

**What is the role of civil society in advocacy for resource mobilization for noncommunicable diseases and mental health and holding governments accountable for noncommunicable diseases and mental health?**

**Technical paper #7**

This background paper has been developed by the NCD Alliance and United for Global Mental Health, at the request of the WHO and the World Bank, and has all benefited from the review and feedback of an External Technical Expert Group appointed to support the International dialogue on sustainable financing for NCDs and mental health. The papers will undergo further review by the WHO and the World Bank; therefore, they do not represent the official positions of both organizations. The papers are the property of the WHO and the World Bank. They may only be downloaded for the purpose of this web consultation and their content cannot be used for any other purpose.

## Summary

- CSOs including communities and individuals affected by NCDs and mental ill health can use their capacities, experience, and connections to advocate for resources for NCDs and mental health and hold governments accountable. As well as providing services directly to communities, CSOs act as key change agents. They draw attention to pressing issues; rally public, political and financial support; and hold governments and other stakeholders responsible for their promises.

## Key findings

National and sub-national governments and international institutions should ensure CSOs, communities and individuals affected by NCDs and mental ill health can:

- Inform multisectoral budget-planning and priority-setting priorities; the implementation, monitoring, and evaluation of NCD and mental health-related interventions; and the fulfilment of NCD and mental health commitments, targets and financing.
- Support community engagement and involvement of people with lived experience, establishing collaborative and mutually supportive policymaking processes.
- Support governments in creating demand for patient-centred, community-based NCD and mental health services, and advocate for building more resilient health systems based on strong primary health care.
- Play a vital role in public budget development and tracking and needs to be given the space to do so through transparent and consultative budget processes.

## Introduction

Civil society plays a critical role in all health systems, with some relying heavily on service provision by civil society organisations (CSOs). CSOs reach and represent marginalised people, working closely with communities of which they are often members, and provide care for deprioritised conditions. This gives CSOs a unique perspective on what communities need and what resources they require, making them effective advocates for resource mobilisation.

During the First WHO Global Dialogue on Partnerships for Sustainable Financing of Noncommunicable Disease (NCD) Prevention and Control (Copenhagen, 2018), there was consensus that civil society can play a crucial part in advocating for the mobilisation of resources for NCD prevention and control at all levels – local, national, and global(1). The meeting included a partnership session, led by the NCD Alliance, that reflected on the role of civil society in:

- mobilising resources
- creating links between NCDs and other sustainable development priorities

- holding stakeholders accountable during financing processes, recent examples of which are given below.

The session, however, noted that a lack of data on the investment of resources to tackle NCDs makes tracking resource mobilisation difficult. It called for strengthened data collection and monitoring to be made priority.

## **Section 1: Why civil society should be at the forefront of resource mobilisation advocacy**

By taking the lead in advocacy, CSOs can use their capacities, experience and connections to make significant progress in addressing NCDs and mental health. As well as providing services directly to communities, CSOs act as key change agents. They draw attention to pressing issues; rally public, political and financial support; and hold governments and other stakeholders responsible for their promises.

This change-agent role can be particularly important when it comes to relatively unknown or ‘forgotten’ issues and marginalised groups. CSOs frequently have a thorough understanding of the needs and issues confronting communities affected by NCDs and mental health. They are often the first to identify emerging issues or those that have been neglected by policymakers and the public. Within health financing, this could involve:

- identifying gaps in benefit packages of social health insurance schemes
- highlighting significant differences between sub-national health authority budgets
- suggesting evidence-based alternative resources to support health and development.

Civil society can generate demand for action on crucial topics like NCDs and mental health by rallying communities, engaging stakeholders and advocating for policy reforms. They elevate the voices of those lived experience of the issues, putting pressure on decision-makers to prioritise these problems and provide sufficient resources to address them. Civil society advocacy initiatives can generate momentum for change and catalyse action on a national, regional and global scale.

CSOs also play a crucial role in helping support policy implementation – particularly when governments lack the necessary infrastructure and resources – by, among other things, identifying practical solutions, providing technical support and even delivering services.

### ***Facilitating collaboration between stakeholders to push for policy change***

For health systems that require significant external finance, civil society can play a key role in making the case for investment. Not only can CSOs provide insight and expertise to investment case development, such as with the UN Interagency Task Force on the Prevention and Control of NCDs national investment cases, but can also demonstrate the need and effectiveness of external investment as service providers.

CSOs are a key part of service provision in almost all health systems, and in many low- and middle-income countries (LMICs), funding will come through a blend of on- and off-budget finance. Where coordinated off-budget finance is provided, CSOs have built direct relationships with donors and can reaffirm domestic government investment cases for NCDs and mental health.

In the development of the funding requests for the Global Fund's Grant Cycle 7, national and global CSOs have worked with global technical agencies to make the case for mental health services to be integrated into person-centred HIV and TB programming. They have set out how investing in mental health leads to improved HIV and TB outcomes,(2) and drawn upon their expertise as Global Fund Implementing Partners. This national advocacy has occurred in tandem with global and regional civil society advocacy, through mechanisms such as the Global Fund Advocates Network and Asia Pacific Council of AIDS Service Organisations. This has involved national, regional and global CSOs encouraging the Global Fund Secretariat and Board to integrate mental health into investment strategies.

This has also been the case in advocacy for domestic resource mobilisation at national and sub-national levels. In South Africa, the NCD Alliance, the South Africa Federation for Mental Health, and the South African Disability Alliance worked with grassroots and community organisations. They focused civil society engagement in the 2023 National Health Insurance bill public consultation on having stronger and more effective NCD and mental health services packages.

In 2023, the Tanzania Universal Health Insurance Bill was signed into law. Following advocacy by the Tanzania NCD Alliance and wider civil society, the health insurance scheme supporting the implementation of the legislation includes a special fund for people living with NCDs like cancer and chronic kidney disease. This will ensure that many Tanzanians will be able to access treatment that was previously out of reach due to its prohibitively high cost.

### ***Participation and the benefits of participatory processes***

Civil societies can benefit from participation and participatory processes to foster inclusive decision-making and drive positive change in policies and programmes. Participatory approaches also help to redress disparities by ensuring that marginalised and underrepresented groups have a seat at the table when it comes to decisions affecting their human rights. This is particularly important for people living with a mental health condition, older people and those receiving higher levels of care, who are at greater risk of experiencing human rights abuses. By actively involving these groups in decision-making, participatory processes enable them to contribute to solutions that are rights-based, reduce inequities and stigma, and promote social justice. The result is more transparent, inclusive, and responsive policies.

The role of civil society remains an active discussion across the global health sector. Several WHO member states have proposed a draft decision on social participation for adoption at the 77th session of the World Health Assembly.(3) It calls for the institutionalisation of social participation for health and well-being, building on national contexts and laws. The draft decision highlights the important role that empowered

people and communities have to play in achieving universal health coverage (UHC) and urges member states to strengthen, institutionalise and sustain meaningful social participation.

As noted above, civil society's participation makes policy processes more responsive to the population's needs. In financing activities, such as budget planning and resource allocation, civil society can:

- help identify and recommend resource direction to remote, rural and hard-to-reach areas
- advise on what locally appropriate medicines and diagnostics should be included in basic national health benefits packages and strategic purchasing decisions
- offer technical assistance by modelling budgetary impact analysis and complex pricing models for NCD medicines and diagnostics.

For this to be effective, budget transparency and consultation processes, enshrined in legislation, need to adhere to best practices in budget tracking and shadow budgeting.

There are also social and economic benefits of meaningfully engaging people with lived experience (4). They can contribute to bridging the gaps between the design and implementation of health interventions, which helps sustain return on investment. These voices and expertise should be seen as complementary support for government decision-making across planning, procurement and resource allocation processes.

### ***Civil society's role in accountability for implementation, monitoring and evaluation***

Global commitments are only as good as their implementation to positively affect health and wellbeing. Civil society plays a critical role in independently overseeing NCD and mental health progress within and outside of health systems. This is most effective when it takes place alongside government self-reporting. Community-led monitoring, analysing and advocating is a vital part of quality of care.

Positive examples include the Ghana NCD Alliance who use community-led monitoring as an accountability tool to independently monitor, analyse, and report on the performance of local primary healthcare to improve healthcare system delivery. Community-level data collected by CSOs is part of a larger feedback loop that can and should inform these greater policy and financing dialogues by giving enhanced information on service delivery realities, as well as driving innovation and social justice. For this to happen, civil society must be given space to fulfil this function and be supported by adequate and independent resources.

The scale of current data gaps on NCDs and mental health, especially in LMICs, is an increasing cause for concern. For example, global coverage of prevalence data for six mental disorders in young people aged 5-17 years is just 6.7% (5). Having timely, representative, good-quality data on mental health is essential to provide an evidence base for decision-making, drive policy change, ensure accountability, and make a case for increased investment and improved access to services.

### ***Investing in civil society capacity***

As well as more investment to tackle NCDs and mental health overall, sustainably financing CSOs and community systems, particularly in LMICs, require prioritisation. This has been a successful approach for HIV/AIDS, with donors like the Bill and Melinda Gates Foundation and the Ford Foundation directly funding CSOs to build skills in advocacy, budget tracking and documenting best practices to professionalise the sector. When it comes to NCDs, investment to strengthen civil society is rare. The most notable example is Bloomberg Philanthropies' investment in tobacco-control and promoting cardiovascular health, though a number of bilateral development agencies have begun integrating capacity building for local and national advocacy into their strategy. In mental health, such investment is even rarer, with the *Being* initiative for adolescent mental health being an emerging exception(6).

More funders should see investment in NCD and mental health civil society as a global public good and emphasise the value it brings to developing holistic and responsive policies and responses.

## **Section 2: Tools and frameworks for meaningful engagement**

There are several tools and frameworks available for meaningful civil society engagement, particularly on NCDs and mental health. These include:

- the NCD Alliance's Our View, Our Voices (OVOV) initiative (7)
- the NCD Alliance's Introductory Guide to Community-Led Monitoring for Noncommunicable Diseases (8)
- The Global Charter for Meaningful Engagement of People Living with NCDs (9) from the NCD Alliance OVOV
- The Global Mental Health Peer Network's guidelines on Lived Experience Engagement and Consultation for Policymakers (10)
- the Global Mental Health Action Network's Guiding Principles and Recommendations for Effective Lived Experience Youth Engagement Practices (11)
- WHO's Framework for Meaningful Engagement of People Living with NCDs, Mental Health Disorders, and Neurological Conditions (12)

By embracing these principles and practices, stakeholders can work together to build more equitable, responsive, rights-based and person-centred health systems that fulfil the needs and preferences of every individual, including those living with NCDs and mental ill health.

## **Recommendations**

- National and sub-national governments and international institutions should ensure that civil society, including those with lived experience of NCDs and mental ill health, are given space to be key participants in multisectoral national, regional and global budget-planning and priority-setting priorities; the implementation, monitoring and evaluation of NCD and mental health-related interventions; and the fulfilment of NCD and mental health commitments, targets and financing in line with the WHO Framework.
- Governments and donors should invest in developing civil society's capacity to support community engagement and people with lived experience in NCD and mental health responses, establishing collaborative and mutually supportive policymaking processes.
- Civil society and communities affected by NCDs and mental ill health should support governments in creating demand for patient-centred, community-based NCD and mental health services, and advocate for building more resilient health systems based on strong primary health care.
- Governments should acknowledge the key role of civil society in NCD and mental health service delivery, including in meeting needs that have not yet been addressed. Civil society can play a vital role in public budget development and tracking and needs to be given the space to do so through transparent and consultative budget processes.

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