s)	Key message

Resources and funding

What resources are needed for each of the identified activities?

Activities	Resources needed	Funding source

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*[3] at:
https://qualityrights.org/wp-content/uploads/CBM-2013-CBM-The-Self-Advocacy-Toolkit-for-Mental-Health-Service-User_0.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[4] at: http://ctb.ku.edu/en/creating-and-maintaining-partnerships.

For guidance on increasing participation and engaging stakeholders in change efforts, see[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 under-represented 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 the people, groups or organizations that may be threats to the success of the campaign. For more information on allies and opponents maps, see page 54[3]:
https://qualityrights.org/wp-content/uploads/CBM-2013-CBM-The-Self-Advocacy-Toolkit-for-Mental-Health-Service-User_0.pdf

3.3 Carrying out a situational analysis

The **WHO QualityRights assessment toolkit**[5] can be used to provide a situational assessment of the quality of care and human rights conditions in mental health and social services.
The toolkit provides practical guidance for:

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

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[3] Ntulo CA. Self advocacy tool kit: for mental health services users [online publication]. Kampala: CBM and Basic Needs UK in Uganda (BNUU).
(https://www.mhinnovation.net/sites/default/files/downloads/resource/%28CBM%2C%202013%29%20CBM%20The%20Self%20Advocacy%20Toolkit%20for%20Mental%20Health%20Service%20User_0.pdf, accessed 3 March 2019).

[4] Community Tool Box. Tools to change our world [website]. Lawrence (KS): University of Kansas; 2014.
(http://ctb.ku.edu/en, accessed 16 February 2017).

[5] WHO QualityRights toolkit to assess and improve quality and human rights in mental health and social care facilities [online publication]. Geneva: World Health Organization; 2012.
(http://apps.who.int/iris/bitstream/10665/70927/3/9789241548410_eng.pdf?ua=1, accessed 2 February 2017).

The toolkit 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, intellectual and cognitive disabilities.

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

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 effects of an identified problem and can be a helpful tool when developing a visual structure of the solutions and how these can have an impact on change. For more information, see page 19 [6] : https://www.unicef.org/evaluation/files/Advocacy_Toolkit.pdf

https://qualityrights.org/wp-content/uploads/Advocacy_Toolkit.pdf

A **gap analysis** is a tool is used to identify current gaps (issues) and steps to improving a situation. This is a good pre-planning tool for developing a future action plan. To find out more, see page 75 of the *Self advocacy tool kit for mental health services users*[7]:
https://qualityrights.org/wp-content/uploads/CBM-2013-CBM-The-Self-Advocacy-Toolkit-for-Mental-Health-Service-User_0.pdf

A **Duty Bearers Analysis** is a tool that helps advocacy groups analyse influential people, their institutions, 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 *Self advocacy tool kit for mental health services users*[7]:
https://qualityrights.org/wp-content/uploads/CBM-2013-CBM-The-Self-Advocacy-Toolkit-for-Mental-Health-Service-User_0.pdf

A **SWOT analysis** is a tool used to identify areas where improvements can be made. The analysis looks at both the internal and the external environments. SWOT stands for strengths, weaknesses, opportunities and threats. It is presented in a square with four quadrants. For more information, see page 8 of the People's Peace-making Perspectives project's *Advocacy capacity building: a training toolkit*[8] at:
https://qualityrights.org/wp-content/uploads/AdvocacyCapacityBuildigToolkit_201110.pdf

https://www.c-r.org/downloads/AdvocacyCapacityBuildigToolkit_201110.pdf

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[6] Advocacy toolkit: a guide to influencing decisions that improve children's lives [online publication]. New York (NY): United Nations Children's Fund (UNICEF); 2010. (https://www.unicef.org/evaluation/files/Advocacy_Toolkit.pdf, accessed 16 February 2017).

[7] Ntulo CA. Self advocacy tool kit: for mental health services users [online publication]. Kampala: CBM and Basic Needs UK in Uganda (BNUU).
(https://www.mhinnovation.net/sites/default/files/downloads/resource/%28CBM%2C%202013%29%20CBM%20The%20Self%20Advocacy%20Toolkit%20for%20Mental%20Health%20Service%20User_0.pdf, accessed 3 March 2019).

[8] Advocacy capacity building: a training toolkit. Produced as part of the People's Peace-making Perspectives project [online publication]. London: Saferworld and Conciliation Resources; 2011. (http://www.c-r.org/downloads/AdvocacyCapacityBuildigToolkit_201110.pdf, accessed 16 February 2017).

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[9]:

http://www.thechangetoolkit.org.au/writing-submissions/

https://qualityrights.org/wp-content/uploads/Chapter-7-Writing-submissions.pdf

3.5 Letters to politicians

To learn more about the structure of writing a letter to a politician, see page 56 of the *Public health advocacy toolkit, Third Edition*[10] at: https://qualityrights.org/wp-content/uploads/PHAIWA-Advocacy-in-Action-Toolkit-3rd-Edition.pdf

3.6 Writing a petition

For details on how to write a petition, see page 68 of the *Self advocacy tool kit for mental health services users*[11] at:
https://qualityrights.org/wp-content/uploads/CBM-2013-CBM-The-Self-Advocacy-Toolkit-for-Mental-Health-Service-User_0.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

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[9] Hey - I've got something to say..! Tips for writing a submission to government [online publication]. Melbourne: Mental Health Legal Centre; 2011. (http://www.thechangetoolkit.org.au/writing-submissions/, accessed 16 February 2017).

[10] Public Health Advocacy Institute of Western Australia (PHAIWA). Public health advocacy toolkit, Third Edition [online publication]. Perth: Curtin University; 2013. (https://www.phaiwa.org.au/the-advocacy-toolkit/, accessed 16 February 2017).

[11] Ntulo CA. Self advocacy tool kit: for mental health services users [online publication]. Kampala: CBM and Basic Needs UK in Uganda (BNUU).
(https://www.mhinnovation.net/sites/default/files/downloads/resource/%28CBM%2C%202013%29%20CBM%20The%20Self%20Advocacy%20Toolkit%20for%20Mental%20Health%20Service%20User_0.pdf, accessed 3 March 2019).

[12] Guidelines for writing a policy brief [online publication]. Manila: Community-Based Monitoring System (CBMS) Network Coordinating Team and Partnership for Economic Policy. (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, accessed 16 February 2017).

https://qualityrights.org/wp-content/uploads/CBMS-Network-Coordinating-Team._Guidelines-for-Writing-a-Policy-Briefpdf.pdf

3.8 Letters to the editor

To learn more about the structure of writing a letter to the editor, see page 64 of the *Public health advocacy toolkit, Third Edition*[13] at: https://qualityrights.org/wp-content/uploads/PHAIWA-Advocacy-in-Action-Toolkit-3rd-Edition.pdf

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*[14] at:
https://qualityrights.org/wp-content/uploads/CBM-2013-CBM-The-Self-Advocacy-Toolkit-for-Mental-Health-Service-User_0.pdf

3.10 Press/media release

For information on creating media releases, see page 49 of the *Public health advocacy toolkit, Third Edition*[13] at: https://qualityrights.org/wp-content/uploads/PHAIWA-Advocacy-in-Action-Toolkit-3rd-Edition.pdf

3.11 Interviews

To learn more about the structure of interviews, see page 60 of the *Public health advocacy toolkit, Third Edition*[13] at: https://qualityrights.org/wp-content/uploads/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, see The Community Tool Box's *Using social media for digital advocacy* [15] at: http://ctb.ku.edu/en/table-of-contents/advocacy/direct-action/electronic-advocacy/main.

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[13] Public Health Advocacy Institute of Western Australia (PHAIWA). Public health advocacy toolkit, Third Edition [online publication]. Perth: Curtin University; 2013. (https://www.phaiwa.org.au/the-advocacy-toolkit/, accessed 16 February 2017).

[14] Ntulo CA. Self advocacy tool kit: for mental health services users [online publication]. Kampala: CBM and Basic Needs UK in Uganda (BNUU).
(https://www.mhinnovation.net/sites/default/files/downloads/resource/%28CBM%2C%202013%29%20CBM%20The%20Self%20Advocacy%20Toolkit%20for%20Mental%20Health%20Service%20User_0.pdf, accessed 3 March 2019).

[15] Community Tool Box. Tools to change our world [website]. Lawrence (KS): University of Kansas; 2014. (http://ctb.ku.edu/en, accessed 16 February 2017).

3.13 Strategic litigation

The Global Initiative for Economic, Social and Cultural Rights website[16] provides additional information on strategic litigation and legal advocacy. To learn more, see: http://globalinitiative-escr.org/strategic-priorities/strategic-litigation-and-legal-advocacy/.

3.14 Implementing activities[15]

To learn more on implementing campaign activities. See the Community Tool Box's *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.

[16] Strategic litigation and legal advocacy [website]. The Global Initiative for Economic, Social and Cultural Rights; 2012. (http://globalinitiative-escr.org/strategic-priorities/strategic-litigation-and-legal-advocacy/, accessed 16 February 2017).

Annex 4: Template for developing the advocacy goal and objectives

Below is a blank template that provides guidance in developing and organizing 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:	

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

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

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

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

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