

# Mosaic toolkit to end stigma and discrimination in mental health





# **Mosaic toolkit to end stigma and discrimination in mental health**

**Abstract:**

Stigma and discrimination related to mental health conditions are widespread and harmful. Reducing stigma and discrimination can benefit families, societies and economies – it can save lives. The toolkit offers practical guidance on how to achieve this, based on three core evidence-based principles: leadership or co-leadership by people with lived experience, social contact, and inclusive partnerships. These 3 principles can be realized using a four-step process: identify and define aims, plan and prepare, launch and learn and reflect and proceed. Twelve case studies from all across the world are provided to demystify the process. Stigma and discrimination can be ended if each of us acts as one using the principles in this toolkit.

**KEYWORDS: MENTAL HEALTH, SOCIAL STIGMA, SOCIAL DISCRIMINATION, SOCIAL INCLUSION, LEADERSHIP, EMPOWERMENT**

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## Corrigendum

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1. On page vi

Dion Ras (expert by experience, Netherlands (Kingdom of the)) is added to the 5th paragraph of the acknowledgement section thanking him for the expert contributions to the toolkit.

This correction was incorporated into the electronic file on 10 October 2024.

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## Foreword

We can end stigma and discrimination in mental health.

This was the clarion call of the Lancet (1) Commission on Ending Stigma and Discrimination in Mental Health, laying out eight recommendations on how this can be achieved. One of those recommendations is now before you: the Mosaic toolkit.

The Lancet Commission synthesized evidence from over 200 systematic reviews worldwide. The results could not be clearer: mental health stigma and discrimination is pervasive and can be incredibly harmful; it is considered by many people with lived experience of mental health conditions as worse than their conditions. Because of stigma, people with mental health conditions worry about whether they will be able to find or keep employment if they disclose their condition. Just because they have a mental health condition, many people are effectively barred from full and equal participation in society. This cannot continue.

Luckily, nobody needs to start from scratch. As you will find, reducing stigma and discrimination is accessible and often straightforward. No matter your culture, resource level or experience, stigma and discrimination can be reduced by supporting authentic human connection between people with lived experience of mental health conditions and those without.

The key is not just social contact, however; it is also meaningful collaboration – collaboration led or co-led by people with lived experience, within and across health and other sectors. This toolkit itself is the result of such collaboration: as a product of the pan-European Mental Health Coalition, it harnesses the enormous richness of experience and knowledge of professionals and people with lived experience.

This kind of collaboration, I am proud to say, is central to WHO's work on mental health. Strengthening such collaboration is why we created the pan-European Mental Health Coalition, which is made up of more than 300 policy-makers, academics, professionals and people with lived experience. At the WHO Regional Office for Europe, we are approaching mental health from every angle: from the perspectives of quality of care, health financing, the health and care workforce, digital health, healthy ageing and more. Mental health follows us everywhere, so it is clear that every aspect of society is relevant to its promotion and protection.

These three principles – leadership and co-leadership by people with lived experience, social contact, and inclusive collaborations – are the backbone of the Mosaic toolkit and of anti-stigma work in general. They are brought to life through case studies from contexts across the world. Indeed, our contexts are where we have power: we know them better than anyone. That knowledge is the lifeblood of the processes described in this toolkit.

When this knowledge is used collectively, with each of us working in our contexts to change minds, we can see the component parts of the mosaic for which this toolkit is named. By contributing to this bigger picture, we can play our part in building a world without mental health stigma and discrimination.

Dr Hans Henri P. Kluge  
Regional Director  
WHO Regional Office for Europe



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# Abbreviations

**ARTEMIS** Adolescents' Resilience and Treatment Needs for Mental Health in Indian Slums

**BNBR** Basic Needs Basic Rights

**COVID-19** coronavirus disease

**CRPD** United Nations Convention of Rights of Persons with Disabilities

**EU** European Union

**LMIC** Low- and middle-income country

**NGO** Nongovernmental organization

**READ-MH** Responding to Experienced and Anticipated Discrimination Mental Health

**SMART MH** Systematic Medical Appraisal, Referral and Treatment Mental Health

**ZEST** Zone of Expression Against Stigma

# Glossary

- Anti-stigma activities and programmes** Activities: events or actions intended to reduce stigma and discrimination, incorporating principles of leadership/co-leadership by people with lived experience, social contact and inclusive collaborations; programmes: coordinated sets of activities intended to reduce stigma and discrimination.
- Core management group** The team that leads and is responsible for the anti-stigma programme and/or activity.
- Lived experience** All aspects of what a person has undergone and learned based on their history, perspective and identity.
- Partner** Member of the core management group.
- People with lived experience** Anybody with the lived experience (all aspects of what a person has undergone and learned based on their history, perspective and identity) of any type of mental health condition.
- Recovery** This is not about “being cured” or “being normal again”: it is about the person gaining control of their identity and life, having hope for their life, and living a life that has meaning for them – whether that be through work, relationships, community engagement, or some or all of these.
- Stakeholders** Individuals and groups outside the core management group who are interested in the programme and/or the activity, and who may wish to be involved in an advisory role.
- Stakeholder advisory group** A group of stakeholders in the programme and/or activity (usually without decision-making power) who provide advice on aims, design, implementation and evaluation, as well as dissemination of the results.
- Target group** The group targeted for stigma reduction by an anti-stigma activity or programme.

# Overview

## About this toolkit

WHO's Mosaic toolkit is intended to promote action to end stigma and discrimination against people with mental health conditions. Its central message is that relatively little is needed to get started – just knowledge of the core principles, skills to collaborate and communicate, and patience and persistence.

## Who this toolkit is for

WHO's Mosaic toolkit is designed for everyone who wants to be involved in anti-stigma work. It aims to demystify the process of reducing stigma and discrimination, and to lower barriers to entry for individuals and organizations that have conducted no or few anti-stigma activities so far. Those who have engaged in anti-stigma work in the past may also find it useful, however – for example, to use as a reference when advocating buy-in from stakeholders, and to promote adoption of evidence-based stigma-reduction principles in sectors where such work might not have been conducted before.

## How to use this toolkit

WHO's Mosaic toolkit demonstrates why it is important to reduce stigma and discrimination, and sets out practical steps to achieve this. The toolkit does not provide a checklist for setting up and running anti-stigma activities. Rather, it presents information about what is necessary, which can be adapted to fit any context.

First, the toolkit lays out the necessary components of any effective anti-stigma programme or activity (Chapter 1). Anti-stigma programmes should:

- be led or co-led by people with lived experience of mental health conditions.
- use strategies based on social contact.
- be built on inclusive collaborations.

The toolkit then sets out a four-step process, incorporating these principles, to run activities or programmes to reduce stigma (Chapter 2)

Step 1. Identify and define aims.

Step 2. Plan and prepare.

Step 3. Launch and learn.

Step 4. Reflect and proceed.

This process is brought to life through 11 case studies on successful or promising anti-stigma activities and programmes at different scales from across the world (Chapter 3).

The case studies are organized from small to large scale – from individuals to national organizations. Following the case studies, a spotlight on the situation in the European Union is provided to give a sense of international work on stigma reduction.

Following a brief conclusion, Annex 1 sets out frequently asked questions about the Mosaic toolkit and anti-stigma work; Annex 2 lists useful tools and resources; Annex 3 sets out rights-based and disability perspectives in mental health; and Annex 4 outlines some common myths and misconceptions about mental health stigma and discrimination and how to tackle them.

Effective, evidence-based ways to reduce stigma exist. It is time to accelerate and scale up anti-stigma programmes worldwide. It is time to end stigma and discrimination for good.

## Mosaic

A **mosaic** is a pattern or picture made up of smaller component parts. Mosaics have a long history, starting from Mesopotamia in the 3rd millennium BC. Over the centuries, mosaics have been used all across the world. Mosaics are symbolic of efforts to end stigma and discrimination in mental health as each programme, small or large, is part of a bigger picture. Together, these harmonious elements can enable a future where no one has to suffer stigma and discrimination due to their mental health condition.



# Chapter 1. \_\_\_\_\_

## **The overwhelming case for ending stigma and discrimination in mental health**



# The importance of reducing stigma and discrimination

Most people living with a mental health condition consider the stigma associated with it to be worse than the condition itself (1). People with mental health conditions must contend with more than just the symptoms of the condition. They also face a range of negative and incorrect beliefs (misinformation), negative attitudes (prejudice) and negative behaviours (discrimination) related to their condition, which make it harder for them to live and flourish. These three components make up stigma.

Stigma and discrimination are prevalent across cultures, regardless of the specific symptoms or diagnosis. Their impacts are many and mainly harmful: from personal to social and economic harms; from distress in daily life to direct harms to health, according to WHO's world mental health report (2). For example, people who experience stigma and discrimination:

- ➔ are less likely to seek health care when needed;
- ➔ report lower quality of life and greater hopelessness about life;
- ➔ are less confident and more likely to be lonely;
- ➔ find it more difficult to build relationships or start a family;
- ➔ are more likely to have suicidal ideation;
- ➔ find it harder to get work, study or have secure housing;
- ➔ live up to 20 years less than the rest of the population and
- ➔ often refrain from seeking help, putting them at greater risk of physical illness and exacerbated symptoms.

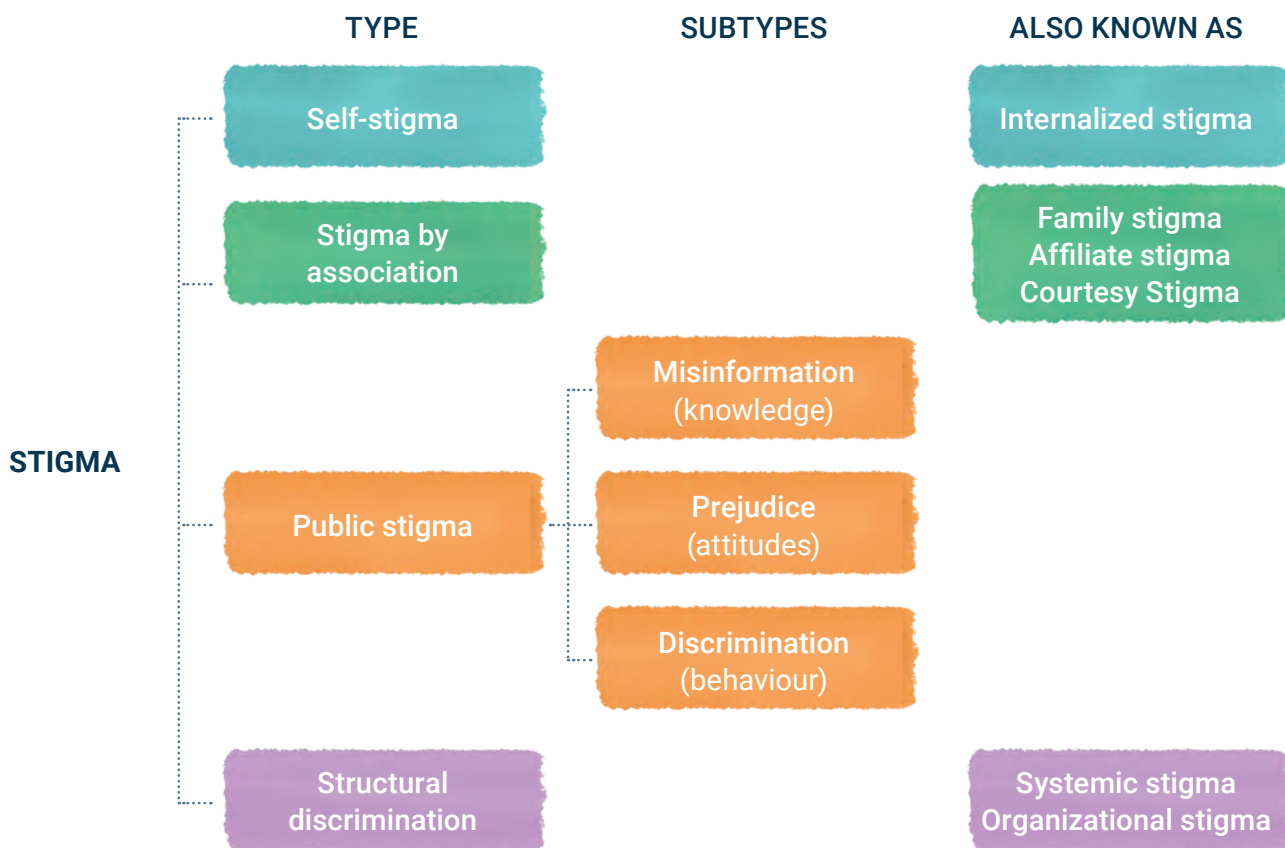
## Types of stigma and discrimination

Stigma occurs when a specific trait of a person or a group of people is viewed negatively (3). Society may come to see any person with that trait as different in an undesirable way – as “other” – leading to an unnecessary division between “us” and “them”. This is often followed by different and often worse treatment for the stigmatized group. For example, having a mental health condition may be seen as a weakness and as the person's fault.

Four types of stigma can be identified (Fig. 1), according to the *Lancet* Commission on Ending Stigma and Discrimination in Mental Health (1).

- ➔ Self-stigma is when a person internalizes others' prejudicial attitudes (e.g. “I'm not well because I am weak” or “It's my fault that I am unwell”).
- ➔ Stigma by association is when a person is viewed negatively or treated poorly because of a relationship or association with somebody from a stigmatized group, such as a person with a mental health condition. In many countries, family or friends are the primary targets of such stigma, but it can also include staff of mental health centres or hospitals.
- ➔ Public stigma refers to negative knowledge, attitudes or behaviours of large groups within society towards people with mental health conditions.
- ➔ Structural discrimination refers to larger-scale injustices, such as discriminatory laws or policies, or inadequate allocations of funding for mental health care.

**Figure 1.** Types of stigma and discrimination



Source: adapted with permission from Thornicroft et al. (1).

## The harmfulness of all types of stigma

Self-stigma can make people feel powerless to change their situations or make them feel that they need to give up on things that are important – the “why try” syndrome (for example, “Why should I try to live independently? I can’t manage a household on my own”) (4).

Stigma by association can lead to shame and guilt among families, who may feel blamed for “causing” the mental health condition. It may also result in careers in mental health care being perceived as less prestigious than those in physical health care.

Because of public stigma, people may avoid seeking help for their condition, which can cause it to be prolonged and to worsen.

Structural discrimination can shape systems in a way that makes it hard for people with mental health conditions to find and keep work, or to receive high-quality mental health care.

## Reducing stigma and discrimination to save lives

Reducing stigma and discrimination in mental health can help people feel more accepted in their communities, more capable at work and more optimistic about the future. Stigma reduction can benefit families, societies and economies (5). It can encourage people to get help to recover, and can reduce social exclusion and isolation. Lessening stigma can also improve access to physical health care, reducing premature mortality.



## Three core principles of reducing stigma and discrimination

Stigma and discrimination in mental health can be effectively reduced by embedding the following three core principles into any anti-stigma activity:

- ➔ leadership or co-leadership by people with lived experience
- ➔ social contact
- ➔ inclusive collaborations.

### Leadership or co-leadership by people with lived experience

The meaningful participation and leadership of people with lived experience (Box 1) of mental health conditions leads to more effective anti-stigma activities, and may promote their recovery and build skills for further anti-stigma work (1). “Nothing about us without us” is a cornerstone of anti-stigma activism, originating in the disability rights and recovery movements (6). This motto means that anyone affected by a policy or programme has the right to participate in creating it. This right is also enshrined in the United Nations Convention on the Rights of Persons with Disabilities (7).

## Box 1. What does “people with lived experience” mean?

“Lived experience” refers to all aspects of what a person has undergone and learned based on their history, perspective and identity. It is distinct from professional or educational experience, which is more often determined by common shared standards, giving it an equal value to those involved in it. Lived experience should be seen as a hugely valuable asset. It is a form of expertise that can improve societal systems, research, policies and programmes. Even so, lived experience is sometimes difficult to conceptualize or put into words (8).

People with lived experience do not have to be in treatment; nor do they need to have had care or treatment at any time. For that reason, they are not necessarily “patients”, “clients” or “service users”, and may reject these terms.

The term “people with lived experience” emphasizes the expertise gained through experience of a mental health condition. However, it is important that lived experience is understood as one facet of an individual – alongside the experience of a mental health condition, they also have a diverse range of other abilities, skills, roles and experiences that may add value to anti-stigma work.

For the purposes of the Mosaic toolkit, “people with lived experience” refers to anybody with the lived experience of any type of mental health condition. The term is an identity marker, not a diagnostic label. Further, despite its use in this toolkit, the term is not proposed as universally applicable. Some people will prefer to use the term “lived experience”, while others will prefer different terms – such as “experts by experience”, “people with experiential knowledge” or “people with rare experiential knowledge”. Others may prefer to use no identifying term at all. When working with people who have experience of mental health conditions, taking the time to establish acceptable and agreed terminology is crucial.

People with lived experience should be involved from the beginning of any anti-stigma work, preferably in leadership or co-leadership positions where their contributions are valued equally to any other expertise shaping the activities.

Every effort should be made to empower people with lived experience to lead, co-lead or participate in the way that is most meaningful and safest for them. Mere participation is not enough, however: participation must be meaningful. Drawing on the definitions of WHO (9) and the Global Mental Health Peer Network (10), “meaningful participation” can be secured through commitment to the following considerations.

- People with lived experience should be treated with dignity and respect. The expertise of people with lived experience should be given equal value to that of professionals. The preferences of people with lived experience should be considered carefully because it is their lives that will be affected by the activity.
- Every effort should be made to correct imbalances of power, and to ensure equity and safety. In group discussions, people with lived experience may not feel comfortable speaking alongside professionals. Creating a sense of safety is important, which means listening to what people with lived experience say and need. Sometimes, people with lived experience may feel safer in a self-help group composed only of people with lived experience.
- People with lived experience should not be viewed as a single group. They have different experiences, identities and priorities. This diversity is an asset.

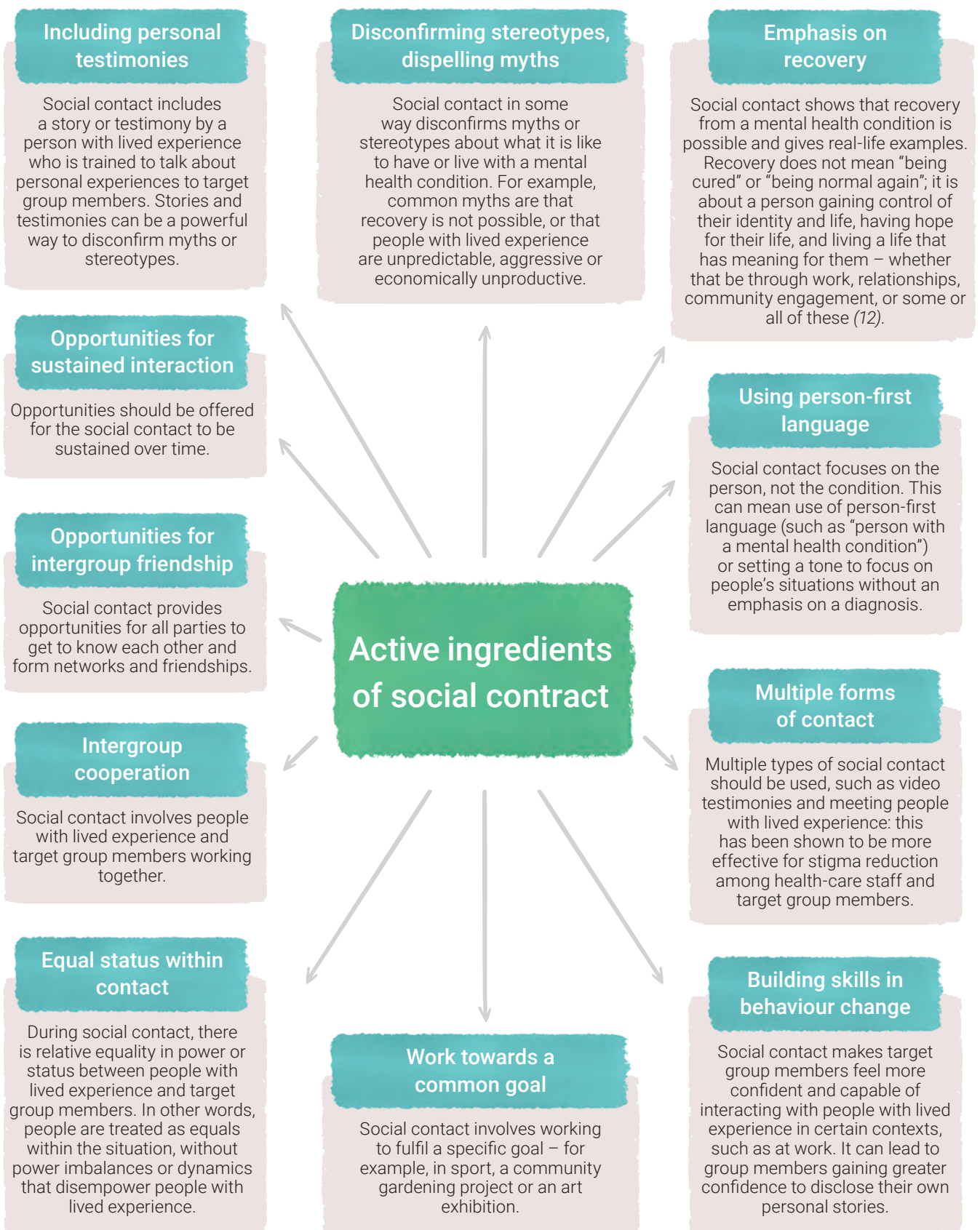
- Engagement should be consistent and transparent. What is expected of people with lived experience should be communicated consistently, along with any potential harms and what the planned impact of their participation will be. Any restrictions to participation should be clear and explained.
- “Tokenism”, where people with lived experience contribute but are not fairly valued, or where their contributions have no actual impact, should be avoided.
- Participation should be a core facet of the activity’s culture and ways of working. Inclusion is a human right.
- Stakeholders should not overprotect or be paternalistic towards people with lived experience, as this might make them feel uncomfortable.

## Social contact

Evidence shows that the best way to reduce stigma and discrimination is through social contact between people with and without the stigmatized feature (1). In the case of mental health-related stigma, this means social contact between people with lived experience of a mental health condition and those who do not have that experience. Social contact is not any kind of contact. It has distinct features (11), which are summarized in Fig. 2.



**Figure 2.** The active ingredients of social contact



These active ingredients play a crucial role in reducing stigma and discrimination by achieving several key outcomes. First, they foster empathy within the target group, promoting understanding and compassion towards individuals with lived experience. Second, they enhance the target group's ability to see the world from the perspective of those affected. Finally, they alleviate anxiety within the target group, facilitating more positive interactions with people with lived experience (13). These effects of social contact help to reduce prejudice and improve behaviour.

A specific anti-stigma activity or programme does not need to include all the active ingredients of social contact. Each may be more or less relevant, depending on the activity or target group, and this should be considered during the planning stages (see Chapter 2, Step 2 for more information).

Social contact can be direct or indirect (14), as shown in Table 1.

**Table 1.** Types of social contact

Type of contact	Description
<b>Direct contact</b>	In-person, live contact with people from the stigmatized group: interactions between people with and without a mental health condition
<b>Indirect contact</b>	Contact between people with and without a mental health condition that does not happen in the same physical place and/or concurrently  Achieved by electronic, digital or remote communication methods
<b>Electronic contact</b>	Interactive contact with a person or people from the stigmatized group via electronic means (generally computer-mediated technologies) – for example, contact via social media, text-based chat rooms and other online interactions
<b>Imagined contact</b>	Using mental simulation to imagine positive social contact with people from the stigmatized group – for example, visualizing interacting with a person with a mental health condition at work or as a part of a social activity
<b>Vicarious contact</b>	Observing interactions between people with and without a mental health condition – for example, through watching TV, listening to the radio, or reading a book or news story describing positive intergroup contact
<b>Parasocial contact</b>	Exposure to positive portrayals and representations of people with a mental health condition on TV, on the radio, in print and so on (such as fictional characters in a film or documentary)
<b>Extended contact</b>	Awareness that someone a person is associated with has direct contact with a person from the stigmatized group – for example, knowing that a friend has a close connection with a person with a mental health condition





## Inclusive collaborations

In addition to strong partnerships with people with lived experience, anti-stigma activities and programmes tend to have greater impact when they are built on strong collaborations with a wide variety of groups in society, including:

- members of the target group for stigma reduction;
- members of the local community, such as community or faith leaders;
- health and social care providers;
- not-for-profit or civil society organizations;
- policy-makers or members of local, regional or national governments;
- people working with media, including social media;
- researchers and academic institutions;
- other individuals or organizations already involved in anti-stigma work.

Each of these groups can bring unique insights from their perspectives, which can enrich the planned anti-stigma work, and can make it more relevant to the specific context and acceptable to its stakeholders. For example, collaborating with the media may enable anti-stigma activities to reach wider audiences and decrease the likelihood that stereotypes will be spread or reinforced in storytelling. Researchers can join as evaluation partners, helping to monitor how activities are running and what impact they are having. Involving leaders in government or at the community level can help sustain larger programmes, through financial support or by connecting the work with systems and other ongoing programmes. Collaborating with peer communities and self-help groups made up of and led by people with lived experience can offer spaces to promote empowerment and self-esteem. Furthermore, all stakeholders involved in an activity or programme can use their networks to support communication of its insights and lessons learned, to inform anti-stigma activities nationally or even globally.

## **In focus**

Both traditional media (e.g. newspapers, television, radio) and new media (e.g. social media) can play a role in perpetuating stigma. They may use language that misrepresents or dehumanizes people with mental health conditions, reinforcing harmful and false stereotypes (such as linking mental health conditions with violence) that may be used to justify poor treatment. Media can, however, also act as a powerful agent in efforts to reduce stigma and discrimination (see Case study 6. Working with the media).

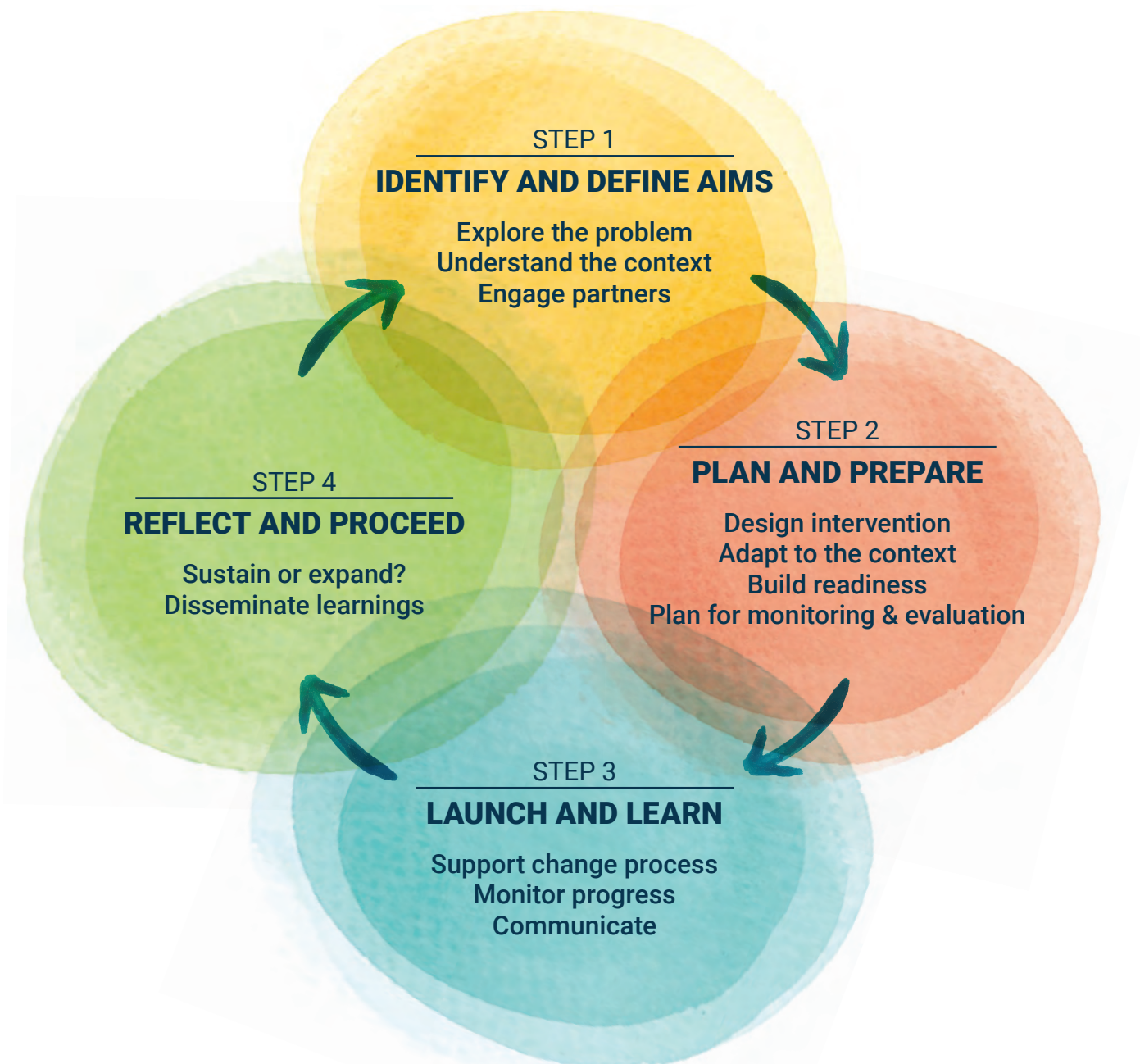


# Chapter 2. ---

## What to do to reduce stigma and discrimination

Chapter 2 details how to set up and launch a programme that uses evidence-based activities to reduce stigma and discrimination using the three core principles outlined in Chapter 1. Fig. 3 summarizes the four steps involved in this process.

**Figure 3.** Four steps to creating evidence-based activities and programmes to reduce stigma and discrimination



Rather than provide a comprehensive checklist of activities under each step, this chapter summarizes the overall process, noting – where possible – what can be scaled up or down depending on the aims and resource levels of the activity or programme. Stigma and discrimination are pervasive, but how they manifest depends on the culture. For the same reason, anti-stigma activities must be based on a clear understanding of the context in which they will take place; what can most effectively produce changes within that context; and the tools, resources and human connections available. The three core principles laid out in Chapter 1 – leadership/co-leadership by people with lived experience, social contact and inclusive collaborations – should be built into the entire process.



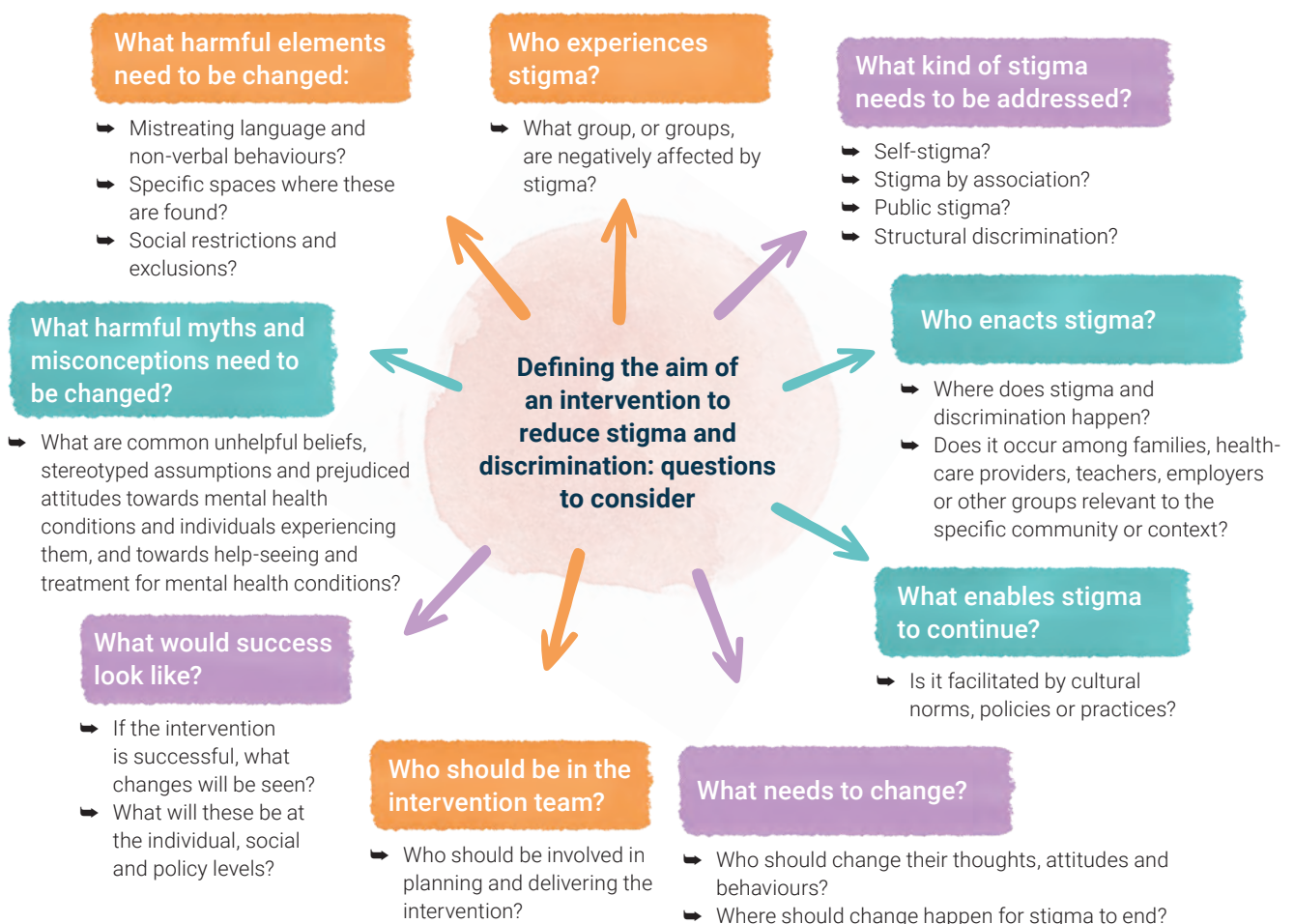
## Identify and define aims

An effective anti-stigma activity or programme requires a clear sense of the overall aim of the work and the context in which it will take place. It involves asking questions about the type of stigma that will be targeted for reduction, who will be the target group of the activity, and what success looks like.

### Identifying the aims

Stigma-reduction activities benefit from clear aims, a defined target group and a strong understanding of the context in which the work will take place. To establish these, a number of questions and subquestions need to be answered (Fig. 4). Key elements to consider include what and who needs to change in that specific context, why nothing has changed before, and what success would look like.

**Figure 4.** Questions to answer when defining the aims and context of anti-stigma activities



Source: adapted from concepts used in the RESHAPE project (15).

Regardless of the chosen aims of an anti-stigma activity, it is important that all partners endorse them to some extent – particularly those directly involved in management of the activity: the core management group or inner circle.

In the case of larger programmes, producing a shared set of aims endorsed by all partners is more difficult and may take more time to create. Time should be set aside for this purpose. The process will be aided by co-creative approaches, such as regular meetings facilitated by a project management lead, possibly using digital platforms.



## Understanding the context

Anti-stigma activities should be designed with a specific place or context in mind. Stigma manifests differently depending on the culture and context (16), and each context has specific factors that will help or hinder the success of an anti-stigma activity.

The following questions offer a starting-point for identifying these factors:

- What are the relevant social factors in the local context, including the social structure or ethnic groups (such as socioeconomic conditions, cultural practices and values, traditions and social norms, and political systems)?
- What is the local political situation, and what kinds of limitations or opportunities does this provide (e.g. are local government budgets increasing or decreasing)?
- What is the wider social, economic or political climate in the country and region?
- Which are the local groups supporting people with lived experience and their carers? Do they have experience of anti-stigma work? Do they want to be involved in this planned work? If no such groups exist, is it possible to establish one?
- Are there any ongoing activities or programmes with which the planned anti-stigma work could connect or combine?
- Is any relevant information available about previous anti-stigma activities? What was learned?
- Will the planned work form partnerships with local health-care services? How will this be done?
- What local resources, including funding, may be available to support the planned work? How can these resources be accessed?

In the case of larger programmes or work with organizational backing, a situational analysis may be suited to identifying the more diverse range of factors to be considered. Situational analyses are systematic processes to gather, examine and interpret information to help gain a detailed understanding of the context. They may include systematically searching available scientific literature, conducting surveys or organizing focus groups (Box 2). Information on these and other methods can be found in the Centre for Society and Mental Health Research Methods Toolkit (17).



## Box 2. Approaches to gather information about the context

- Insights from past work in this context, including work undertaken by the project members, should be considered.
- Research evidence in databases such as PubMed and Google Scholar should be reviewed.
- Consultations should take place with partners and stakeholders through workshops or community forums, making sure to involve groups of people with lived experience.
- Project members should conduct their own research, gathering verbal or textual information about what people think in that context. Methods include carrying out in-depth interviews and focus groups, or using surveys and questionnaires to gather information on knowledge, beliefs, attitudes, intentions and behaviours towards people with lived experience of mental health conditions.
- Social interactions within a community or in specific settings should be observed to understand how stigma manifests – for example, how health-care clinic receptionists behave towards people with and without a mental health condition.

A key aspect of contextualizing the activity is identifying the group or groups to be targeted for stigma reduction (for example, police, journalists or emergency room doctors and nurses). The target group should be considered a key partner in planning and executing the activity: members can provide insight into the unique challenges and experiences they face that influence stigma, as well as the impact of the anti-stigma activity.

When engaged as partners or stakeholders, members of the target group can help reduce resistance to behaviour change in fellow members of that group. Such an inclusive approach can foster a sense of shared ownership of the programme between people with lived experience and the target group. This allows activities to be made more respectful, more likely to be embraced by the communities affected, and more effective in reducing stigma.

### “Nothing about us without us” – respecting people with lived experience

People with lived experience are fundamental to every stage of anti-stigma activities. From the design and start of any anti-stigma activity, people with lived experience should play a central role as leads or co-leads in this work. Such involvement can also serve as a form of social contact itself, breaking down prejudice and discrimination in the core management group (1).

In addition to having experience of mental health conditions, people with lived experience bring a wide range of practical and professional skills from their work and life experiences (such as relevant higher education, project management capabilities and technical expertise). Many of these skills can add value to the anti-stigma activity.

*People with lived experience should not be seen as different from the rest of stakeholders, with no more or less value than them. Anything that can make them different in any way, including excessive benevolence or overprotection, may be seen as a lack of respect. People with lived experience may be or may not be more fragile, this lies above all on giving them a space to express a vulnerability, just as it could ideally be for any other stakeholders.*

**Arnaud Poitevin, person with lived experience**

Leadership or co-leadership by people with lived experience should be non-tokenistic, reflecting genuine co-design, co-creation and co-production of the work, and using equitable power relations between programme partners. Usually, the more people with lived experience involved the better, as this enables inclusion of a wider and more representative range of views.

The *Lancet* Commission on Ending Stigma and Discrimination in Mental Health surveyed people with lived experience on their perspectives of what to consider when engaging them in anti-stigma activities. The results are summarized in Table 2.

**Table 2.** Perspectives on participating in anti-stigma programmes

<b>What made your involvement in anti-stigma programmes difficult?</b>	<b>What made your involvement in anti-stigma programmes easier or more rewarding?</b>	<b>What are your recommendations for how best to involve people with lived experience in a programme?</b>
➔ Encountering stigma (e.g. ignorance, lack of sympathy, blame, pity)	➔ Training and support with shaping one's narrative	➔ Include people with lived experience at every stage of the programme
➔ Reliving past difficult experiences	➔ Practical support at an organizational level	➔ Include people with lived experience in leading positions for programme activities
➔ Coping with others becoming upset	➔ Receiving payment for involvement	➔ Arrange participation with the consent of people with lived experience
➔ Challenging interpersonal encounters – during and after programme involvement, and with health professionals	➔ Having expertise through experience validated	➔ Involve people at all stages of their recovery
➔ Tokenistic involvement	➔ Feedback on the impact of the programme	➔ Involve a diverse range of people
➔ Practical challenges (e.g. time commitments)	➔ Peer support	➔ Provide a platform to share lived experience
➔ Feeling anxious or nervous	➔ Personal sense of satisfaction	➔ Include facilitative factors such as training, payment and instrumental support
➔ Lack of awareness and recognition of mental health conditions		➔ Prepare for challenges
➔ Engaging the target group of the programme		

Source: based on findings from the Lancet Commission on Ending Stigma and Discrimination in Mental Health (1).

Based on these considerations, some practical ways to support participation of people with lived experience are as follows:

- financial support or payment for participation, according to their contribution to the project;
- providing information and training about recovery, rights and resilience – such as the WHO QualityRights Toolkit and its related materials (18);
- implementing “safe spaces” during programme work, where people can express their needs and preferences without fear of judgement (see Step 3 for more information);
- providing educational courses and materials or training as mental health ambassadors or peer workers (also called peer supporters or peer-support specialists) (see Annex 2);
- offering leadership training or training in programme or project management;
- involving or creating a community of people with lived experience – especially people who participate in social contact activities and
- protecting anonymity and confidentiality, and ensuring that participation does not compromise privacy, decisions and preferences regarding disclosure of personal experiences (Box 3).



### Box 3. Disclosure of mental health conditions

The core team should be mindful when the involvement of people with lived experience in an activity involves disclosing a mental health condition. In some countries, such disclosure can have highly negative consequences, such as job loss or social exclusion. The benefits and risks of sharing this information should be considered carefully beforehand. People with lived experience need to understand fully how they will be involved, and whether disclosure is a part of that. Disclosure cannot be taken back.

Disclosure can be done gradually: some people with lived experience may agree to disclose information only in face-to-face discussions; others only in self-help groups, small diverse groups, conferences, or on social or mass media. Disclosure may be different depending on the type of the audience: a person with lived experience may not be willing to disclose the same information to peers, health professionals, law enforcement agents, relatives/families or the larger public.

Time to Change, a pioneering anti-stigma programme (19), uses a levels of disclosure tool to support decision-making of people with lived experience. The levels are:

- ➔ I will share everything;
- ➔ I will reveal a lot about my own experience, but will keep some elements of my story to myself;
- ➔ I will only say that I have experience of mental health problems, without going into detail;
- ➔ I will only say broadly that I have a health issue or a disability in general and
- ➔ I won't reveal anything about my personal experience, but will talk more generally about the campaign.

Often, people with lived experience may wish to contribute to an anti-stigma activity but choose not to disclose anything. This can be accommodated while continuing to promote social contact. Contributions can be made in any form – such as putting on short plays or dramatic productions in which the actors do not say whether they have lived experience; contributing to audiovisual activities, such as cartoons or animations; fundraising or event management; or contributions using their professional expertise.

It helps to have a clear written objective – including scope and responsibilities – for all partners, outlining what their involvement entails. This should clearly state that the involvement of people with lived experience is voluntary, and it should contain explicit, written, informed agreement of roles and responsibilities. The agreement can also cover consent for plans of any specified personal use of information or material (such as story transcripts, quotations, photographs and recordings). Each person must be able to withdraw their consent to participate at any time.

### Identifying and forming partnerships

There are several ways to reach out to people with lived experience, depending on the context. Contact can be made via:

- ➔ peer-led organizations and advocacy groups;
- ➔ social media groups and online communities;
- ➔ organizations that represent mental health service users;

- social and community support organizations, such as homeless shelters, public employment services, social security bodies and medico-social services;
- self-help groups (online or offline);
- community leaders;
- health-care services, including psychiatry departments, psychosocial rehabilitation services, day care centres and outpatient care services (e.g. assertive community treatment teams, mobile crisis teams) and
- word of mouth.

It can be challenging to reach people with lived experience, especially if little anti-stigma work has been done in the area where the activity is intended to take place. In some contexts, there may not be any organizations or resources that connect groups of people with lived experience. In this case, one of the first steps can be to create a community of people with lived experience (see Step 3 for more information).

In addition to people with lived experience, other stakeholders in the community or context can be valuable partners at all stages of programme planning and development (see Chapter 1).

It can be useful to distinguish between two levels of involvement: the partners in the core management group or inner circle, and a wider set of stakeholders in an advisory group.

The core management group will be smaller and charged with decision-making around the stigma-reduction activities. It is advisable that some people with lived experience form part of this group whenever possible, along with members of the target group and any other stakeholders whose expertise or influence can help in achieving the goals of the programme or activity. A group agreement (also called terms of reference) may be co-written to ensure alignment on ways of working to achieve the activity's aims and objectives, and to define participants' roles clearly (Box 4).

#### **Box 4. What to include in a core management group agreement**

Core management group agreements or terms of reference serve to align members on the work and support collaboration. They may include:

- a description of the programme's aims and the roles and responsibilities of each partner;
- an understanding of the partners' financial and other liabilities;
- a description of the management, governance and oversight arrangements;
- an agreement or framework for dispute resolution;
- a list of anticipated risks and risk mitigation measures and
- a timeline and project management plan.

The wider advisory group of other partners may be less involved in day-to-day decision-making, focusing instead on providing knowledge about the context, identifying feasible or acceptable activities, or disseminating information about the activity through their networks.

Stakeholders can be invited to collaborate in several ways.

- A positive approach involves thinking about who can contribute to the activity meaningfully, and teaming up with them.
- A negative approach involves thinking about who could delay, impede or even stop the activity if they do not agree or align with the plans, and inviting them to participate from the start.
- A snowball approach involves asking stakeholders who join the activity to refer others who may be interested, and selecting relevant partners through these recommendations.
- An open-door approach involves being open to partners at all stages of the activity or programme implementation, even if they ask to contribute at a later stage (unless there is a strong reason not to do so).

Active mapping may also be employed, whereby the core group brainstorms local groups that could become stakeholders currently or in the future – such as health-care providers, community organizations or local government institutions. A stakeholder list is compiled, using local directories, online resources or consulting with experts in the field. Stakeholders are prioritized according to their importance, power and influence, and then narrowed down to the groups most likely to contribute positively to the activity. Embracing diverse perspectives can ensure a more thorough understanding of the issue, and promotes inclusivity in the programme.

## Identifying misconceptions among partners and stakeholders

Early in the process of designing the activity, it is advisable to identify any misconceptions among partners and stakeholders about stigma and discrimination in mental health that may impede the work or dissuade people from getting involved. These may include viewpoints such as “Stigma is a bad thing, but there isn’t enough evidence about what to do about it” or “Reducing stigma will increase demand for mental health care, so we should increase access to services, which are already under great stress, before doing anything” (see Annex 4 for some common myths and suggestions on how to respond to them).

The core management group might identify these and other misconceptions and develop scripts to argue against them. A similar tactic can be used to improve knowledge of mental health conditions in the target group or among the general public: this involves combating known myths about mental health conditions (such as the myth that having a mental health condition makes you more likely to be violent or not want to work).



## Plan and prepare

Step 2 is about preparing the activity or programme to reduce stigma and discrimination, drawing on the information gathered in Step 1.

### Selecting and designing anti-stigma activities

The next stage is to plan and prepare the practical details of the specific activity to reduce stigma and discrimination, and to identify how it will be delivered to achieve the aims laid out in Step 1. “Activity” here refers to the events or actions intended to reduce stigma and discrimination in the target group. Anti-stigma activities can be either designed for a specific setting or adapted from past work to suit the current context. Both have their advantages and disadvantages.

Creating a new activity takes time and effort. However, it may not be necessary if an existing activity can be adapted to the context or target group. On the other hand, while adapting an activity may take less time and enable a degree of comparison across contexts, it may be less effective if care is not taken during the adaptation process. Local partners and other stakeholders are useful in either case, as they can help to tailor the activity to best suit the target group and context.

For smaller programmes, activities can usually be carried out by the core management group. Larger programmes may require project staff specifically hired to run activities, engage with the target communities, and aid in monitoring and evaluating the success of the programme. Depending on the nature of the activities, this may involve recruiting individuals with backgrounds in psychology, public health, social work, business, marketing or community outreach, all of whom may be people with lived experience.

Whether an activity is developed or adapted, it needs to incorporate the three core principles outlined in Chapter 1:

- ➔ leadership or co-leadership by people with lived experience
- ➔ social contact
- ➔ building inclusive collaborations.

Table 3 summarizes the key considerations for anti-stigma activities, which can be useful in planning the activities based on the context.

**Table 3.** Key considerations in designing or selecting anti-stigma activities

Category	Key consideration
<b>Focus of the activity</b>	
Type of stigma targeted	<ul style="list-style-type: none"> <li>➔ Is the target self-stigma, stigma by association, public stigma or structural discrimination?</li> </ul>
Target group (who the activity aims to reach)	<ul style="list-style-type: none"> <li>➔ Is the target group the general population, police or law enforcement officers, housing providers, young people, media workers, politicians or other groups?</li> </ul>
<b>Key principles in practice</b>	
Leadership or co-leadership by people with lived experience	<ul style="list-style-type: none"> <li>➔ How will people with lived experience have a key role in planning, design and delivery of the social contact activity; programme management; monitoring and evaluation; and knowledge dissemination?</li> <li>➔ Do people with lived experience want or need training or support to lead, co-lead or otherwise participate meaningfully?</li> </ul>
Social contact	<ul style="list-style-type: none"> <li>➔ How will social contact be delivered within the activity?</li> <li>➔ Will social contact be direct or indirect?</li> <li>➔ What active ingredients of social contact will be included (emphasizing recovery, disconfirming stereotypes, including personal testimonies, or opportunities for intergroup cooperation, interaction and friendship)?</li> </ul>
Inclusive collaborations	<ul style="list-style-type: none"> <li>➔ Alongside people with lived experience, which other core partners and stakeholders are involved in designing or selecting the activity?</li> <li>➔ What are the roles and responsibilities of partners in the core management group?</li> <li>➔ What are the roles and responsibilities of stakeholders in the advisory group?</li> <li>➔ How will team members communicate with each other and coordinate their actions?</li> </ul>
<b>Practical issues</b>	
Scope of the activity	<ul style="list-style-type: none"> <li>➔ Is the activity international, regional, national, local, sectoral or organizational?</li> </ul>
Location	<ul style="list-style-type: none"> <li>➔ Will the activity take place at a school, health-care facility, workplace or local community hub?</li> <li>➔ Will it be part of a larger cultural or public health event?</li> </ul>
Duration of the activity	<ul style="list-style-type: none"> <li>➔ Is it a one-off event, multiple sessions or part of a long-term programme?</li> </ul>



Category	Key consideration
Delivery of the activity	<ul style="list-style-type: none"> <li>➤ Will the activity be delivered in person, in print, via traditional media (radio or TV) or online – via social media, streaming, video, vlog, blog or a podcast?</li> <li>➤ How are the physical safety and mental well-being of people with lived experience and other participants being protected?</li> </ul>
Training and support needs	<ul style="list-style-type: none"> <li>➤ Is any training required to ensure that the activity runs according to plan?</li> <li>➤ Do partners require training in social contact, cultural competence, safeguarding, public speaking, leadership, lived experience storytelling or monitoring and evaluation methods?</li> <li>➤ How much time is needed for training?</li> <li>➤ Are good reporting and feedback mechanisms in place?</li> </ul>
Monitoring and evaluation	<ul style="list-style-type: none"> <li>➤ What are the main intended impacts and outcomes?</li> <li>➤ How will the outcomes and impact of the activity be evaluated?</li> <li>➤ What indicators will be used to assess these outcomes?</li> <li>➤ What methods will be used to collect information?</li> <li>➤ What is the time frame for the evaluation?</li> </ul>
Sustainability	<ul style="list-style-type: none"> <li>➤ What should the long-term impact of the activity be?</li> <li>➤ What partners need to be involved for long-term success?</li> <li>➤ Can these stakeholders be involved from the very start?</li> <li>➤ Does the activity have a defined end or closure? Did it achieve its ultimate objective? Does it need to continue?</li> </ul>
Funding opportunities	<ul style="list-style-type: none"> <li>➤ What opportunities are there for funding from public or government institutions, private entities, self-funding, nongovernmental organizations (NGOs) or philanthropic organizations?</li> <li>➤ What do the funder(s) need to fund the programme in the short or long term?</li> </ul>

Reducing stigma and discrimination is an incremental process – large impacts can be made through small steps (Box 5). Each small action helps to create a more accepting and inclusive society. Over time, these actions can lead to positive changes in policies and practices.

The case studies in Chapter 3 show how these principles have been realized in different kinds of anti-stigma activities across the world. They provide examples from different contexts, showing how projects ranging from large-scale programmes to small-scale and even individual-level activities can make a difference.

## Box 5. Creating impacts from small-scale work

- Anti-stigma activities can be done simply and at low cost. They do not necessarily require a large budget or an extensive team. Anyone – regardless of their resources or background – can take a stand against stigma and make a difference.
- Grass-roots movements and individual contributions can lead to the creation of support networks and organizations, and community-driven campaigns. These can act as building blocks for larger programmes later on.
- Simple actions like initiating conversations, sharing personal stories or improving understanding through social media can reduce stigma and discrimination.
- Personal stories and experiences are powerful tools for breaking down barriers and promoting understanding. Sharing experiences of stigma or supporting someone who has experienced it can inspire empathy and change minds.
- Anti-stigma activities can lead to the formation of groups – including peer communities – and programmes to address stigma on a larger scale.



## Adapting an existing activity to the local context

If the core management group decides to use an existing activity rather than create a new one, it will usually require adaptation to the new context. This may mean:

- adapting written, multimedia or other materials to be more relevant to the target group, context and culture, using insights carried out in Step 1;
- seeking permission from the originator of the materials to use and adapt their work;
- identifying the specific barriers to implementation within the current context;
- ensuring that all activities use non-stigmatizing language and terminology that is largely preferred by people with lived experience in that context (e.g. “person with mental health conditions” versus “expert by experience”);
- using local words, expressions or phrases to describe distress;
- using local examples of activities and settings when stigma and discrimination are described in scenarios;
- ensuring that the names of locations and people are adapted for the context (e.g. using locally relevant names for health services, places and people) and
- modifying descriptions of the people delivering the activity and the target group to match the objectives of the programme.

Adapting an existing anti-stigma activity or programme can be made much easier by engaging partners with different and complementary skill sets. Project managers, communications experts, financial managers, event organizers, fundraisers and trained public speakers can all play a part, depending on the scope of the activity. Such a blend of expertise and perspectives can result in a more comprehensive, inclusive, balanced and successful approach to reducing stigma and discrimination. Involving people who approach the work from different perspectives and positions can lead to development of an activity that is more convincing and gains broader support because it is closely aligned with the views of local people – and specifically the target group (Box 6).

### Box 6. The case for designing activities for the programme context

The Adolescents’ Resilience and Treatment Needs for Mental Health in Indian Slums (ARTEMIS) programme is a great example of co-designing and adapting activities for a specific context (20). Programme team members worked with their Youth Expert Advisory Board to use games as a key approach to engage with young people. Specifically, they used adapted versions of traditional board games like Monopoly and Snakes and Ladders, and interactive games like Hopscotch. The ARTEMIS games incorporated information on mental health and help-seeking barriers, such as the snakes and ladders representing obstacles and facilitators; and jumping on one foot versus two feet in Hopscotch was used to discuss how people can balance their challenges. In programme delivery, these mental health messages were discussed while playing the games. This interaction was tailored to specific age groups (for example, younger children played the game, while older adolescents helped to explain it and discuss the topics).

## Developing a monitoring and evaluation plan

Regardless of the scope of the activity or programme, it is important to discuss how it will be monitored and evaluated. Monitoring refers to collecting data on a regular basis and reflecting periodically about how the activity is being delivered. This may include assessing whether the activities are taking place as intended, how they are being received by the target group, and what can be modified to ensure greater impact. Evaluation refers to assessing the impacts or outcomes of the activities – that is, whether the activities have had an effect over a certain period. In the case of anti-stigma activities, effects of interest may be improvement of stigma-related knowledge, attitudes or behaviour in the target group.

Monitoring and evaluation do not have to be complex or scientifically rigorous processes. The aim of such assessments is to determine how an activity has been delivered and what its impacts have been. As such, gathering any form of information on the activities can benefit future anti-stigma work. Examples of small-scale or light-touch evaluations may include:

- making a video of stakeholders talking about their experiences of being involved with the work;
- using free online survey tools or social media polls to create short and clear feedback surveys;
- collecting data from social media channels, such as the number of shares, impressions or other engagement and
- talking to participants and asking for their feedback informally (e.g. over a coffee) or by creating more formal individual or group interviews. It may be useful to note or record actual verbatim quotations (and obtain permission to use these).

Collection of data for monitoring and evaluation requires some consideration of data protection and consent. It is important that people are informed about what information is being collected from them, why and what will happen to the data. Permission should be obtained to use any information that is shared, especially if people can be identified (e.g. videos, photos, voice recordings or other personal information). For evaluation that qualifies as research (where the aim is for generalizable findings rather than findings that apply only to a particular programme), ethical approval should be sought. Further information about ensuring ethical standards is available on the WHO website (21).

For programmes with sufficient resources, it is advisable to contract a research organization or research partner to conduct the monitoring and evaluation. However, it is possible to carry out simple and rapid assessments using existing questionnaires, interviews or focus groups (Box 7).

Monitoring and evaluation plans usually delineate the methods used, sources of data and timing of the assessments. It is advisable to undertake an initial baseline assessment before any activities begin. This provides a point of reference against which later data can be compared. Data can then be collected immediately after activities and, depending on the scope of the programme, at various time points afterwards, to compare with the baseline findings.

Note that while analysing the evaluation results, even small changes in values can lead to a large change in reality.

## Box 7. Assessing stigma and discrimination

In many cases, evaluation of the impact of a programme will involve measurement of stigma and discrimination. This can be done through questionnaires or interviews, depending on the programme size and resources. Published questionnaires for assessing stigma-related knowledge (misinformation), attitudes (prejudice) and behaviour (discrimination) have several advantages: they are readily available (often free of charge), in many cases they are valid and reliable, and they enable comparison of results across different contexts. Their disadvantage is that they may not be valid for the target group or cultural context, and thus may require adaptation. In particular, for older scales or measures, the language used may no longer be acceptable to people with lived experience in that context. In such cases, the language can be adapted with the support of evaluation partners.

One source of questionnaires on stigma and discrimination is the INDIGO Network (22). These tools are free of charge, for authorized use, and are available in over 25 languages. The tools include measures to assess:

- ➔ barriers to accessing care
- ➔ costs of discrimination
- ➔ discrimination and stigma (including a long and a short version of the scale)
- ➔ mental health knowledge
- ➔ clinicians' attitudes to mental illness
- ➔ reported and intended behaviour.

Other tools include the Community Attitudes toward Mental Illness scale (23) and questionnaires under the WHO QualityRights initiative (18).

Individual or group interviews can also be conducted to assess the impact of anti-stigma activities. This may involve asking about individuals' experiences of stigma and discrimination, or about changes perceived as a result of the activity. Interviews may provide positive or negative feedback about the programme, or they can be evaluated with qualitative analysis methods such as thematic analysis to yield a richer understanding of people's viewpoints (see Annex 2 for further tools and resources).



## Building readiness for implementation

The rollout of anti-stigma activities may require consideration of more than the roles of stakeholders, the specific activities to be implemented, and how these will be assessed. Before launching any activity, it is advisable to consider what else could be put in place to promote the success of the work and strengthen its impact. This can be considered a final “check-in” to evaluate whether the activity is ready.

It is also necessary to consider how to initiate the activity – such as whether to organize a launch event. Such events can serve as pivotal moments to rally support from stakeholders, and to communicate the aims, strategies and intended outcomes of the activity. They can also foster a sense of shared purpose and commitment, and allow stakeholders to ask questions, provide input and clarify expectations, laying the groundwork for effective collaboration and communication throughout the planned work.

### In focus

Access to funding can greatly benefit activities and programmes, facilitating recruitment of skilled staff to run activities and coordinate programmes, implementation of more comprehensive campaigns, and financing of education and training for core partners. Potential sources of funding can be identified during Steps 1 or 2. Funding can be sourced through government grants, private foundations, corporate sponsorships and community fundraising efforts. However, funding is not required to implement impactful activities or programmes. It is absolutely possible to conduct anti-stigma work without funding by leveraging volunteer efforts; collaborating with like-minded individuals, groups and/or organizations; and utilizing online resources and social media to spread awareness and educate the public (see Case study 1. Activity by an individual).



## Launch and learn

Once anti-stigma activities are launched, the focus changes to making sure that they work in practice, and identifying aspects that need to be adapted or corrected to improve their impact. Taking time to plan the activity during Steps 1 and 2 will make it easier to keep the work on track.

### Communication and coordination

Clear and consistent communication among partners and stakeholders is the basis of effective collaboration to achieve the aims of the activity. A continuing exchange of information among everyone involved with the work is needed, related to:

- setting clear overall products and deliverables for the activity, including breaking down into smaller tasks the steps to achieve the aims;
- providing feedback on ongoing and completed tasks;
- asking and answering questions related to each partner's roles and responsibilities and
- initiating discussions on progress and any necessary changes to optimize performance, with the aim of achieving consensus at each step of the programme.

Project management expertise may be necessary to coordinate activities effectively – especially for larger programmes (Box 8).

#### Box 8. Project management

Having dedicated training on project management or hiring project management experts can be a helpful asset for setting up and delivering anti-stigma programmes – particularly those that are larger scale and long term. Active project management provides a structured approach to planning, executing and completing work efficiently and effectively. It ensures that the planned activities are delivered on time, within budget and to the required quality standards.

Project management can support definition and communication of clear objectives and scope for the planned activities, keeping the work focused on these, and ensuring that all stakeholders understand these goals. It can also optimize use of resources – including time, money and personnel. Through identifying potential risks and developing risk mitigation strategies, project management can reduce the likelihood of adverse outcomes. It can also involve quality control measures to ensure that deliverables meet required standards. Additionally, project management can facilitate clear and consistent communication among stakeholders, keeping everyone informed about progress, changes and issues.

## Using online resources and social media

Online resources – and particularly social media – can be powerful tools for communicating about anti-stigma activities to target groups, current and potential stakeholders and the general public. Social media can even be a viable means of delivering social contact and improving knowledge (24), and of connecting communities that are facing similar disadvantages or discrimination (25).

Increasingly, people with lived experience are using social media to create peer-support communities, sharing their experiences in public, private or semi-private spaces (26).

Other ways of using social media for anti-stigma work may include:

- sharing the stories or experiences of people with lived experience, with their consent;
- providing self-help information or peer support to people with lived experience;
- seeking advice or support from wider communities;
- creating new peer-support communities;
- providing updates on the progress or impacts of anti-stigma activities;
- initiating and sustaining crowdfunding for current or future activities;
- working with social media influencers or content creators to increase the reach of activities and
- sharing events, webinars and audiovisual content (e.g. via podcasts, blogs, vlogs or videos).





However, excessive use of social media can be harmful. For example, it can expose people who are distressed to information about self-harm or to misinformation about how to get help (23). As with any anti-stigma activity, activities on social media may expose people with lived experience – especially those who are disclosing their stories – to further stigmatization and possible harassment. It is essential to monitor activity on social media channels and take appropriate measures in response to negative engagement (such as harmful or aggressive comments), including reporting or deleting comments.

## Facilitating peer communities

Peer communities enable people with lived experience to share knowledge of how to promote social contact and navigate mental health services. They can also build solidarity with wider human rights movements and organizations, strengthening their ability to address discriminatory policy-making or laws, and to participate in policy-making and legislation (see Annex 2). They can even lead to opportunities (sometimes paid) to speak or participate in research.

Participating in anti-stigma activities may be an impetus for people with lived experience to come together and share their stories or offer mutual support, leading to creation of peer communities. These can foster connection, support and growth among individuals with shared experiences, challenges and interests. They can be supported as follows.

- ➔ Social gatherings (online or offline) and opportunities to connect in informal ways can be organized.
- ➔ Collaborative projects, such as events or working groups, can be set up outside the context of anti-stigma activities. This kind of action-based approach is widespread in recovery-oriented practices.
- ➔ Existing self-help groups may help lay the foundation for new peer communities. In many countries, funding of self-help groups is becoming common practice in public health policy, as these groups have a recognized role in promoting citizenship, fighting isolation and enhancing self-determination, thereby fostering recovery.
- ➔ Setting up a formal structure such as a civil society organization may offer further opportunities for peers (such as paid employment), as long as this process does not become a perceived burden for them.

Peer communities can provide the basis for future anti-stigma work in a given context. They may start as self-help groups, but may sometimes become the seed of patient and user organizations. This may be especially important in settings where public disclosure of mental health conditions carries greater social or economic risks. A backing of like-minded people with similar experiences can provide a strong foundation for establishing anti-stigma programmes where none have existed (see Annex 2 for further resources), and can promote system change. Peer communities can also become advocates of the rights and interests of people with lived experience, mainly in development of mental health services.

Some self-help groups and peer communities operate at a local level – such as the Mental Health Service Users Association in Ethiopia (27) – sometimes spreading to other regions with the support of existing groups. Other communities have a global reach (see Annex 2).

## Ensuring safety for programme staff, stakeholders and participants

It is essential that anti-stigma activities consider the safety of participants and staff throughout their engagement in the work. By taking a few simple steps, activities can serve as “safe spaces” – in particular for people with lived experience.

- Partners and stakeholders – especially people with lived experience – should be asked whether they give clear permission to be quoted, photographed, videotaped, shown on social media or otherwise featured in an identifiable way in any communication materials linked to the activity.
- For events, a team of “safers” who are trained to recognize and mitigate discrimination and physical or verbal aggression should be established. These trained personnel can be identified through peer-support groups or via peer and self-help platforms.
- Programme staff may also be designated as safers to support people with lived experience who might feel unsafe during an activity.
- Physical safe spaces in work or event spaces, or designated “safe words” to use when a person with lived experience needs a break or needs more support should be created.
- Emergency contacts and preferred ways of responding to mental health crises, if they arise during participation, should be identified.
- Peer communities among participants should be facilitated to ensure that the activity responds to the needs of people with lived experience.
- Good practices on safeguarding, such as those developed by the Global Mental Health Peer Network (28), should be adopted.

## Reflecting, reacting and adapting

No matter how comprehensive the planning process, implementation of anti-stigma activities rarely happens as envisaged (Box 9). In some cases, not all aims of the work will be met. By allocating sufficient time to reflect on what went according to plan and what did not, the core management group and stakeholders can improve future activities and inform later anti-stigma programmes.

Activities should involve regular check-in meetings with partners to reflect on and adapt the ongoing work to align better with the initial plans and aims. Discussions may focus on understanding what is not going well, what can be improved and how to go about correcting the course. It is also important not to be discouraged by a possible lack of big improvements. Positive changes to stigma may be modest in the short term, but they can lay the foundation for further reduction of stigma and discrimination in the long term.

It is also important to celebrate successes, which can sustain motivation. A healthy culture for anti-stigma activities is one that appreciates success; offers challenges; and encourages brainstorming, risk-taking, creativity and a proactive approach to problem-solving.

## Box 9. Understanding negative outcomes

The outcomes of an anti-stigma activity are generally expected to be positive: to reduce stigma and discrimination. However, monitoring and evaluation results may indicate no change in these outcomes, or may even show an increase. For example, evidence has found that programmes using virtual reality have increased levels of stigma when they involve simulating the symptoms of conditions like schizophrenia (29). If findings indicate that harm is being done to participants while the work is ongoing, it may be necessary to pause all activities temporarily and evaluate what harm has been done and why it occurred. All relevant partners should be informed, and efforts to ensure that no further harm takes place should be implemented. Harm reduction protocols can be created during Step 2 to make this process of acting on negative outcomes easier.

It is very important to identify and avoid covering up such negative outcomes, and to share the lessons that arise from them.





## STEP 4

### Reflect and proceed

As funding runs out, contracts end and activities wind down, the core management group will need to decide whether to stop and consolidate lessons learned to inform future work or to start a new cycle of work.

#### Continuing or ending the activity

The end of an activity cycle is an opportunity to reflect on overall lessons learned, to consolidate monitoring and evaluation data, and to gather stories and feedback from stakeholders – especially partners with lived experience. A lessons learned meeting or exercise can be run with partners and stakeholders, deliberately including a wide range of perspectives and with a focus on the future: should the activity continue or end?

Planning for sustainability may be done early as part of the planning and preparation in Step 2, but decisions may rest on several factors at the end of the activity or programme. The following questions offer a starting-point for identifying these factors.

- ➔ Have the original aims and objectives been met?
- ➔ Has the feedback from participants – and especially the target group – been positive?
- ➔ Are the main partners and stakeholders interested in continuing?
- ➔ Are sufficient time, funding and other resources available to continue?

#### Keeping up momentum: sustaining and expanding

Anti-stigma activities and programmes around the world have shown that stigma and discrimination can be reduced, but it takes time. A specific anti-stigma activity will probably produce benefits – especially if it follows the principles and steps laid out in this toolkit. However, it is unlikely to eliminate stigma in the target group completely.

Ending stigma requires a long-term commitment by many different groups of people around the world. It is important to manage expectations around the impact of anti-stigma activities, and to avoid being frustrated when a given activity does not change the attitudes and behaviour of everyone it targets. The key to sustaining momentum lies in continuing engagement with the target group, maintaining good working relationships between partners, continual adaptation of the activities to the changing circumstances of society, ongoing evaluation, and creating or identifying resources to help the work continue in the longer term.

When an activity cycle ends, the core management group may review whether to continue the work, perhaps refining it through considerations within the different steps of the implementation process

outlined in this toolkit. Specific actions can help sustain motivation for initiating a new cycle of activities, such as the following.

- The core management and stakeholder advisory groups may continue to operate if time and resources to meet are available.
- Updates can be shared with partners and stakeholders on the continuing impacts of the previous activities and what was learned from the process.
- Stakeholders can be consulted on the target group(s) for the next cycle of work.
- Partners involved with the completed work may engage in teaching, training and mentorship opportunities for people who want to learn from their experiences of delivering an anti-stigma programme.
- Experiences, successes and challenges, and knowledge of the activities' outcomes and impacts can be disseminated to key audiences – such as potential future funders – via articles in scientific journals or popular media (including social media), using audiovisual material (e.g. videos or podcasts), or consolidated into best practice guidance materials.
- Peer-support activities can be sustained to enhance the confidence and expertise of people with lived experience to be involved in anti-stigma activities.

Long-term sustainability may mean embedding anti-stigma activities into larger operations, such as a public health promotion campaign or initiative to promote access to care. Flexibility is important: goals and activities may need to be adapted to fit the aims of the larger programmes, but they should retain the core elements that yielded positive outcomes. The activities should also still incorporate the main stigma-reduction principles: leadership/co-leadership by people with lived experience, social contact and inclusive collaborations. Striking a balance between maintaining effectiveness and adapting to changing circumstances can be critical for long-term sustainability.

Scaling up may also be possible and relevant for the context. WHO's ExpandNet framework and tools (30) can be useful in this regard, offering key considerations and guidance on scaling up public health projects, including:

- keeping activities simple
- planning for health-care institutional support
- carrying out budget planning at a very early stage
- active advocacy for ongoing donor or funding support.

Scaling up proposals are likely to be more effective with a clear monitoring and evaluation plan for the programme and robust data on the impacts and outcomes of the activities. Future funders will want to know the probable return on investment and value for money offered by the programme or its activities, which will be greatly aided by data from previous achievements.

## Ending the activity responsibly

It is advisable to plan a responsible end for anti-stigma activities, whether they are expected to operate for a fixed time period or have no definite end. An exit strategy may help to preserve the benefits of the stigma-reduction activity for the target group, even after the programme has concluded. It may be developed by core partners and wider stakeholders – ideally including the target group – at a very early stage in the design of the activity. Depending on the scale of the activity, any of the following may be implemented to promote a responsible exit:

- ensuring that the activities have been implemented with input from the local community and key stakeholders, to increase community ownership and buy-in and to ensure that the work is aligned with local values and priorities;
- ensuring that employed or volunteer staff in the programme gain transferable skills through their involvement to strengthen their future work and employment prospects;
- setting up mentorship schemes for staff and/or local advocates involved with the work, to train and support local individuals who can continue the anti-stigma efforts after the end of the activity;
- sending reports – including monitoring and evaluation data – to funders and other sponsors to show the impacts of the activity for its beneficiaries and the target groups;
- communicating information about the activities in the local and national context, if possible – including their aims, delivery methods, impacts and what has been learned for future programmes and
- sharing details about whether any of the groups, platforms or structures will continue after the activity period with stakeholders who will coordinate and resource any ongoing networks or activities.

## Disseminating, networking and inspiring

Feedback should be given to participants about the results and impacts of the anti-stigma activity, showing appreciation to everyone who took part.

Whether an anti-stigma activity continues or ends, it is vital to share the experiences of those involved and the impacts of the work widely. Planning and executing anti-stigma activities, regardless of their scope and whether they achieved their aims, provides a wealth of knowledge to peers and partners, inspiring them to fight against stigma in their respective contexts.

Supporting replication of a successful approach to reduce stigma and discrimination in other local contexts helps to build a community of practice for sharing knowledge, feedback and strategies, and aids in successful adaptation of activities for that context. This form of support may even be built into programme planning from as early as Step 1 or Step 2. Efforts to disseminate successes and provide mutual support contribute to an ever-expanding global movement of activities, partners and stakeholders with a shared long-term commitment to reduce and eventually end stigma and discrimination in mental health.





# Chapter 3. \_\_\_\_\_

## **Case studies**



## Case study 1. Activity by an individual

Ben Ogden visited a number of train stations in the United Kingdom to share his lived experience of mental health, to break down stigma, and to encourage others to speak up. He built an online community to combat the stigma around mental health further by reaching a larger audience who could talk to and support each other.

### STEP 1. Identify and define aims

Ben realized he needed to do something to tackle mental health stigma when he learned that both he and his best friend were depressed but neither had known about the other's condition. Neither had felt comfortable talking about their experiences – something Ben felt was especially common among young men. Approaching it from the perspective of their work as content creators, Ben wanted to grab people's attention by doing something unexpected to create an impact. He sought to break down the stigma around mental health by engaging with the general public in an attempt to spark a reaction and ignite conversations about this taboo topic.



*I thought, "How can I get people's attention?" A lot of people want to make an impact in the field of mental health, but it's really difficult to get people's attention and to get people to take a second out of their busy schedules and actually think, "Am I okay?"*

### STEP 2. Plan and prepare

Using his own lived experience, and after weeks of building up his courage, Ben went to the central train station in Leeds and held up a sign that read "Hi, my name's Ben and I get depressed sometimes". Then he waited for people to engage with him.

Ben opted for a public space to "do the last thing that people expected". He was amazed at the number of people who approached him. Some wanted to know why he was reaching out, but many wanted to talk about what they were feeling or to ask how they could support loved ones experiencing mental ill health. He was pleased to see that many were older men. In his experience of growing up in the United Kingdom, Ben had seen a powerful stigma against older men talking about their mental health.

Direct engagement with the public also offered him clear feedback – both positive and negative. He did face stigma: some people told him that "mental health problems don't exist" or suggested that he "just man up". Overall, while the majority of the interactions were positive, the negative encounters did cause a considerable amount of self-doubt.

The activity was affordable due to collaborations with London Northwestern Railway – a train company in the United Kingdom – and gym apparel companies.

### STEP 3. Launch and Learn

Ben took his activity to other train stations in the United Kingdom. He posted videos of his conversations on his social media channels (Instagram and TikTok), before switching to livestreaming. Livestreaming

began the formation of a community where people would interact with him and each other (verbal consent to being recorded was obtained from everybody he talked to in person). Administrators of the community proposed creating a more stable online community that was not attached to Ben's streams, using the Discord platform.

He credits social media for having been able to build an anonymous community where people could feel safe and comfortable to talk about their experiences and help each other.

Ben admits that he often felt responsible for people who contacted to him online – that he needed to answer each one of their messages. This took a toll on his own mental health. The creation of the Discord group – a space where people could support each other without his direct input – helped to alleviate some of the pressure.



*What I realized is that I cannot take all of the weight on my shoulders. I kind of went in with the intention of helping a few people. But because it just kept on growing and growing and growing, I felt responsible for all of those people.*

#### STEP 4. Reflect and proceed

The community formed by Ben's work was not created overnight: it was the result of months of building trust with followers and other social media users. For him, social media is a tool to help "real people connect with real people" – something that users of social media too often forget. He reflects on how doing something small can make a big difference. For him, his activity was successful because he used the story of his own lived experience to build trust and cultivate connections.



*We content creators think, you know, "I've just got to put something in front of the people and hope it sticks". People don't really care about that. They just want to feel connected or to feel thought about or to feel not alone.*

### Final reflections

In anti-stigma work, Ben feels that "a little goes a long way". He aimed to help just a few people in his local area. He ended up with a community of hundreds of people from across the world who felt safe enough to disclose their experiences.



*The reason my intervention worked is that it's not a scenario – it's not text on a screen. It's real people connecting with real people.*

### Further resources

- Ben's story on the WHO website (31).
- Ben's story on the LADBible website (32).
- Ben's story on the BBC News website (33).
- Ben's TikTok account (34).
- Ben's Instagram account (35).

## Case study 2. Activity created by young people

Facettes Festival is the first festival in France aimed at promoting mental health among young people.

### STEP 1. Identify and define aims

Facettes Festival was created to expand the horizons of people who are experiencing mental ill health. The project sought to target young people aged 15–30 years, as this is one of the most vulnerable populations for development of mental health conditions, and a population that is discriminated against because of their young age.

The core management group sought to create a festival of well-being, one accessible to all, bringing people together through social contact who would otherwise never meet.

The Facettes team mostly consisted of young people with lived experience or who had a personal interest or connection with mental health. It was important to them that a wide mix of people in different mental health pathways were included. The team also included individuals close to the young people, such as parents, as well as curious members of the public.



*There's self-stigmatization, and not just among people with mental health problems, but really among young people, many of whom say to us: "Oh yes, but I've got no reason to be unhappy, I've got no reason to be unwell. If I'm not doing well, it's because I'm lazy or not brave". They didn't allow themselves to seek help or go for treatment.*

### STEP 2. Plan and prepare

Within the core management group, two individuals with project management experience were integral to structuring the approach. A psychiatrist was also a key member in liaising with the scientific committee, who screened all plans to ensure the appropriateness of the activities.

The Facettes team highlighted the importance of building collaborations from the start. The involvement of Union Nationale des Amis et Familles de Personnes Malades et/ou Handicapées Psychiques and Fédération Santé Mentale – prominent mental health organizations in France – created opportunities for the project.

However, at the start of the project, the core management group had no funding; this led to team members spending a lot of time responding to calls for projects. They were able to obtain funds from public funding, private philanthropy, family philanthropy, some corporate sponsorship and a portion of individual donations through crowdfunding.

All activities were conducted as a collective, from design to implementation. Brainstorming workshops were used to come up with ideas, and decisions tended to be made using votes.



*We did everything as a collective, from design to implementation. The Festival's atmosphere and even its name were defined in collective workshops where we used design thinking methods.*

### STEP 3. Launch and Learn

On 15 October 2022 the two-day free festival was launched, including but not limited to showcasing music and theatre, workshops and activities promoting relaxation. The event enabled peer-support mechanisms to be created for the community – without judgement, allowing people to be who they are.

While many volunteers wanted to get involved, the core management group encountered issues with varying degrees of availability and commitment. Subsequently, they opted for an organizational structure with a core group that runs the project and volunteers who contribute on a more limited basis.

The Facettes team members reflected on how they were able to build up a social network with three levels. The first level consists of those involved in the project – as an attendee or assisting in organization of the Festival. The second level is the “direct relays” – individuals or organizations who are in contact with the target audience of young people, who may be interested in their work. The third level comprises people contacted by the Facettes team to give them more information about their work. Through this avenue, the team found that people they thought would never take an interest in them did just that, and even applied to take part in the Festival.

The project was evaluated through two areas. First, the impact of the Festival on attendees was evaluated through observations and questionnaires. Second, the impact of participation among the people involved was assessed via a focus group. The results of the evaluation were then published (see further resources below).



*I realized that it was much more than a simple project with a beginning and an end. Between the people involved and even at the level of the whole community, there were real peer-support mechanisms being created. It was something very benevolent and non-judgemental.*

### STEP 4. Reflect and proceed

Following the Festival, the Facettes team developed a project management service dedicated to non-profit organizations, and organized a community of young volunteers affected by the Festival.

The core management group members highlight the importance of initiatives sharing practices to disseminate joint learning. They hope to be able to scale up the Festival by forming further collaborations with other festivals, places and initiatives.



*We're interested in being able to collaborate with other festivals in other places. We think that this is more likely to lead to an expansion of projects than if there's one player taking over all the initiatives.*

## Final reflections

For those who wish to create their own anti-stigma activity, the Facettes team encourages anyone to go for it! The key is to find people who share the same level of commitment and are keen to support and help, and to surround yourself with them.



*I'd recommend going with your gut. In other words, if you feel like doing a project, maybe it won't be as sparkling as you imagined at the beginning. But there's no reason why it shouldn't work.*

## Further resources

The Facettes Festival website (36).

The Facettes Festival story on the Sortiraparis website (37).

The Facettes Festival Instagram account (38).

The Facettes Festival on YouTube (39).

A webpage featuring reports measuring the social impact of the Facettes Festivals in 2022 and 2023 (40).

A webpage featuring the methodological kit for the Facettes Festival in 2024 (41).

## Case study 3. Workplace anti-stigma programme

Bearapy is a social enterprise based in Beijing, China, that partners with corporations to reduce mental health-related stigma in workplaces and promote well-being in the Asia-Pacific region.

### STEP 1. Identify and define aims

Bearapy was founded by Enoch Li to address stigma and discrimination in mental health, specifically in the corporate environment. Many employees and managers are afraid to reveal struggles with mental ill health for fear of being seen as weak or a failure. Enoch had worked in such environments and had experienced similar self-stigma due to her own struggles with burnout, depression and suicide attempts. She saw no initiative in Beijing that focused on mental health at work – and nothing with the goal of stigma reduction. She started Bearapy as a way to reach people working in corporations – especially those in leadership positions – to bring awareness of mental health into the workplace, help them understand their responsibility for mental health, and assist them in changing the workplace culture to promote well-being.



*I was really approaching it as: “How do we give people a language to talk about something like this?”, as this is difficult for them to articulate in the local and regional context.*

### STEP 2. Plan and prepare

Enoch martialled her prior experience in management and leadership roles in corporations with training in organizational behaviour, her own lived experience of mental ill health, and plenty of research, to design a training module based on social contact.

People with lived experience have always been at the heart of Bearapy. Enoch’s team consists of individuals who have their own lived experience, or who have cared for somebody with a mental health condition. She highlights the value of having both perspectives when approaching corporate organizations.

Enoch quickly realized that the vocabulary surrounding mental health, including the term “mental health” itself, was not acceptable for many multinational corporations with offices in China. She translated terminology into language suitable for a corporate audience, focusing on empowering terms such as “well-being” and “resilience”. Additionally, she focused on practical outcomes – how changing workplace cultures to support well-being can have economic benefits such as increased productivity, resilience and better relationships.

Bearapy was initially targeted at human resources managers, who could serve as the basis for organizational culture change, and chief financial officers, who were considered key to supporting sustained engagement. In the last few years, the focus has shifted to chief executive officers and board members to implement the programme.

The methodology of Bearapy is based on experiential learning, where the knowledge taught is applied practically through activities. Participants are then debriefed and reflect on the key learning points. Crafting vignettes of case studies based on current issues in the organization allows training to be focused on relatable topics. This form of indirect social contact gives participants the opportunity to articulate their own feelings and to realize the impacts their actions can have on the mental health and well-being of colleagues and subordinates.

### STEP 3: Launch and Learn

Bearapy grew steadily since 2016, and now has a mixture of short-term one-off and long-term repeat clients.

Monitoring and evaluation are performed frequently, facilitating continual refinement of the training. After every workshop or activity, participants complete a feedback survey, consisting of closed and open questions to allow individuals to provide greater detail on their experience. Bearapy team members also conduct interviews with human resources officers to evaluate the project.

Enoch reflects on the importance of social contact in Bearapy's workshops, which aim to create a psychological safe space for individuals to talk about mental health.



*I don't expect 30 people to change their minds overnight. But if there's a seed that is growing, that's how de-stigmatization works.*

### STEP 4. Reflect and proceed

Bearapy's for-profit model enables its continued engagement with corporations in Beijing and globally. As of 2024, it has a staff of six consultants, with around 20 associates who help to run the training sessions.

Enoch's challenge in establishing Bearapy was trying to get people interested in a topic no one spoke about. The challenge now is to get corporations to continue investing in mental health in the aftermath of coronavirus disease (COVID-19), which led to an upsurge in interest in Bearapy's work. This surge is declining again as employers move to regarding mental health as an issue of crisis management as opposed to sustainability.



*I find that a key challenge is: How do we sustain the conversation, making it a pillar for workplaces and not just crisis management?*

### Final reflections

Enoch advises those interested in anti-stigma work to be clear about their outcomes and, despite voices around them that may be discouraging, to persevere.



*Destigmatization at work is not easy: we are essentially going against the flow. By persisting, you will find allies who believe in you, and champions to help you.*

### Further resources

The Bearapy website (42).

## Case study 4. Grass-roots activities

Zone of Expression Against Stigma (ZEST) is a global system of actions aimed at combating stigma. Its “Living Libraries” programme sought to combat prejudice by enabling people with lived experience to share their stories publicly face-to-face, when one person adopts the role of the “book” and another of the “reader”.

### STEP 1. Identify and define aims

The ZEST Living Libraries programme in France involves “living books”. These are people with a mental health-related experience, who share their stories (within 30 minutes) with an individual who feels unaffected by such an experience – the reader. The aim is to combat stigma related to mental health, promote dialogue through these encounters and break down barriers.

### STEP 2. Plan and prepare

The ZEST team members were familiar with the Living Libraries format, which had been used in the context of other types of discrimination – notably from consulting the Council of Europe’s guide to Living Libraries (43). They also studied what was being done in Canada on the *à livre ouvert* [open book] project, and work by Psycom, a French national public resource.

The project is run collectively by both participants and coordinators at the Centre ressource de réhabilitation psychosociale and the Centre référent lyonnais de réhabilitation psychosociale. The co-leadership revolved around discussions of how to adapt the Living Libraries model – what works and what needs amending – and inviting people with lived experience to be co-trainers with coordinators on Living Libraries events and training courses.

The ZEST team worked to ensure that the environment was one where everyone could feel comfortable to share their story and safe to be themselves. For example, the person who adopts the role of a living book can choose whether they feel more comfortable to be in a conversation with one, two or three readers, and decide how many readings they want to do.

The first target audiences were students, firefighters and caregivers.

To evaluate the project, the ZEST team contracted a consultant to build an evaluation guide and then carried out individual interviews with participants, conducted focus groups, administered questionnaires and collected some data at events. As part of the evaluation, they asked readers three questions:

How did you experience the event?

Is there anything you remember in particular, and do you think your view of mental health conditions changed after this exchange?

Do you have any questions about mental health?

A questionnaire is sent out six months after the Living Libraries event, asking whether the programme has changed anything in their lives.





*We debrief the participants each time, and think about what can be adapted in the model. For example, we thought about making a sign if the living book [i.e. the person with lived experience] was feeling unwell, because it could be complicated for some people to verbalize this when there was a reader. We tested it. But after a while, we decided to rely on the explanation of the library rules with readers and coordinators, who check in every 10 minutes to ensure a respectful and secure setup.*

### STEP 3. Launch and Learn

The ZEST team's comprehensive evaluation of the programme's impact on participants (living books) and readers yielded encouraging and positive results. Notably, the impact on people with lived experience participating as living books was substantial in terms of improved self-esteem, empowerment and a sense of ultimate legitimacy in sharing their experiences.

Feedback showed that when the texts were gloomy and devoid of hope, this tended to reinforce readers' prejudices. Accordingly, workshops were amended to pay particular attention to the message the living book wants to deliver, and what can be helpful for this to succeed.

When Living Libraries was newly launched, the ZEST team was more successful in getting readers to come and listen by saying not "Would you like to listen to a testimonial about mental health?" but "Would you like to listen to a living book?"

The Living Libraries programme enables readers to identify with the living book in unexpected ways. They found that, as readers, people reveal themselves and often share very personal things – including health professionals talking about their own experiences of disorders.

The programme facilitated creation of peer communities. Friendships have been formed, and some participants are now involved in other associations or projects such as exhibitions and videos.

ZEST's Living Libraries are based on a system where participation is free and therefore there is no obligation for people with lived experience to participate. However, coordinators reflected that they felt discomfort that participants do not receive compensation. Conversations with participants demonstrated that they did not actually wish to be paid, but these discussions increased the coordinators' desire to provide collective opportunities to develop skills.

For the first two years of running the Living Libraries, ZEST had virtually no external funding. However, this was not enough to keep up with the ambitions of the project participants. Ultimately, the team received several grants – first from the Caisse Nationale de Solidarité pour l'Autonomie, then from the Fondation de France, Fondation Aesio and Fondation IF.



*It bothers us in the end to be paid for what we do and for the participants not to be paid. In Canada, they have a selection process for living books. There's an expected format that has to be respected and, in the end, our system is based on the fact that participation is free: there is no obligation.*

## STEP 4. Reflect and proceed

Wanting to share their experience with others, the ZEST team developed a practical feedback guide and set up free training modules. They hope to continue offering Living Libraries in different locations, and to help others wanting to take over the concept.



*We used to provide a lot of individual support to teams who came to us and said, “I’d like to set up a living library, to get started”. We decided to offer free training modules instead. So we developed a two-hour training module delivered through videoconference. Then we send out a guide and have a one-day face-to-face meeting.*

## Final reflections

The ZEST team reflects on the importance of being comfortable with what parts of their story people with lived experience wish to share. A closing thought is: Always think about the impact of your story on the audience.

## Further resources

*Don't judge a book by its cover! The Living Library Organiser's Guide (43).*

*Set up a living library: a feedback guide (44).*

ZEST's website (45).

A guide accompanying the Living Libraries project (46).

An article on combating mental health stigma with Living Libraries (47).

A video on the introduction of ZEST (48).

Videos of the workshops on recovery (49).

Feedback on the first Living Libraries (50).

## Case study 5. Scaling up activities

Yellow September is a suicide prevention project that began in 2023 in Iceland.

### STEP 1. Identify and define aims

The Yellow September project aimed to increase people's awareness of the importance of mental health and suicide prevention. Using the colour yellow as a "a sign of love, care and concern for our neighbours and friends", and extending from 1 September to World Mental Health Day (10 October), involving World Suicide Prevention Day (10 September), the project was created in 2023.

Yellow September was a collaboration between the Directorate of Health in Iceland and several organizations and NGOs focusing on mental health and suicide prevention. The large number of partners meant that they were never at a loss for ideas, but it also meant that they could be overambitious. The project manager, who was from the Directorate of Health, helped to guide the team in deciding what they could and could not do through the first year.

### STEP 2. Plan and prepare

Due to financial constraints, the core management group chose to use social media for the campaign, asking people to talk more openly about their mental health and where to get help. Yellow September was built on a model that was well known in Iceland at the time: Pink October, a campaign around cancer prevention. Thus, the target audiences already had an idea of what to do to show support.

The team chose to use the logo of a semicolon – a symbol often used for mental health awareness and suicide prevention. They also coined the phrases "Is everything yellow?", "Are you yellow?", "Is everything yellow in your workplace?", intending to convey the message that people were encouraged to ask for and discover where to find help. Yellow clothing became a symbol of solidarity. The team also organized events – including concerts, interviews with media, seminars, webinars and walks – to provide spaces for social contact.

With limited time to execute the campaign, the Yellow September team chose to focus on workplaces in the first year. This led to some criticism – particularly from schools, which would have liked greater involvement. Therefore, the focus for 2024 is on all school stages, from kindergarten to high school, with involvement of relevant stakeholders.

Each organization had its own audience, which helped extend the campaign's reach. The team worked with individuals in marketing at one of the NGOs involved to help identify audiences and build a social media strategy, involving the social media teams of the participating organizations.

The limitation of having only one individual with lived experience on the team was addressed in the early stages of preparation. Subsequently, during the planning phase for Yellow September 2024, a brainstorming meeting was held with a group of people with lived experience; this had great results, and many interesting ideas were developed.



*One of the most difficult parts was to focus we were doing, to remember that we are not going to eat the whole elephant.*

### STEP 3. Launch and Learn

The campaign was launched on 1 September 2023 in the presence of the Minister of Health and several media outlets. Over the month, the Yellow September team tracked social media data and the numbers of calls to helplines and articles written about mental health and suicide prevention.

As the campaign began on a Sunday, it was launched in many churches, which were a very active presence. The Icelandic mental health organization Geðhjálp – which works with people with lived experience, their families and mental health professionals – was very involved in participating in the events. The campaign was also spoken about within primary health care.

People were encouraged to use the colour yellow in their social media profiles, and to add the campaign hashtag to promote awareness. New material in Icelandic was also published, including information on how to support someone who has been bereaved and affected by suicide.

On 10 October 2023, the results of a survey on stigma and discrimination in Iceland were released, which were positively received by people with lived experience and professionals. The Yellow September team members reflected that they would like to showcase this research more.



*One of the lessons learned was that it's not enough to have one representative of people with lived experience. For the 2024 Yellow September, we established a new group of people with lived experience. We had a brainstorming meeting and their ideas were included in the preparation.*

### STEP 4. Reflect and proceed

Yellow September has several plans for 2024 and beyond. These include translating their social media posts into English and Polish to be used in workplaces that have requested access to their materials, creating a prize for media reporting on mental health and suicide prevention, and implementing training for media using the updated WHO guidelines for media professionals on reporting about suicide (51).



*You cannot do it yourself. You need to use the right professionals and media channels.*

## Final reflections

To others who wish to create an anti-stigma programme, the Yellow September team highlight the importance of collaboration and planning. Their advice is: “Stop trying to do everything. Focus on what you want to do well.”



*Give yourself time to build up the right network because many hands make light work.*

## Further resources

The Yellow September website (52).

A publication on how to support someone who has been bereaved and affected by suicide (53).

## Case study 6. Working with the media

Speak Up (2020–2023) was an anti-stigma project delivered in Nairobi, Kenya, led by the NGO Basic Needs Basic Rights (BNBR), working in partnership with the international NGO CBM UK. The project originally started as one of five global anti-stigma pilots in the Time to Change Global programme (2018–2020), run by a partnership of mental health NGOs.

### STEP 1. Identify and define aims

Strong public stigma and stigma by association were making it hard for people with mental health conditions to live in their communities in Kenya. Negative depictions in the media created further shame around mental ill health. Politically, mental health was a key focus in Kenya at the time, and young people were especially vocal about needing to change how mental health conditions were seen and talked about.

Drawing on expertise gained working with people with lived experience, BNBR created the Speak Up project, with an overall aim to tackle youth mental health stigma. One of the project targets was to improve media reporting and social media discussion of mental health.



*There is no shame around mental ill health, but what people see in the media, the kind of images they see, they do not want to be associated with it. They see a destitute person, somebody who is hopeless, who's always needing help, who has no agency. Nobody wants to be portrayed that way.*

### STEP 2. Plan and prepare

The Speak Up project included a social marketing campaign, social contact events, training for caregivers and community health volunteers, and training and support for over 60 lived experience champions. Champions were involved throughout the design and delivery of the project, and became active campaign advocates, publishing their stories via their own social media accounts and working with the media to improve coverage.

BNBR understood that journalists can either perpetrate or combat mental health stigma, and therefore identified the media as a key target audience. In collaboration with the Media Council of Kenya, BNBR developed four workshops. These entailed sensitization training for journalists, editors and social media influencers on mental health and best practices in mental health reporting. Media reporting guidelines and a mental health reporting curriculum were also developed.

Communicating to editors and journalists that this training aligns with their existing priorities of producing good media stories around mental health encouraged their engagement.

BNBR commissioned P&L Consulting to conduct a baseline analysis (2020–2021) and follow-up study (2023) of media coverage on mental health in Kenya. Additionally, 20 Kenya-based journalists completed an online questionnaire, assessing their understanding and opinions in relation to mental health and their coverage of the issue.

The Speak Up project received funding for 1.5 years from Time to Change Global, and for a further 3.5 years from the United Kingdom-based charity Comic Relief.



*We trained journalists to cover stories in an empowering way. To not just capture someone at a low moment without any follow-up story after that. It leaves you with that perception – that that’s what mental illness is. So we provided journalists with access to the champions we had trained, so they could do a story and get the person’s viewpoint.*

### STEP 3. Launch and Learn

Comparing the baseline and follow-up data, the findings showed a significant increase in positive coverage of mental health conditions and a significant reduction in negative media coverage. The volume of both news coverage and hashtags on social media platforms related to mental health conditions exhibited an upward trend over time. Importantly, BNBR’s endline report reflected that 104 of the 542 news stories reviewed were a direct result of the Speak Up project.

The Media Council set a challenge for social media influencers and “citizen journalists” – those not in a regulated profession – to enforce the guidelines. The approach adopted was to reach out to those with high numbers of followers to adopt the guidelines and influence others.

While unfortunately funding did not allow champions to be paid for their time, they were frequently reminded of the voluntary nature of the position, and were supported to take time off when needed. Partnering with caregivers and monthly peer-support groups also helped in creating a more supportive environment.



*Having champions aware of the guidelines was very helpful as they could react to stories. The champions could have a conversation with a journalist or influencer and propose images that they could use, or offer alternative language/tone for the story.*

### STEP 4. Reflect and proceed

BNBR reflected on how partnering with media bodies supported greater engagement and a stronger impact of training and resources on editors and journalists. This supported the sustainability of their work.

The guidelines currently exist as a soft copy document. The Media Council plans to distribute physical copies to media houses and to journalists training in institutions run by the Council. They also intend to train “master trainers”, who will cascade the training to other journalists countrywide.

## Final reflections

When targeting the media, including people with lived experience can help to transform how media professionals view people with lived experience if they are actively delivering and facilitating the training. Additionally, having champions who are aware of the guidelines serves as an empowering tool when influencing how stories are portrayed in the media. Overall, when planning anti-stigma projects, BNBR highlights the essential need for people with lived experience to be a focal part of all aspects – from conception to evaluation.

*You must have the people who have lived experience at the centre of your programme. They must be in the planning of it, they must be in the implementation of it, in the monitoring and evaluation – they must play a part in all of it.*

## Further resources

The BNBR website (54).

The baseline report (2020–2021) (55).

The follow-up report (2021–2023) (56).



## Case study 7. Activities for health-care personnel

The research programme INDIGO Partnership launched the Responding to Experienced and Anticipated Discrimination Mental Health (READ-MH) programme to train mental health professionals in responding to experienced and anticipated mental health-related discrimination. The training was implemented across five low- and middle-income countries (LMICs); this case study focuses on its application in Tunisia.

### STEP 1. Identify and define aims

Experiences of stigma and discrimination towards people with lived experience can be enhanced or reduced by mental health and other health professionals working in mental health care. The READ-MH programme sought to achieve two aims in LMICs:

- to create training for mental health professionals (especially psychiatry residents) to raise awareness of stigma, and of how people with mental health conditions experience stigma in both everyday life and health-care settings and
- to teach and empower training recipients in ways to reduce stigma, and facilitate a sense of advocacy through the ability to effect change through everyday interactions with patients.



*It doesn't have to always be big things. Every resident can make a difference and think about what they can do at their level.*

### STEP 2. Plan and prepare

READ-MH was part of a larger research programme (the INDIGO Partnership, funded by the United Kingdom's Medical Research Council), from which the project manual was provided. The programme was informed by a situational analysis, as well as reflections from the project lead, providing contextual insight from their years of experience working clinically as a senior psychiatrist in the programme's context.

The project team also included a clinical academic, staff at the teaching complex where the training was held and others to facilitate practical implementation of the work – including the hospital administrator and hospital director. The team also partnered with the Tunisian Association of Young Psychiatrists and Residents in Psychiatry, who supported READ-MH with publicity and selection of eligible participants.

The project team found it challenging to convince people to come in to talk about their experiences during training. To help manage this, they followed guidance on how to prepare people with lived experience for involvement.

Pilot training with eight residents provided READ-MH with feedback to refine the training activities. For the training sessions, there was both an in-person contact and a pre-recorded question and answer session with a person with lived experience that mapped onto training content.

The evaluation element was built into the larger programme within which this specific programme was situated.



*This [referring to patient interactions that could be more helpful] might also have happened to me when I first started working with patients. If you can't do a pilot study, at least speak with the target group about the intervention plans and how to adapt it locally. I believe this would be helpful. For our work we got a lot of insights and a lot of help. I always believe it's better to do something than nothing at all!*

### STEP 3. Launch and Learn

The training was delivered at the only psychiatric hospital in Tunisia, where the majority of psychiatrists in the country trained. This positioned the venue as an ideal location to reach resident psychiatrists. No compensation was provided for participants – receiving the training and getting a certificate of attendance was enough to incentivize participation.

Residents reported that direct contact (whether in person or remote) was preferred to a recorded testimonial, as it promoted interactivity. Additionally, the inclusion of roleplay scenarios in the training allowed participants to notice the direct beneficial impacts of training on their daily context.

The training sessions unexpectedly evolved into becoming similar to a peer-support group for the participants. It was essential for the group to be a safe space for participants, to facilitate open discussion – including critical reflections on their own professional practice.

### STEP 4. Reflect and proceed

READ-MH received positive feedback from participants. The project team plans to run annual training to benefit new residents, provide refresher training to previous participants, and issue training to nurses – even after the wider INDIGO Partnership research programme ends.

To carry out these plans for expansion, READ-MH needs more resources, and the project team will propose that their programme is added as a training component to the College of Psychiatrists in Tunisia, embedding the training into the residents' curriculum. The team also plans to continue the training, moving its focus from a research context into practice, given the positive feedback and tangible practical benefits.

The project team has communicated the READ-MH programme impacts through many avenues, including academic publications, providing stigma training sessions in LMICs and presenting to the Tunisian Society of Psychiatry Congress. These have emphasized the importance of involving people with lived experience, which is still an unusual approach for many in the Tunisian context.

## Final reflections

The READ-MH project team reflects on the continued need to get both families and professionals on board to combat mental health stigma and improve the lives of people with lived experience. Team members highlight that it is the small changes that can make a big difference – after all, “All that is needed can be a smile or one nice word” to have an impact on someone’s life.

*“ Training can really change lives. Even a small change in attitude towards people with lived experience can make a big impact. Not much is needed to make an impact for an individual service user. All that is needed can be a smile or one nice word, which can be achieved even in contexts with limited resources and busy clinical schedules.*

## Further resources

WHO case study on the READ-MH programme (57).  
The READ-MH programme’s protocol (58).  
An article about the INDIGO Partnership (59).

## Case study 8. Adapting an anti-stigma activity to another culture

In India, the vast majority of individuals with mental health conditions do not receive adequate mental health care – especially in rural communities. Stigma is a contributing barrier to accessing care. To address this gap, the Systematic Medical Appraisal, Referral and Treatment Mental Health (SMART MH) project was implemented across 12 villages in the West Godavari district of the southern Indian state Andhra Pradesh.

### STEP 1. Identify and define aims

India has a notably disproportionate lack of resources and services for those with mental health conditions. This leads to delays in accessing appropriate support and/or services, and demand to address the lack of awareness of mental health conditions is increasing. The SMART MH project aimed to provide affordable and accessible mental health care for people in rural settings in India, with a focus on three pillars:

- ➔ addressing stigma and discrimination;
- ➔ task sharing and upskilling primary health-care providers; and
- ➔ training primary health-care providers in screening, diagnosing and managing common mental health conditions.



*I am quite clear on one thing: don't start talking about any kind of issue, be it mental health or tuberculosis, without also providing care for that kind of health condition in a community. This was a community-based initiative, and we were talking about mental health, and about stigma in mental health. So ethically I feel we were bound to provide care also.*

### STEP 2. Plan and prepare

The SMART MH project involved formative work (2014–2019) and a full trial delivered through the government health system (registered 2018; implementation and evaluation 2020–2021).

The formative work during the pilot phase was conducted in south India, and included material development (informed by the limited prior Indian mental health stigma work and insights from Indian anti-stigma work in the fields of HIV and leprosy), testing and evaluation. Discussions with the community were integral to the project's development. SMART MH formed key partnerships with local NGOs familiar with the specifics of the local context. The materials were revised and refined further for the full trial, including translating from Telugu to Hindi, and checked for appropriateness in the trial context in north India.

The pilot work was quantitatively evaluated pre- and post-test, and a two-year follow-up was carried out. At the time, this was the only LMIC-based longitudinal anti-stigma campaign evaluation. The pilot was also qualitatively evaluated to assess operational challenges, during the programme and at

its completion. The formative aspect of the full trial was evaluated in north India, followed by multiple detailed evaluations of the trial overall. Publication of the trial's full findings is forthcoming.

All SMART MH project activities were supported by peer-reviewed funding from entities including the DBT/Wellcome Trust India Alliance, Grand Challenges Canada, Australian National Health and the United Kingdom's Medical Research Council.



*Do not use brochures and pamphlets for a health awareness campaign: it simply does not work. Make the activities more interactive and interesting!*

### STEP 3. Launch and Learn

A key element of SMART MH materials was use of drama as a tool. A regionally popular drama unit was involved and staged plays in communities. One example was a play on the topic of domestic violence leading to depression. The storyline displayed an initial lack of awareness of symptoms, until the individual's symptoms were identified by a village leader, who was more aware of mental health conditions. The person was then supported to receive care and treatment, eventually recovered and shown was in remission by the end of the play. The plays lasted around 40 minutes and were delivered either as live shows or recorded productions.

SMART MH materials also included recorded narratives (due to a lack of resources to support live narratives) of people with lived experience and caregivers sharing their stories.

The programme was delivered at a household/door-to-door level (showing videos on portable tablets, sharing pamphlets and so on) and at a community level (the play). On reflection, the project team discourages using brochures and pamphlets, highlighting the need for greater interactivity for a health awareness campaign.

### STEP 4. Reflect and proceed

SMART MH demonstrated that stigma reduction principles work across different communities and settings. The project team plans to support scale-up of the work through the Indian government (or other governments around the world), adapting elements to local contexts. The insights gained from SMART MH have also been transferred to other projects in India (including ARTEMIS and SATHI – see further resources below).

The programme's activities have provided training for a cadres of health workers and doctors, who are continuing to use the skills gained beyond the trials. Additionally, individuals who accessed care through the programme's activities are still receiving appropriate treatment.

## Final reflections

While obstacles will arise, the SMART MH project emphasizes that you can always find a way to overcome unexpected challenges. For those planning a programme, the project team highlights the importance of piloting in the success of their project – always test the work before launch.



*Whatever you do, do it sincerely and take your time to think through what you want to do.*

## Further resources

The pilot project website (60).

A longitudinal evaluation of the pilot anti-stigma campaign (61).

The trial website (62).

The full trial protocol (63).

The process (64).

An article on the operational challenges (65).

An overview of ARTEMIS work with adolescents in urban slums (20).

ARTEMIS results, with information on the programme's components including games and videos (66).

An overview of SATHI work in tribal communities (67).

An overview of the Healthy Mind Street Art event (68).

## Case study 9. National anti-stigma programme (Czechia)

*Na Rovinu* [On the level] is a destigmatization initiative created as part of Czechia's five-year Reform of Mental Health Care programme (2017–2022).

### STEP 1. Identify and define aims

Mental health-related stigma in Czechia exists among both the general population and experts (including social workers and health professionals). This has been identified as having real effects of discrimination on people with mental health conditions. In 2017, Czechia began a reform of psychiatric care, with an emphasis on transformation of large-capacity psychiatric hospitals, strengthening of community care, and creation of a new element of community care – centres of mental health – at the intersection of social care and health care.

As part of the reform, the *Na Rovinu* initiative was created. The aim was to reduce stigma towards people with mental health conditions, and to raise awareness about mental health – in particular for six target groups: people with lived experience, carers, social workers, health professionals, communities and public administrators.

### STEP 2. Plan and prepare

A situational analysis was prepared in 2016, before the start of the project, from which the programme and activities were designed. This also considered international experiences.

The goals of *Na Rovinu* were:

- to develop programmes that strive for change;
- to create change in media communications, moving towards non-stigmatizing reporting about people with mental health conditions;
- to support establishment of user and carer self-help groups and movements and
- to communicate about the ongoing reform, with the aim of connecting individuals and raising public awareness of ongoing activities.

These goals were interconnected with the need to work with the attitudes and actions of people in the community to reduce stigmatization.

The project team involved sociologists, psychologists, a statistician and other professionals. There were 14 regional teams, coordinated by core team members, and almost half of the staff were people with lived experience. Three worked in the core team and the rest were employed as regional specialists. Members of the target groups were involved as experts and lecturers. Other stakeholders were involved, mainly in piloting and realization of programmes. A Czech Advisory Board and an International Advisory Board were also established and worked throughout the project.

The programmes for each target group contained several “packages”, which were prepared, lectured or co-lectured, and monitored by people with lived experience. All programmes were subject to a three-step evaluation process: before the initiative, immediately after it had been completed, and three months later, conducted by an internal evaluation team. The overall reports were developed in cooperation with an external company.

This project was funded by the European Union (EU).



*Co-creation and direct participation of people with lived experience in all stages of the project was crucial.*

### STEP 3. Launch and Learn

Piloting and monitoring the programmes enabled the *Na Rovinu* team to make adaptations during the initiative, including adjusting the length of the overall programmes, but the core settings remained unchanged.

*Na Rovinu* programmes helped to create peer self-help communities in at least three regions. Many user activities – including self-help groups and user meetings – continued after the end of the project, and the media environment visibly improved in favour of non-stigmatizing communication about people with lived experience.

*Na Rovinu* encountered many challenges – notably from 2020, due to COVID-19. Some target groups were particularly affected – including health and social workers, people with lived experience and their carers – not by stigmatization, but by availability of health and social services. Subsequently, the programmes were adapted due to changing needs, including offering new programmes about self-care. Delivery of the programme was transferred to online variants through the Webex platform. The project team discovered that the online version appealed to more participants in the target groups, and the impact was similar to that of the offline version.

### STEP 4. Reflect and proceed

The final evaluation of the initiative demonstrated that there was a slight reduction in the stigmatization of attitudes among people who were in contact with the *Na Rovinu* initiative, or with the reform in general. However, there was no change in the discriminatory behaviour targeted.

The need to expand anti-stigma activities with more elements focused on general literacy about mental health, and the need to support one's own mental health via programmes focused on self-care became evident during the project.



*COVID-19 showed us the importance of self-care for all people, and helped us to raise this topic with the restrictions that affected everyone.*

## Final reflections

Many people with lived experience who participated in the project are still active in the field of anti-stigmatization in regions of Czechia. The *Na Rovinu* project team reflects that it is thanks to the project that many reform activities are ongoing.

## Further resources

The *Na Rovinu* website (69).



## Case study 10. National anti-stigma programme (Denmark)

EN AF OS [One of us] is the national anti-stigma programme of Denmark. It was launched in 2011 and was formally made a part of the Danish Health Authority in 2021.

### STEP 1. Identify and define aims

Several public and private organizations across Denmark, including the Danish Health Authority, started EN AF OS with a clear aim “to promote inclusion and combat discrimination related to mental illness”. The impact of stigma had been made clear a year earlier, when EN AF OS, in partnership with a research institute, ran a nationwide survey which showed that stigma related to mental health was a major barrier to getting help. Stigma presented an additional burden for people with lived experience on top of the stress that comes with having a mental health condition, and the language associated with mental health was an important stigmatizing factor.



*When we got together these different actors within the field, both private and public, ending stigma and discrimination was what they all agreed on. They disagreed on many different areas within the field of mental health. But to reduce stigma discrimination was something that they could all very easily agree on.*

### STEP 2. Plan and prepare

EN AF OS has five target areas: people with lived experience and their relatives, young people, the labour market, the public and the media, and professionals in the health and social care sectors.

The team adapted its organizational structure from the United Kingdom-based anti-stigma programme Time to Change. It created a steering group with representatives from each founding organization. Among these were an umbrella organization of mental health service user organizations and regional health service organizations, as well as other individuals with lived experience who became the programme’s “ambassadors”.

EN AF OS ambassadors received the programme’s training in direct social contact. The training focuses on how to share stories in a way that creates empathy and disconfirms stereotypes. Staff then facilitate meetings between ambassadors and target groups, such as journalists and the media, policy-makers, medical staff and public housing janitors.

Staff maintain an ongoing dialogue with ambassadors to ensure that their well-being is sufficient to take on ambassador tasks, keeping their development in the role as ambassadors in mind. Staff also help ambassadors prepare for meetings, providing support before, during and after.

The EN AF OS team has also created a toolkit containing videos of ambassadors sharing their stories. If ambassadors are unavailable, they have the option to show these videos to target groups as a form of indirect social contact.



*We had to get the people on board and train them and then realize, how do we do this? How do we get people in and part of all of what we do? I think it's developed throughout the years to be more and more sophisticated. The ambassadors have developed as well.*

### STEP 3. Launch and Learn

EN AF OS was launched in 2011 with a public campaign focused on the stigma surrounding mental health, and its ambassadors gradually became part of the activities.

Now, in nearly all regions of Denmark, ambassadors are part of the introductory course for new staff in mental health services, where their personal stories continue to be the highlight of the programme. EN AF OS demonstrates that social contact through sharing experiences in a way that does not live up to prejudice is an impactful way to reduce stigma.

Regional meetings of ambassadors are held on a regular basis, and a national meeting of all ambassadors in Denmark is held annually. These offer ambassadors a chance to connect, talk about challenges, plan new activities and offer each other support.

EN AF OS has focused on implementing targeted activities over big campaigns. Measuring those at a local level has shown positive effects.

Although EN AF OS received public and private funding, the team highlighted the difficulty of the amount of time and motivation spent on fundraising.



*It's so important to make a sense of community grow among ambassadors, so that they can reflect off each other and grow from that and grow their commitment.*

### STEP 4. Reflect and proceed

In 2021, EN AF OS was integrated into the Danish Health Authority, which allowed people with lived experience to have greater opportunities within different aspects of the organization. For example, ambassadors participate in the national council overseeing implementation of Denmark's 10-year action plan on mental health. There are also plans to develop a new toolkit for professionals in mental health services, where ambassadors will be an integral part of the groundwork. This ensures that the views of people with lived experience are always included.



*You have to have a personal commitment and really truly believe that ambassadors are equals to everyone else. And you should have a deep belief in recovery and to want to nurture people.*

## Final reflections

EN AF OS highlights the fact that people with lived experience are of utmost importance; they should be nurtured and supported professionally and personally, and should always be treated as equals.

The project team members do not consider their work to be different from that of other anti-stigma programmes. They attribute their success in many ways to their focus on specific groups. Their advice to others is to start small and to include both people with lived experience and the target group for behaviour change in planning.



*We can all make a difference. Absolutely everything, all this work, it makes a difference. And if you just change one department in mental health services, then you are taking a step forward.*

## Further resources

The EN AF OS website (70).

A video about the EN AF OS project (71).

## Case study 11. Structural change through decriminalization of suicide

Taskeen is a non-profit organization working to bring mental health awareness, provide free-of-cost mental health support to individuals, and advocate for mental health policy change in Pakistan.

### STEP 1. Identify and define aims

On 22 May 2021, the Police of Punjab (a province in Pakistan) uploaded a tweet from their official account that stated how attempting suicide is a crime and that if the victim survives, they will be subject to one year of imprisonment and a monetary fine. This tweet referred to Section 325 of the Pakistan Penal Code that criminalized suicide – a law inherited from the colonial era during the 1860s.

Until 2022, Pakistan was one of the 20 countries that criminalized suicide. As a result, when a person attempts suicide and survives, the focus shifts to medico-legal procedures and reporting rather than providing adequate emergency care and psychiatric or psychosocial support to the survivor and their family.

Consequently, families hide suicide attempts; this leads to further stigmatization. In addition to this punitive law, a religious perspective also forbids attempting suicide, although Islamic law does not prescribe any punitive measures against survivors of suicide.

Although the tweet was deleted after receiving backlash, this compelled Taskeen to initiate a structured suicide decriminalization campaign against this law, and it was repealed in September 2021.



*The reporting process by law enforcement agencies can be dehumanizing for the survivor and their family, who are already traumatized by the situation. It also leads to mistreatment and exploitation of people with mental health conditions, as law enforcement agencies may extort money from the family under the threat of filing a medico-legal case. Fear of reporting and litigation prevents victims and their families from seeking support.*

### STEP 2. Plan and prepare

Taskeen developed a multifaceted strategy for one of the biggest legislative reforms in Pakistan, which included campaigning and lobbying for suicide decriminalization at all structural and legislative tiers.

Taskeen planned to use social and mass media channels to engage the public, develop evidence-based video content and partner with leading news channels and media outlets to talk about suicide decriminalization.

### STEP 3. Launch and Learn

In August 2021, Taskeen initiated the campaign Mujrim Nahi Mareez (Patients Not Criminals). To engage the public and shift the paradigm around suicide, Taskeen leveraged National Suicide Prevention Month (September), developed and disseminated evidence-based content (videos, webinars) on social and mass media channels, and partnered with leading news channels and media outlets, where leading academics, specialists and policy-makers talked about suicide, addressing it as a medical issue.

A joint petition against Section 325 was circulated among organizations and individuals working for mental health in Pakistan to garner unified support from civil society members. By leveraging the Pakistan Mental Health Coalition Advocacy Subcommittee, Taskeen spearheaded the suicide decriminalization campaign in collaboration with other coalition members.

One of the biggest challenges for this campaign was to gather religious buy-in and overcome bureaucratic delays. This made Taskeen realize that amplifying the voices of people with lived experience is critical in bringing about a shift in socioreligious perspectives. Therefore, the project team convened meetings with the Council of Islamic Ideology, showed interviews of survivors, and contextualized the history of suicide criminalization for the Council members. This was an incredibly impactful strategy that helped foster empathy for survivors, and engaged religious leaders in a meaningful way.

In 2022, the amendment bill was passed in the National Assembly, which repealed Section 325, and suicide was finally decriminalized. This repeal prompted strong opposition from the Federal Shariat Court – a constitutional court with the power to determine whether a specific law complies with Islamic law. A petition was filed that called for re-criminalization of suicide; however, no verdict was passed.



*In 2017, the amendment bill was moved to the provincial assembly, where it was adopted by the Senate and Council of Islamic Ideology, but it later lapsed due to strong opposition from religious stakeholders.*

*This time, when the amendment bill was again moved in 2022, it had buy-in from political and religious stakeholders, a favourable political climate and the powerful momentum of the suicide decriminalization campaign.*

### STEP 4. Reflect and proceed

Taskeen is now designing steps for effective implementation of suicide decriminalization by developing guidelines with the provincial and federal governments, law enforcement agencies and health-care commissions that can offer guidance to public and private facilities about how to address medico-legal cases.

To inform its public awareness strategy, the project team is designing a perception-based study on suicide decriminalization to gather public perspectives on this instrumental reform.

Taskeen is also strengthening its multisectoral and civil society partnerships to carry out consultative sessions and sensitization training for provincial law enforcement agencies, with an emphasis on how suicide is a public health issue and should be treated as one.

## Final reflections

Taskeen's powerful statement is that "Suicide is not an individual issue but a societal failure. Any civilized society needs to ask itself this question: Why do people who attempt suicide not have the necessary support? The decriminalization of suicide requires an empathetic and rights-based approach towards ending the structural stigma, and providing those suffering with the help that they need."

## Further resources

The Taskeen website (72).

The Pakistan Mental Health Coalition website (73).

## Spotlight on policies and actions across the EU on stigma and discrimination in mental health

Mental health problems were estimated to affect about one in every six citizens in the EU (84 million people) in 2018 before the COVID-19 pandemic (74). Prevalence of symptoms of depression doubled during 2020–2022 compared to pre-pandemic levels, as shown by national estimates for several EU countries, with vulnerable groups of the population – such as young people and those with chronic conditions – most affected (75). The 2023 Country Health Profiles, prepared in the context of the State of Health in the EU cycle, included a spotlight on mental health (76). One of the main messages highlighted in the project’s synthesis report was that breaking stigma and discrimination surrounding mental health is key among other actions, such as stepping up investment in mental health systems reforms.

The European Commission is committed to supporting EU Member States in reaching the Sustainable Development Goals – in particular, target 3.4: “by 2030, reduce by one third premature mortality from noncommunicable diseases through prevention and treatment and promote mental health and well-being”. The strategic framework for this support is the Healthier Together initiative. This includes a focus on mental health, and is accompanied by a toolkit for action by Member States and stakeholders to address mental health and other key public health challenges (77).

### A comprehensive approach to mental health

The 2023 Commission Communication on a comprehensive approach to mental health provides a strategic framework for action to promote good mental health and address mental health issues and related stigma through a holistic, prevention-oriented and multistakeholder approach (78). It has 20 flagship initiatives and provides €1.23 billion in funding opportunities via several EU funding instruments – including the EU4Health programme, Horizon 2020 and Horizon Europe – for joint actions between national authorities and projects implemented by civil society organizations and other relevant stakeholders, including the following.

- ➔ The joint actions PreventNCD (79) (with a budget of €76 million) and MENTOR (80) (with a budget of €6 million) address stigma among their activities.
- ➔ Stakeholder-led projects include Let’s talk about Children, which supports families in vulnerable situation through provision of multidisciplinary interventions and training of health professionals and social workers (81). The Icehearts project implements a model that provides long-term and holistic support for vulnerable children by engaging children through sports with social work (82). The MENTALITY project includes activities that address stigma and discrimination as a major barrier to mental health support (83).
- ➔ Other projects funded under the EU research programmes include the MENTUPP project (84), which focuses on promoting mental health in small and medium enterprises operating in the construction, health, and information and communication technology sectors, and the EMPOWER project (85), which aims to diminish stigma within the workplace.

The European Health and Digital Executive Agency manages implementation of these projects (86). To monitor implementation of the Communication and its 20 flagship initiatives, the Commission has developed a tracking framework, which will be updated regularly (87).

The Communication builds on the efforts of the Commission to improve mental health and integrate mental health in all policies over the past 25 years, such as the EU-Compass for Action on Mental Health and Well-being, which included promotion of social inclusion and combating stigma as one of its priority areas (88). The Communication on the European Health Union of May 2024 highlighted the Commission's ongoing efforts to prioritize the promotion and protection of mental health in Europe – in particular of the most vulnerable groups in society (89).

## Flagship initiative on tackling stigma

One of the 20 flagship initiatives addresses stigma surrounding mental health (78). The Commission allocated €18 million to:

- ➔ improve the quality of life of patients, their families and (in)formal carers, including cancer patients, with a particular focus on addressing stigma and discrimination by supporting Member States to identify and implement best practices;
- ➔ support stakeholders to implement projects, such as awareness-raising activities to break through stigma and address discrimination, ensure social inclusion, protect the rights of patients, focusing on vulnerable groups;
- ➔ develop EU guidance on breaking through stigma and tackling discrimination with the Member States under the Expert Group on Public Health and stakeholder groups and
- ➔ introduce communication activities to promote awareness in the fight against stigma.

To implement this flagship, the Commission set up the Drafting Group on stigma and discrimination on mental health under the Expert Group on Public Health (90). The Drafting Group, composed of national experts, met three times in 2023–2024 and agreed to develop an EU support package to address stigma surrounding mental health, including best and promising practices on stigma and an awareness-raising campaign.

The Commission's #InThisTogether campaign, to be launched in October 2024, seeks to raise awareness of the importance and benefits of tackling stigma around mental health, and to increase understanding about the role everyone can play. It will confront misconceptions and myths around mental health and provide reliable sources of information and support. The campaign will have a special focus on anxiety and depression, as these conditions are particularly prevalent among teenagers and young adults – the main target audience. #InThisTogether will feature testimonials, teaching materials, sharable social media content, webinars, and collaborations with influencers and content creators, all available on a central campaign hub. The campaign will run until early 2025 in all EU languages, with paid promotion in Greece, Ireland, Poland, Romania, Spain and Sweden.



## Best and promising practices to tackle stigma

National initiatives have been collected through the EU's Best Practices Portal – a repository for best and promising practices on mental health submitted by Member States and stakeholders (91). The following best and promising practices address stigma surrounding mental health.

- ➔ ABC of Mental Health (Denmark) aims to improve mental health by creating mentally healthy and inclusive sports communities. In this context, decreasing stigma around mental health represents a founding pillar on which the programme is built (92, 93).
- ➔ EN AF OS - Landsindsatsen for afstigmatisering [One of us - the national campaign for anti-stigma in Denmark] (Denmark) focuses its activities on anti-stigma efforts that facilitate identification, empathy and reflection through challenging myths with facts, social contact activities where target groups can meet people with lived experience of mental health problems and dialogues at schools, workplaces and other settings (see Case study 10. National anti-stigma programme (Denmark)) (70, 71, 94).
- ➔ Beyond Barriers (France) promotes the introduction of innovative roles in the provision of mental health services, with the aim of improving empowerment through reduced stigma and enhanced quality of care (95).
- ➔ Living and Learning Together (Greece) aims to strengthen the mental health resilience of learners and young people in school communities through a multidisciplinary approach that includes raising awareness, promoting human rights and eliminating stigma (96, 97).
- ➔ H-WORK (Italy) project aims to improve mental well-being in the workplace by evaluating psychosocial risks and implementing targeted interventions that address stigma related to mental health (98).





# Chapter 4. \_\_\_\_\_

## **Conclusion**

WHO's Mosaic toolkit describes how to develop and implement evidence-based actions to challenge mental health stigma and discrimination in diverse contexts and populations. The ongoing fight against stigma requires collective action: individuals, communities, organizations and institutions all have vital roles. Most importantly, action can be taken right now, regardless of access to resources, as long as it incorporates the three core evidence-based principles for reducing stigma and discrimination.

**Figure 5.** The three core evidence-based principles to reduce stigma and discrimination



The case studies in Chapter 3 reflect a broad range of strategies and approaches to reduce stigma and discrimination. They differ according to the human, financial and knowledge resources available. Each case study activity and/or programme illustrates how cultural, regional and practical political realities can be taken into account in conducting this work.

It is important to remember that change starts with each of us. By taking action, big or small, we can collectively dismantle the walls of stigma, and build a world where mental health is understood, and people with experience of mental health conditions are respected and supported.

When using the Mosaic toolkit, it is essential to be creative in thinking about how activities and programmes will develop, who can participate in them, and what resources can be drawn upon. It is helpful to learn from, adapt and use materials from other people, and to share ideas (the annexes offer many such materials). Opportunities for people with lived experience to lead and/or co-lead anti-stigma activities are crucial, as is their active participation and inclusion in every step of anti-stigma programmes. “Nothing about us without us” is the central message. Once a community of like-minded people comes together with a commitment to stop stigma, it cannot be undone.

No initiative to reduce stigma and discrimination is useless. No matter the barriers, everyone has a right to try, to succeed and to fail. Stigma is in the eye of the beholder, and change lies in changing perceptions – both those of others and our own.

Everyone can be part of a wider and expanding global movement of activities, partners and stakeholders who come together with a shared and long-term commitment to reduce and ultimately end stigma and discrimination in mental health. In collaborating to realize this vision, the following key criteria should be borne in mind:

- ➔ keep it simple
- ➔ learn as you go along
- ➔ share with others
- ➔ do what you can with the resources you have
- ➔ use the ideas, materials and approaches that make sense in your context
- ➔ network and create communities
- ➔ you are stronger than you think.

*We are active subjects who can take a stand towards a diagnosis and forge a meaningful life. I am a person, not an illness.*

**Patricia E. Deegan (99)**

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Annexes\_\_\_\_\_



## Annex 1. Frequently asked questions

This annex includes questions that are often asked about anti-stigma programmes, and offers some answers, along with information about how to access more resources.

### The Mosaic toolkit

#### ***Why was the toolkit organized in this way?***

WHO's Mosaic toolkit was designed to be a usable, evidence-based guide for engaging in anti-stigma activities. Theory has been kept to a minimum to aid readability. If you would like to know more about how stigma is defined, its impacts on people and the evidence for what works in anti-stigma programmes, please read the information in the *Lancet* Commission on Ending Stigma and Discrimination in Mental Health umbrella review (1). This is available in Arabic, Chinese, English, French, Russian and Spanish.

#### ***People with mental health conditions are not the only stigmatized group in society. Can this toolkit be used to reduce stigma for other types of conditions or characteristics?***

Stigma affects people with a range of characteristics that can lead to them being treated badly (for example, they may experience discrimination on the basis of sexuality, gender, ethnicity or homelessness). The Mosaic toolkit principles for reducing stigma (leadership or co-leadership by people with lived experience, social contact and inclusive collaborations) may also apply in these situations. However, this toolkit has been designed specifically based on experience and evidence related to mental health, so caution is recommended in using or adapting it for other types of stigma.

#### ***Is this toolkit suitable only for large-scale projects or can it also be used to run smaller projects?***

The Mosaic toolkit is designed to be useful for all kinds of anti-stigma work. Chapter 2 describes principles of how to implement such programmes at a small or large scale, and the case studies in Chapter 3 provide examples of small- and large-scale projects.

#### ***I want to use this toolkit, but it is not available in my language***

WHO has six official languages: Arabic, Chinese, English, French, Russian and Spanish. WHO has produced this version of the toolkit in English, and may also produce translations in one or more of these other languages. If you create a translation of this publication available under the CC BY-NC-SA 3.0 IGO licence, the following disclaimer should be included, as applicable: "This translation was not created by the World Health Organization (WHO). WHO is not responsible for the content or accuracy of this translation. The original English edition "[Title]. Geneva: World Health Organization; [Year]. Licence: CC BY-NC-SA 3.0 IGO" shall be the binding and authentic edition". The use of the WHO logo on the translation is not permitted.

Requests for permissions to translate can be submitted through WHO website (2). You are welcome to share the translation with WHO for storing in Institutional Repository for Information Sharing (IRIS) (3).

## Anti-stigma work and how to get involved

### ***Is anti-stigma work the same thing as “raising awareness” or improving mental health literacy?***

Anti-stigma work is often considered the same as raising awareness of mental health conditions or increasing mental health literacy. However, there are several important differences. The focus of the Mosaic toolkit is on tackling prejudice and discrimination to reduce social exclusion and increase social inclusion. Awareness-raising specifically refers to improving knowledge about mental health and – while important to anti-stigma work – increasing knowledge is not enough to improve attitudes and behaviour (see Chapter 1).

### ***Nobody seems to think that mental health stigma and discrimination is a problem in my context. How do I get leaders to pay attention?***

The reason leaders are not paying attention may actually be because of stigma! In fact, this proves the value of beginning this kind of work, even if only small changes are possible at first. It may be useful to start at a small scale, with individual or grass-roots initiatives. When designed and implemented well, using the principles outlined in Chapter 1, activities are more likely to get leaders to pay attention. Good data on impact and outcomes, as well as powerful quotes from people involved, can be especially convincing. This is why it is so important to create a proper monitoring and evaluation plan. Annex 4 provides further information to use when advocating for anti-stigma programmes.

### ***I am a person who has experienced a mental health condition and I want to help reduce stigma, but I am afraid of speaking out. What can I do?***

Many people with experience of mental health conditions very understandably feel uneasy about disclosing this in any context, including in anti-stigma work. There are risks in disclosing – because of stigma! Remember that you do not have to do this alone. You may wish to spend some time looking for organizations in your local area that you can contact for help. Many international organizations offer guidance on how you can get involved without making you feel unsafe. In fact, it is important that anti-stigma programmes create a “safe space” to help you decide whether you want to talk openly about your experience. It is your choice.

There are ways to share your experience anonymously, if you wish. Or if you decide that you would like to contribute but not disclose your own experience, there are also many ways to do this. For example, you could help with fundraising for a programme, or you could volunteer to arrange meetings or help with development of training materials in a project’s office. Or you could use your specific skills to contribute to the initiative – perhaps as an artist, an accountant, a poet or a blogger.

### ***I have no training in public health or psychology, and I don’t consider myself a person with lived experience. But I want to get involved. Is there a role for me in anti-stigma efforts?***

You do not have to be a health expert, researcher or person with lived experience to be involved in anti-stigma work. As with many issues related to human rights and social justice, it is helpful to start by talking to people involved in stigma reduction or who have lived experience to learn about the issues. Questions to consider are: What is stigma and how does it affect people? What is life like for people living with mental health conditions where you are? What do people with lived experience consider to be non-stigmatizing language in your country? This knowledge can help inform you about how you can participate in or initiate anti-stigma activities in your local context.

## Designing and implementing anti-stigma interventions

### ***I am planning an anti-stigma programme, but I am struggling to find people who are willing to talk about their experiences with mental ill health. What can I do?***

This is a common challenge. You can try partnering with an organization of people with lived experience; these may be called “user”, “service user”, “survivor” or “peer” organizations. They may already have strong communities of people with lived experience, and may be providing training on how they tell compelling stories. This would make them a strong partner. However, in many places such organizations do not exist. In this case, you have several options, depending on your context.

- ➔ You could partner with local leaders or health service providers (e.g. primary care doctors) you trust. They may be able to connect you with people with lived experience or family members; this may help in establishing trust and a sense of safety.
- ➔ You could partner with community organizations outside mental health, which may have experience of supporting people living with mental health conditions in other ways.
- ➔ You could contact international mental health organizations, who may be able to connect you with individuals or organizations with similar experiences – such as the Global Mental Health Peer Network (4).

Keep in mind that you should respect the preferences of people with lived experience. Not everyone who lives with a mental health condition wants to get involved in anti-stigma work. Reducing stigma and discrimination takes time. It requires continuing efforts to create conditions in which some people with lived experience feel safe to talk about their experiences to support social contact.

You can also run an anti-stigma programme even if you do not have people with lived experience who want to disclose. For example, you could produce a short play in which volunteer actors play the parts of people with lived experience and family members (see Case study 8. Adapting an anti-stigma activity to another culture). The actors may or may not have experience of mental health conditions, but they do not need to disclose this when taking part in the play. Or you could produce a short video, animation or song. Again, the people making this creative product do not need to disclose any information that makes them feel unsafe or uncomfortable.

### ***I want to do an anti-stigma activity, but I'm just one person. How do I convince partners to join me?***

Trust is fundamental for building partnerships, and this can take time. If you are just starting out in anti-stigma work, you could volunteer at an organization that has experience of anti-stigma activities. Doing so will not only introduce you to others in the field, with whom you can build partnerships and networks, but can also provide you with invaluable experience for your own initiative.

### ***I'm running an anti-stigma programme. So far, feedback from our partners has been generally good. But it seems to be taking a mental toll on the champions we are working with – the people who have chosen to talk about their experience. What can I do to help reduce this burden?***

Every effort should be made to ensure that champions are supported throughout the programme. A range of support can be helpful, such as:

- ➔ listening to identify their priorities and needs;
- ➔ setting up or strengthening local peer networks;
- ➔ organizing informal gatherings in the community (e.g. at cafés or parks);
- ➔ participating in arts or cultural events;

- holding local or regional meeting or conferences that balance capacity-building with enjoyable social events;
- taking part in online experience-sharing events with other programmes or organizations, near or far.

Step 3 in Chapter 2 offers further information on what can be done to support mental health champions. Be careful, and check often to see whether participation in the programme is harming any members of the team. If it is, pause and reflect on what is not working.

***I have met with staff at my local news organizations to cover our anti-stigma programme, but they are fixated on the idea that “mad” people are “dangerous”. How can I work with them in a positive way?***

Stigma is very common in the media. It takes time to change this. See if you can find a particular reporter, editor or producer who has a positive interest in mental health, and develop this relationship. Ask whether that person can arrange a meeting with others in their organization. Bring people with lived experience to these meetings to use the principle of social contact to help media staff to understand the issues. Offer to teach students about mental health on journalism courses. You could organize a special prize or awards event for good practice in positive reporting of mental health issues and stories. What media staff most want is good, usable content or copy for their next deadline, so it helps to offer positive stories about people who are recovering from mental health difficulties.

***I’m running an anti-stigma programme. It has funding for the next two years. I want to make sure that it continues long after that, because I have heard that real impact takes time. What can I do to demonstrate impact and raise more funds?***

A strong monitoring and evaluation plan can be a vital part of your programme. The evaluation results will demonstrate the intervention’s impact, which will help you to argue for continuation of the programme to achieve lasting benefits. This plan should ideally be developed before you start your intervention. You should decide what would make the activity a success, and use that information to plan what impacts you will measure.

Different partners – such as funders or media staff – may have different ideas of success, so you may need to measure a few different types of outcome to show the impact of your programme. For example, some funders are convinced by numbers, while others are convinced by human stories. If you have both, you will be better prepared to show how your programme has been successful in achieving its aims. See Chapter 2 (Steps 2 and 4) for more information on how to demonstrate and celebrate your success.

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3. WHO Institutional Repository for Information Sharing (IRIS) [website]. Geneva: World Health Organization; 2024 (<https://iris.who.int/>).
4. Global Mental Health Peer Network [website]. Global Mental Health Peer Network; 2024 (<https://www.gmhpn.org/>).

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## Annex 2. Tools and resources<sup>3</sup>

### Stigma and discrimination

Much of the research on stigma and discrimination has been consolidated in the *Lancet* Commission umbrella review.

Thornicroft G, Sunkel C, Aliev AA, Baker S, Brohan E, el Chammay R et al. The Lancet Commission on Ending Stigma and Discrimination in Mental Health. *Lancet*. 2022; 400:1438–80 ([https://doi.org/10.1016/S0140-6736\(22\)01470-2](https://doi.org/10.1016/S0140-6736(22)01470-2)).

### Social contact

A number of practical guides and research papers indicate how social contact can be promoted and built into activities. Other research articles can be found in the reference list of the main document.

Abergel R, Rothmund R, Titley G, Wootsch P. Don't judge a book by its cover! The living Library Organiser's Guide. Strasbourg: Council of Europe; 2005 (<https://book.coe.int/fr/jeunesse-autres-publications/3293-don-t-judge-a-book-by-its-cover-the-living-library-organizer-s-guide.html>).

Adu J, Oudshoorn A, Anderson K, Marshall CA, Stuart H. Social contact: next steps in an effective strategy to mitigate the stigma of mental illness. *Issues Ment Health Nurs*. 2022;43(5):485–8 (<https://doi.org/10.1080/01612840.2021.1986757>).

Cangas AJ, Sánchez-Lozano I, Aguilar-Parra JM, Trigueros R. Combination of a serious game application and direct contact with mental health patients. *Int J Ment Health Addiction*. 2022;20:3274–84 (<https://doi.org/10.1007/s11469-022-00752-x>).

Community mental health good practice guide: anti-stigma and awareness-raising. Laudenbach: CBM Global Disability Inclusion; 2021 (<https://cbm-global.org/resource/community-mental-health-good-practice-guide-anti-stigma-and-awareness-raising>).

Conversations change lives: global anti-stigma toolkit. London: Mental Health Innovation Network; 2022 (<https://www.mhinnovation.net/resources/global-anti-stigma-toolkit-conversations-change-lives>).

Quintilla Y, Olié E, Franck N, Gard S, Llorca PM, Maurel-Raymondet M et al. Serious game dans la psychoéducation aux troubles bipolaires. *Eur Psychiatry*. 2013;28(S2):25–6 (<http://dx.doi.org/10.1016/j.eurpsy.2013.09.063>) (in French).

Rai S, Gurung D, Kohrt B. The PhotoVoice method for collaborating with people with lived experience of mental health conditions to strengthen mental health services. *Glob Ment Health (Camb)*. 2023;10:e80 (<http://dx.doi.org/10.1017/gmh.2023.73>).

REducing Stigma among HealthcAre ProvidErs (RESHAPE) training manual. Washington, DC: Center for Global Mental Health Equity; 2023 (<https://www.gwcgmhe.com/reshape>).

Rodríguez-Rivas ME, Cangas AJ, Cariola LA, Varela JJ, Valdebenito S. Innovative technology-based interventions to reduce stigma toward people with mental illness: systematic review and meta-analysis. *JMIR Serious Games*. 2022;10(2):e35099 (<http://dx.doi.org/10.2196/35099>).

<sup>3</sup> All references accessed 29 August 2024.

Tay JL, Xie H, Sim K. Effectiveness of augmented and virtual reality-based interventions in improving knowledge, attitudes, empathy and stigma regarding people with mental illnesses – a scoping review. *J Pers Med*. 2023;13(112):10–12 (<https://doi.org/10.3390/jpm13010112>).

Toolkit: co-creating in mental health. Brussels: Mental Health Europe; 2022 (<https://www.mentalhealthurope.org/library/co-creation-toolkit/>).

## Lived experience, human rights and recovery

The following resources provide further theory on defining lived experience and the importance of rights-based and recovery-oriented approaches.

Casey PJJ. Lived experience: defined and critiqued. *Crit Horiz*. 2023;24(3):282–97 (<https://doi.org/10.1080/14409917.2023.2241058>).

Convention on the Rights of Persons with Disabilities (CRPD). New York: United Nations; 2006 (<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-Persons-with-disabilities.html>).

Deegan PE. Recovery: the lived experience of rehabilitation. *Psychosoc Rehabil J*. 1988;11:11–19 (<https://toronto.cmha.ca/wp-content/uploads/2016/07/Deegan1998-Recovery-The-Lived-Experience1.pdf>).

Gardien E. Between normality and disability: sensitive cognitive boundaries. *Welfare e Ergonomia*. 2021;1:104–16 (<https://hal.science/hal-04405318/document>).

## Implementation, monitoring and evaluation

Several resources offer guidance on how to collect and analyse data, and how to monitor and evaluate anti-stigma activities.

Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77–101 (<https://doi.org/10.1191/1478088706qp063oa>).

Breuer E, Comas-Herrera A, Docrat S, Freeman E, Schneider M, STRiDE team. STRiDE Theory of Change workshops: guidance and resources. STRiDE Research Tool No.1 (version 2). London; Care Policy and Evaluation Centre; 2019 ([https://stride-dementia.org/wp-content/uploads/2019/11/STRiDE-THEORY\\_OF\\_CHANGEWORKSHOPS.pdf](https://stride-dementia.org/wp-content/uploads/2019/11/STRiDE-THEORY_OF_CHANGEWORKSHOPS.pdf)).

Developing a logic model of theory of change [website]. Center for Community Health and Development; 2024 (<https://ctb.ku.edu/en/table-of-contents/overview/models-for-community-health-and-development/logic-model-development/main>).

Implementation science research development (ImpRes) tool. London: Centre for Implementation Science; 2018 ([https://kingsimprovementscience.org/cms-data/resources/ImpRes\\_Tool\\_May\\_2018.pdf](https://kingsimprovementscience.org/cms-data/resources/ImpRes_Tool_May_2018.pdf)).

Monitoring and evaluation [website]. The Grassroots Collective; 2021 (<https://www.thegrassrootscollective.org/monitoring-evaluation-nonprofit>).

Research methods toolkit. London: Centre for Society and Mental Health; 2023 (<https://researchmethodstoolkit.com/>).

Stigma scales, available at: Strengthening Mental Health Worldwide [website]. INDIGO Network; 2024 (<https://www.indigo-group.org/>).

What are evaluation methods? [website]. Funding for Good; 2020 (<https://fundingforgood.org/what-are-evaluation-methods>).

## WHO tools and frameworks

Relevant tools and resources developed by WHO can be used to reduce stigma and discrimination.

ExpandNet [website]. ExpandNet; 2024 (<https://expandnet.net/>).

Preventing suicide: a resource for media professionals, update 2023. Geneva: World Health Organization; 2023 (<https://iris.who.int/handle/10665/372691>). Licence: CC BY-NC-SA 3.0 IGO.

WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions. Geneva: World Health Organization; 2023 (<https://iris.who.int/handle/10665/367340>). Licence: CC BY-NC-SA 3.0 IGO.

WHO QualityRights tool kit: assessing and improving quality and human rights in mental health and social care facilities. Geneva: World Health Organization; 2012 (<https://iris.who.int/handle/10665/70927>).

Youth engaged for mental health: a framework for youth participation under the WHO Pan-European Mental Health Coalition. Copenhagen: WHO Regional Office for Europe; 2023 (<https://www.who.int/andorra/publications/m/item/youth-engaged-for-mental-health>).

## Peer communities

Peer communities are essential in work to reduce and discrimination. Resources include practical guidance on how to engage in peer support and highlight several global peer communities to join.

[Community mental health good practice guide: peer support](https://cbm-global.org/resource/community-mental-health-good-practice-guide-peer-support). Laudenbach: CBM Global Disability Inclusion; 2021 (<https://cbm-global.org/resource/community-mental-health-good-practice-guide-peer-support>).

This practical guide offers guidance on peer support services for people with mental health issues to promote connectedness, inspire hope and offer a level of acceptance and understanding not often found in other professional services.

[Honest, Open, Proud Program](https://hopprogram.org/) [website]. Honest, Open, Proud; 2024 (<https://hopprogram.org/>). This programme aims to reduce stigma and discrimination in mental health through training on disclosure.

[International Hearing Voices Movement](https://www.intervoiceonline.org/about-us/the-hearing-voices-movement#content) [website]. Intervoice; 2024 (<https://www.intervoiceonline.org/about-us/the-hearing-voices-movement#content>).

This is a collection of diverse conversations, initiatives, groups and individuals around the world that share the values that hearing voices, seeing visions and related phenomena are meaningful experiences and are not indicative of illness.

GAMIAN-Europe [website]. [Global Alliance of Mental Illness Advocacy Network](https://www.gamian.eu/); 2023 (<https://www.gamian.eu/>).

This is a user-driven organization that advocates for the rights of people with lived experience in creating inclusive policies and services.

[Global Mental Health Peer Network](https://www.gmhpn.org/) [website]. Global Mental Health Peer Network; 2024 (<https://www.gmhpn.org/>).

This is an international organization that offers opportunities for empowerment, mentorship and support for people with lived experience of a mental health condition.

## Annex 3. Rights-based and disability perspectives in mental health

This passage was adapted from a similar appendix to the umbrella review of the *Lancet* Commission on Ending Stigma and Discrimination in Mental Health (1).

Efforts to reduce stigma and discrimination in the field of mental health are heavily informed by the disability movement and rights-based approaches developed using social models of disability. This movement has positively influenced the field of global mental health – such as through increased recognition of the importance of participation of people with lived experience in service reform. It also provides a useful framework for understanding and responding to stigma and discrimination, including through the evidence-based activities mentioned in the Mosaic toolkit.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) describes disability as follows: “Disability results from the interaction between people with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others” (2). Within this broader scope, the term “psychosocial disabilities” refers to people who may experience negative social consequences including stigma, discrimination and exclusion as a result of a mental health condition.

However, while some people with mental health conditions may consider themselves to have difficulties as a result of the condition, they may not consider themselves disabled, and they may not wish to be seen by others as having a disability. It is vital that people with lived experience decide how they define themselves. Many people have found alignment with the broader disability movement (which has grown as a consequence of the CRPD) to be empowering, to reflect their experiences, and to be useful for understanding barriers and bringing about change. On the other hand, there may be less utility in this model when referring to shorter-term, less permanent or less severe impairment of function associated with some types of mental health problems, and some people may not welcome such labels (3).

This perspective facilitates use of the concept of “disability-based discrimination”, which is defined as “any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation” (2). This is the fundamental basis of the CRPD, which does not confer any additional rights for people with disabilities but rather insists that people are not treated differently on this basis alone.

Using a disability framework in relation to people with psychosocial disabilities offers potential advantages (4), as it:

- includes people with disabilities related to mental health conditions within the broader context of all people with disabilities;
- offers access to legal instruments at the international level, such as the CRPD, and national laws against discrimination against people with disabilities such as the 1990 Americans with Disabilities Act, which can be applied to support the social inclusion of all people with disabilities, regardless of the type of impairment;
- facilitates provisions for “reasonable adjustments” or “reasonable accommodations” to support, for example, people with disabilities in the workplace.

Within the CRPD, “reasonable accommodation” is defined as: “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to people with disabilities the enjoyment or exercise on an equal basis



with others of all human rights and fundamental freedoms” (2). People with disabilities have a right to be provided with reasonable accommodation to enable access to services and their full participation on an equal basis with others. This focus on accessibility is a major strength of the disability approach, and aims to counteract cycles of social exclusion and low social capital. Stigma and exclusion from society, which many people with disabilities experience, can be a major factor in lack of access to social capital (5, 6).

Four dimensions of accessibility have been described:

- freedom from stigma and discrimination
- financial accessibility (affordability)
- communication accessibility
- physical accessibility.

Where access to forms of social opportunities and activities is enabled, the disability approach also includes the obligation to ensure “meaningful participation” – a principle framed in the context of the Aarhus Convention (7) and expressed as “Nothing about us without us”.

Importantly, there are limitations to the disability approach. Currently, the term “psychosocial disabilities” is not in common usage outside human rights, disability and international nongovernmental organizations forums. Moreover, in many countries, psychosocial disability is not routinely recognized by national disability federations, and people may experience stigma associated with mental health conditions in these spaces as well as in wider society.

It is recognized in the preamble to the CRPD that “disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (2, 8). While the interplay between mental health and disability is evolving, this discourse has enriched the wider mental health field (and the disability movement) – particularly as related to stigma and discrimination. These issues need to be understood within the broader perspective of the United Nations Convention on Human Rights, which sets out for Member States the right of everyone to the enjoyment of the highest attainable standard of physical and mental health in resolution A/HRC/RES/42/16 (9).

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## Annex 4. Common myths and misconceptions about mental health stigma and discrimination and how to tackle them

Mental health stigma and discrimination are major barriers to help-seeking; hamper recovery; and make it difficult for people with lived experience to access their rights – to a job, an income, education, relationships and community inclusion.

Nevertheless, there is little investment in structured, evidence-based programmes and activities with outcomes focused on reducing the impacts of stigma and discrimination. Myths and misunderstandings surround work in this field. These are often based on limited knowledge of:

- ➔ the severe impacts of stigma and discrimination;
- ➔ the positive impacts of stigma reduction for individuals, families, communities, societies and economies;
- ➔ the large evidence base of what works to reduce stigma; and
- ➔ how to access tools and methods that have been adapted across global contexts and cultures.

There have also been unintended consequences from describing anti-stigma programmes as “mental health awareness” campaigns. Anti-stigma programmes that are evaluated against defined outcomes are not generic “awareness” campaigns but are evidence-based, targeted and evaluated interventions. These programmes, especially if there is a medium- to long-term commitment from key stakeholders, can lead to significant improvements in public attitudes and behaviour, less discrimination, and greater empowerment for people with lived experience to lead societal change and claim their rights.

This annex addresses some of the prevailing myths about work to reduce stigma and discrimination. These myths can be endorsed by policy-makers, funders and other potential partners, and can stall progress if they are not addressed directly by advocates.

### Myth 1. Stigma is hard to define

#### **How to respond**

There is a global body of evidence highlighting the impacts of stigma and discrimination. The main evidence across global regions is summarized in the umbrella review of the *Lancet* Commission on Ending Stigma and Discrimination in Mental Health, which states: “Stigma and discrimination contravene basic human rights and have severe, toxic effects on people with mental health conditions that exacerbate marginalization and social exclusion” (1).

The *Lancet* Commission also reported the findings of a global survey of 391 people with lived experience of mental health conditions from 45 countries and territories. A key finding was that more than 80% of respondents said that the impact of stigma and discrimination can be worse than the impact of the mental health condition itself.

Crucially, the *Lancet* Commission umbrella review also features a review synthesizing the findings from over 200 scientific studies worldwide on what works to reduce stigma and discrimination. The message is clear: the key, active ingredient to reduce stigma is social contact between people who do, and who do not, have experience of mental health conditions.

## **Myth 2. Improving public attitudes will not have a real impact**

### ***How to respond***

A wealth of evidence has shown how stigma and discrimination have created major barriers to:

- ➔ accessing mental health services and support
- ➔ finding and keeping a job
- ➔ entering or remaining in education
- ➔ securing and maintaining relationships and social inclusion
- ➔ accessing care for physical health problems.

These impacts undermine recovery and well-being. By addressing public attitudes to mental health conditions as part of comprehensive mental health strategies and policies, people with lived experience of mental health conditions and psychosocial problems, their families, communities, and societies and economies will benefit directly.

Published evaluations of strategic anti-stigma interventions have shown strong evidence of significant positive impacts on people with lived experience of mental health conditions at societal levels, resulting from improved levels of empowerment and reduced self-stigma, and improved public attitudes and reduced levels of discrimination.

Improving public attitudes can thus translate into better patient outcomes, population mental health and well-being, suicide prevention and the “well-being” of societies and economies. However, improving attitudes is only part of the process. It is also important to address discriminatory behaviours, such as laws or practices that make it difficult to engage in the workforce or to enjoy normal family and community life.

## **Myth 3. Reducing stigma will increase demand on already overstretched mental health services**

### ***How to respond***

This is an understandable concern and a potential risk that needs considering carefully before any programme is developed and launched. However, forgoing needed programmes due to expected high demand is not a rationale that would be tolerated in other fields of health care (such as heart health or cancer). Accordingly, it should not be tolerated in mental health care either.

Tackling mental health stigma and discrimination can lead to multiple benefits, such as more people engaging in preventive programmes for mental health, earlier help-seeking, and increased public support and political will for increased investment in mental health service provision. Maintaining stigma levels due to fears of increased pressure on services will lead to no change and no progress.

## **Myth 4. Investment in mental health should focus on increased provision of services/support and not on addressing stigma – people need help more than understanding**

### ***How to respond***

Mental health stigma and discrimination have profoundly negative impacts on recovery and other important outcomes for individuals, families, communities, societies and economies. As the *Lancet* Commission reports, the impact of stigma and discrimination can be worse than the impact of the mental health condition itself. If you care about treatment outcomes, community mental health and well-being, mental health prevention and promotion, and suicide prevention, you should care about tackling stigma.

People might receive services or support intended to improve their mental health, but their mental health and well-being will still be undermined if stigma and discrimination compromise underlying determinants of health – such as the ability to secure an income, employment or educational opportunities, to find and keep meaningful relationships, or to have the support of family and friends.

Stigma and discrimination also affect the mental health and well-being of the mental health and social care workforce. These professionals can be affected by internalized self-stigma, public stigma, structural discrimination (including via employers' policies and practices) and family stigma (through being a professional working in a stigmatized sector). This may in turn lead to problems with mental health workforce recruitment and retention, which is a growing concern in many countries (2).

Thus, it can be argued that addressing stigma and discrimination complements and bolsters provision of mental health services and support.

## **Myth 5. Anti-stigma social marketing campaigns are too expensive**

### ***How to respond***

Social marketing campaigns aim to secure positive public attitudes and change behaviour using similar methods to commercial advertising, but with a social rather than a commercial purpose. Local, regional or national programmes to improve public attitudes and behaviours related to mental health may well benefit from such campaigns.

Social marketing campaigns do incur some expenses relative to their size and scale, as well as the context in which they are run. At the same time, not addressing stigma and discrimination can be very expensive. Stigma and discrimination prevent people fulfilling their social and economic potential as active citizens and seeking help (1).

There are some ways to develop and deliver them social marketing campaigns in a cost-effective way.

- ➔ Audience insight techniques – which aim to systematically collect and analyse data about a particular audience to understand their motivations and needs – can be used to ensure that resources are used in the best possible way. The findings of an audience insight process can be applied to understand, for example, how social media can best be used as an effective channel to reach and engage target groups.
- ➔ To increase the reach of the paid-for elements of a campaign and ensure that more people are positively exposed to campaign content, additional impact can be secured by working with employers, schools and colleges, community groups, faith groups, sports bodies and clubs, and local media.

An economic evaluation of the Time to Change anti-stigma social marketing campaign in England, United Kingdom, between 2009 and 2011 found that (based on average national social marketing campaign costs) the economic benefits outweighed the costs (3). The findings suggest that the campaign was both a potentially cost-effective and low-cost intervention for reducing the impact of stigma on people with mental health problems.

If funding is limited, smaller-scale social marketing campaigns – often harnessing the power of social media – can be run (see Chapter 3 for ideas).

## **Myth 6. Tackling stigma does not have popular support**

### ***How to respond***

A lack of public support for mental health and addressing stigma is often tied to a lack of political will in the field of mental health.

Stigma and discrimination have a powerful negative impact on allocation of resources to mental health. For example, governments often see mental health services as a “soft target” for any cuts, as they assume there is a lack of public support for mental health care.

However, if public support is created and increasingly built through tackling mental health stigma, the political profile of mental health will increase. This will secure ever greater support from the public, media, employers, key influencers and high-profile supporters, politicians and political parties. In this way, we can all bring about a change for the better.

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## The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

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