THE MALAWI ADVOCACY AGENDA OF PEOPLE LIVING WITH NCDs

NCDAlliance
MALAWI

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OUR
VIEWS,
OUR
VOICES

An initiative by the NCD Alliance
and people living with NCDs

Acknowledgements

The Malawi Advocacy Agenda of People Living with Non-communicable diseases **(NCDs)** draws on NCD Alliance's "Our Views, Our Voices" initiative to promote meaningful involvement of people living with NCDs in the NCD response globally. Consultative efforts to produce the Malawi Advocacy Agenda of People Living with NCDs were supported by the NCD Alliance as part of its partnership with The Leona M. and Harry B. Helmsley Charitable Trust.

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Contents

We are Malawians living with NCDs and our voices must be heard, and our views taken into action by all the stakeholders of NCDs.

Every Malawians can be impacted by non-communicable diseases (NCDs) in one way or another, as these conditions do not select a particular group, age, gender and socio-economic status. Although NCDs are majorly preventable, they still continue to affect many of us physically, emotionally, economically and mentally.

We, the people living with NCDs have not been meaningfully involved in health governance and social life which concern us as human beings. Our conditions are defining who we are, because there is little that is being done on NCDs in Malawi by stakeholders involved in the NCD response.

We may come from diverse backgrounds with multitude of professions or skills, but our firm desire is to fight for our lives which are at risk, and for the future generations in Malawi and globally. We might be living with one, or multiple, chronic conditions but they should not define or describe who we are. As human beings, our rights are the stepping stone for demanding action from stakeholders and breaking the barriers which prevent us from accessing the best treatment, care and support. We, the people living with NCDs, need to be bold and firm to amplify “our views and our voices.”

We have been challenged with high costs of treatment and medications, delayed diagnosis, lack of counselling services, lack of human resource capacity to handle NCDs issues and high travelling costs to health facilities. We face stigma in our lives at work, schools and in the community in such a way that people living with NCDs are not allowed to participate in community development activities. NCDs are preventable and efforts should be made to avoid catastrophic suffering caused by these diseases. It is less costly to prevent rather than to treat, care and support people living with NCDs.

We, people living with NCDs, have not been meaningfully involved in the national NCD response and discourse around our health. We, people with lived experience need to be involved from the planning to the implementation and evaluation of activities. We have all come together as people living with NCDs to raise our voices and plead for our rights to have NCD prevention, treatment and palliative care accessible and affordable for all.

We call on all stakeholders to play their part in meaningful involvement of people living with NCDs. We bring the value of lived experience, and can more powerfully articulate our first hand needs, challenges and priorities. We are calling on government, CSOs, donor partners, our leaders - including political leaders - and our communities to recognize our lived experiences as a driver for necessary policy interventions.

Through this Malawi Advocacy Agenda of People Living with NCDs, we want to extend our support to those who have lost hope thinking that they are alone in this fight against NCDs

PREFACE

caused due to NCDs that are preventable. Malawi will suffer economic loss by 2030, as NCDs pose a significant risk to the population’s physical, emotional and mental health, which will have an impact on economic growth and development. Driven largely by four main modifiable risk factors which include tobacco use, unhealthy diet, physical inactivity and harmful use of alcohol. NCDs are major cause of poverty and barriers to economic and social development. The four intermediate risk factors are obesity, high blood pressure, raised blood sugar and high cholesterol. One of the key Global objective for combating NCDs which was adopted by Malawi is to promote effective intervention to prevent and control the risk factors of NCDs.

COVID -19 is an ongoing pandemic that emerged at the end of 2019 in china and it speared to all over the world including Malawi, which is affecting both directly and indirectly on the health services of Malawi including the services given to people living with NCDs. Because of the pressure amounted due to the pandemic, some of the service provision like diabetic clinic were closed and a number of people were not attended to during the critical time. The top officials brought much of their effort to combat the pandemic as a result the majority of the resources and human capacity was allocated to the isolation centers. The policy to minimize the movement of people also contribute the low attendance of people living with NCDs to their respective clinic.

Participants of multi-stakeholder meeting

The national Alcohol policy which was signed into legislation in march 2017 with the aim to reduce the harmful use of alcohol in Malawi but is not fully enforced or being implemented in such a way that some of the alcohol products are being sold in open places and to people below the age of 18 without proper supervision. The alcohol abuse, which is a deliberate or unintentional use of alcohol which result in any degree of physical, mental, emotional or social impairment of the user, the user family or society in general. The Nation alcohol policy which was signed to enforce some of the policies like; to ensure the establishment, review and enforcement of regulation over commercial production, distribution and sale system of alcohol products in Malawi. The policy will comprehensive of marketing of alcohol product.

The provision of health care services in Malawi are actually done by the Government health institution which are offering the service for free of charge. Christian Health Association of Malawi (CHAM) are also providing the service to Malawians mostly in the rural areas at a reasonable fee and the Government signed an agreement with CHAM institution to offer the services to the community for free and the Government is responsible to pay the bills. This agreement is called Service Level Agreement (SLA). There other Private Health institution which are offering the NCDs services at higher cost and the majority of People Living with NCDs cannot afford to pay for the service, it’s much easy to those on health insurance.

The prevalence of NCDs in Malawi is very high only that the diagnosis is very difficult and mostly delayed and this contribute to the chronic conditions of the clients. There a challenge in the capacity of Human resource who are capable to interpolate the sign and symptoms of NCDs. The communities are very much exposed to NCDs but they don’t know and understand the concept of NCDs. This brings discrimination, stigma and some human rights being violated.

The five major NCDs: Cancer, Cardiovascular disease, chronic respiratory disease, Diabetes and Mental health conditions are primarily caused due to major risk factors; Harmful use of alcohol, use of tobacco, Physical inactivity and unhealthy diet.

Non-communicable Diseases (NCDs) are the most common cause of death and disability worldwide, accounting for 71% of all deaths. The burden of NCDs remains of public health concern in Malawi, causing a substantial magnitude of morbidity and mortality. This becomes a very big challenge to the rural community who do not have access to medical insurance cover and they live below the poverty line. The marginalized communities are always at risk because of poverty.

A common misconception demands to be challenged; that NCDs are typically condition associated with wealthy, urban, or older populations. Therefore, the need to examine these conditions, their risk factors and policies surrounding how to prevent and treat the NCDs. Among individual who report having a chronic NCD over 40% of these need to borrow money or sell assets to pay for their hospital bills and this affect the individual's economic status.

Our Ministry of health published the National Action Plan (NAP) for the prevention and management of NCDs focusing on four thematic area; (1) Diabetes mellitus, cardiovascular disease and chronic lung disease, (2) Cancer; (3) Epilepsy and mental health disorder, and (4) Injury, trauma and violence. Advocating integrated at the point of delivery, the primary prevention, secondary prevention, treatment, follow-up care and palliative and rehabilitation

Participants of multi-stakeholder meeting.

_______________________Building this Advocacy Agenda_______________________

The Malawi Advocacy Agenda of People Living with NCDs has been developed as a result of the consultations involving voices of people with lived experiences of NCDs, conducted from July up to October 2021. Malawi NCD Alliance brought together over 150 people living with various NCDs from Northern region, Central region, southern region and eastern region, including care partners who identified their needs, challenges, and priorities in relation to NCD prevention, care, treatment, support and control in the country.

The Malawi Advocacy Agenda was built through community conversations, focus group discussions, a survey and key informant interviews. The consultative activities engaged a total of 54 people through face-to-face interviews and online interviews while a total of 16 key informants were also interviewed. Amongst the 16 key informants were 8 people living with NCDs, including: a public figure living with an NCD, 2 national decision makers and 2 community/ traditional leader from two of the communities , 1 NCD Coordinator at a public hospital, a business lady, a civil servant and 1 farmer. In addition, 4 community conversations were conducted with 41 people living with various NCDs including diabetes, kidney failure, dental, stroke, epilepsy, sicke cell, hemophilia and asthma.

Furthermore, the Mw-NCDA facilitated a multi-stakeholder meeting to review and analyze the content of the Malawi Advocacy Agenda of People Living with NCDs. The meeting involved officials from Ministry of health, religious leaders, community leaders, CSOs and 150 people living with NCDs.

The Malawi Advocacy Agenda calls for national and local Government officials, political leaders, social community, donor partners and religious leaders to put the needs of people living with NCDs at the center of NCD policy and practice in Malawi.

This Malawi Advocacy Agenda draws from the power of lived experience and presents the recommendations of those affected, through four key areas: human rights and social justice, prevention, treatment, care and support, and meaningful involvement. It provides a compass for NCD advocacy efforts and functions as a living document that captures the priorities of people living with NCDs. It is intended to guide and support efforts of key stakeholders to improve NCD prevention and control in Malawi.

This Malawi Advocacy Agenda also serves to strengthen the NCD response at national, regional, and rural areas. It is a reference to be used by all stakeholders and people living with NCDs to urge decision makers to take prompt action, to meet agreed upon global and national NCD targets, and to put people first. It can be used strategically according to each setting and the NCD advocacy opportunities that present themselves.

The Malawi Advocacy Agenda of People Living with NCDs calls for action in four key areas:

- **Human Rights and Social Justice**
- **Prevention**
- **Treatment, Care, and Support**
- **Meaningful Involvement**

The four areas of the Malawi Advocacy Agenda of People Living with NCDs are closely interrelated and achieving progress on one will necessitate progress on all others. Human rights, social justice, and meaningful involvement of people living with NCDs are the foundation for all action on NCDs. Our ambitions to reduce the burden of NCDs in Malawi will not be achieved without action on prevention, and we cannot make progress without providing adequate treatment, care, and support.

This is our Advocacy Agenda.

Members of the Lilongwe consultative meeting at Simama Hotel.

HUMAN RIGHTS and SOCIAL JUSTICE

CONTEXT

The employment of the highest attainable standard of health is one of the fundamental right of every human being without distinction of culture, religion, Political belief, and Economic or Social condition. These human right of People Living with NCDs include; An inclusive rights, All services, goods and facilities must be available, accessible, acceptable and of good quality, Freedom of choice of treatment, Equal opportunity for everyone (Entitlement) and Nondiscrimination. Another feature of rights is the meaningful involvement of People Living with NCDs.

Human Rights awareness is central towards the advocacy against NCDs. People living with NCDs face a lot of stigma and discrimination due to the nature of their diseases which are often misunderstood by the majority of people in Malawi, including some medical personnel. Further, since most NCDs are lifelong diseases, it is paramount that health rights become central to the response and all issues related to people's rights are adequately addressed, because we are often denied the opportunity to live in an environment conducive for our good health.

The universal right to health entitles everyone access to a variety of facilities, good services and conditions necessary for the achievement of the highest attainable standards of health. We claim our basic human right to life which is guaranteed from birth in an environment which enables good health and wellbeing, we call for a multi-sectoral and multi-stakeholder approach to NCDs.

We want to exercise our rights to education and information to make health decisions and manage our conditions, our rights to access quality and affordable treatment, care and support, our right to participate by being meaningfully involved in decision making processes, and our rights to be protected from any form of discrimination and stigma. Furthermore, we want the voices of care partners to be heard as they bear a significant proportion of the NCD burden.

We people living with NCDs in Malawi, we call for:

- The right of we people living with NCDs to participate in community activities, and decision-making process that affect our lives and economy.

- Access to high quality and affordable care, treatment and support as part of our universal healthcare including client-health workers providers relationship that treat people living with NCDs with dignity, privacy, compassion, respect and responsibility

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- Improved access of public transport and public space/building and work place to be conducive to people living with NCDs.

- Respect for informed choice on available treatment options for people living with NCDs.

- Addressing discrimination against people living with NCDs in various places including: work places, schools, churches and communities. Development and enforcement of laws/ regulations, policies, by laws and guidelines at all levels that protect the rights of people living with NCDs.

- The right to equal opportunities and treatment in all aspects of life and health rehabilitation. Improved access to health care facilities and good services for people living with NCDs based on universal health coverage.

- Support in initiation of income generating activities to enhance income to meet basic needs of people living with NCDs.

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PREVENTION

CONTEXT

We, people living with NCDs, would like to see improved public access to information that would ensure prevention of NCDs by the people of Malawi because it is cheaper to prevent than to care and treat NCDs. Prevention is the primary focus for any intervention and hence, public awareness about what NCDs are and how they affect people and how they can be prevented becomes a primary focus of our Advocacy Agenda.

We, People living with NCDs recommend investing in NCDs prevention strategies in order to protect our families and communities from NCDs and to create a healthy Malawi society. Placing multi-sectorial collaboration at the heart of the NCD response means we work together and win together. Our communities are constantly exposed to risk factors like unhealthy diet, physical inactivity, use of alcohol and tobacco and marketing of unhealthy foods around community environment. The government should continue to raise awareness on the risk factors for behavior change to reduce the NCDs burden. COVID-19 also poses a great risk to people living with NCDs, and we urge government to place emphasis on all the precautions to minimize the risks. We know that the cost of prevention is far less than the cost of treatment and cure and we, thus, call for strengthened preventive efforts to protect future generations of Malawi.

We people living with NCDs in Malawi, we call for:

- Public awareness campaign in schools and communities on the issues of NCDs and its risk factors through media houses, social networks and the Health Education Unit.
- Increase in the national budget allocation for NCDs program and resources of existing multi-sectorial platform for NCD coordination
- Investment in research and development to quantify Malawi NCDs burden and build a strong evidence of NCDs prevention and control.
- Strategic urban and rural planning to promote physical activities and establishment of national workplace and schools recreation centers to enhance general health and wellbeing of people.
- The review of the national health policy related to regulations and guidance to prevention and control of NCDs in Malawi.
- Inclusion of NCD prevention strategies as part of the school education syllabus, and introduction of a course on NCDs for those pursuing medical degrees to advance understanding symptoms of NCDs for early diagnosis.

- Air pollution in Malawi is recognized as one of the key environmental issue include health risk factor which needs Implementation of strong measures to prevent exposure to tobacco, alcohol, unhealthy foods, beverages and the use of diet food, including the banning of advertisements that promote certain unhealthy commodities

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- The enactment of legislation mandating manufacturers to display food content of the labels that meet national and global standards.

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We people Living With various NCDs are very committed to be engaged in prevention activities with communities and the general public.

TREATMENT CARE and SUPPORT

CONTEXT

We, people living with NCDs in Malawi live with chronic conditions and disabilities that require regular treatments which lead to exponential financial burdens on our families. We deserve to be supported by government institutions, healthcare providers and families. We urge the government and donor partners to strengthen health systems and improve access to essential and effective health care to support people living with NCDs. We people living with NCDs face long-term contact with health facilities at multiple levels.

We need more information on our conditions in order to manage them better, ensure treatment adherence, and ensure our self-improvement. We urge government, stakeholders and donor partners to strengthen the health system by building capacities of the health workforce on NCDs. In most facilities, health care providers are yet to be trained on NCDs ensuring proper education on management of our conditions, especially considering the nutrition aspect. People living with NCDs face out-of-pocket expenditures due to lack of insurance and adequate financial risk protection. The huge costs associated with the treatment and care of NCDs have caused many people living with NCDs to lose their businesses, employment and income.

We have also observed that some health personnel are not trained to give proper care and support to a particular NCDs and our health facilities are not affable towards meeting our needs. We need friendly healthcare personnel. We need our views to be respected and require an enabling environment to freely ask questions with regard to our conditions.

We demand availability of comprehensive services for early detection, diagnosis, treatment, psychological, rehabilitative, palliative care for those with NCDs.

We people living with NCDs in Malawi, we call for:

- Strengthening of primary health care facilities to ensure availability of affordable essential medicines, equipment and capable human resource to reduced distance and out of pocket expenses and provision of timely treatment to people living with NCDs in our communities.
- Availability and implementation of quality training for health professionals and other key actors with necessary skills to address NCDs at all levels.
- Government and other stakeholders to employ more people so that people living with NCDs have access to timely medical checkups.
- Many of People Living with NCDs do not access counselling services before testing, screening and receiving treatment Therefore, there is a need to review the health system and procedure management such that client

should be counseled before tests are done, when giving results and medical prescription as it is done in with HIV clients.

- Respect for people living with NCDs to be able to make an informed choice on available treatment.
- NCD drugs to be subsidized in all hospitals in Malawi, as in the case of antiretroviral drugs for HIV to enable people living with NCDs access them at any hospital in the country.
- We appreciate the effort which our Government is doing to make sure that people are able to get medication and treatment at Christian Health Association hospital (CHAM) using the Service Level Agreement (SLA). But we request that this information on the Service Level Agreement should reach the public.
- Promotion of palliative care services to ease out our conditions, symptoms and stress due to NCDs management, especially in geriatric care.
- The integration of palliative care training as part of the medical curriculum at our Colleges of Medicine, Nursing Colleges and Health Sciences to transfer a deep sense of empathy to build a system of comprehensive care which includes medical, psychological and social support

We people living with NCDs in Malawi, we call for:

- Support (emotional and financial) and counselling, improved attitude and behavior of health care providers to impart empathy
- Human rights based approach to NCDs treatment, care and support, creating a safe space to seek support when dealing with those living with NCDs.

We have first-hand experience
of NCDs
We are
Committed to
Issues of
NCDS

WE ARE INDIVIDUALS WITH

- RIGHTS
- NEEDS
- HOPES
- RESPONSIBILITIES
- ASPIRATIONS

We are

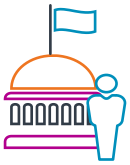
People

Lived experience

Of NCDs

We stand against stigma and discrimination against people living with NCDs at all levels and places

MEANINGFUL INVOLVEMENT



CONTEXT

People living with NCDs must be at the core of efforts against NCDs. Experience sharing and testimonies of people living with NCDs have proven to be a critical tool towards raising awareness and dealing with NCDs. Meaningful involvement of people living with NCDs should be critical to all aspects of NCDs related decision-making, including the planning through to the implementation and evaluation phases.

We, people living with multiple NCDs have a vast experience which is our strength and can be used by other stakeholders to reduce the risks factors of NCDs prevalence. We may not always have technical knowledge, but our lived experiences is a tool to combat the situation which is beyond control in other aspects. We are the living persons who knows the actual feeling and can express the in-depth of the situation when one has the NCDs.

Therefore our involvement in planning and policymaking will bring in fruitful results with appropriate health policies and programs.

Therefore, we People Living with NCDs call to all stakeholder who are involved in planning, making policies and running the programs to involve people living with NCDs in implementing the activities that relate to NCDs. Our involvement in the activities which are related to NCDs needs to be comprehensive and we should be treated as equal partner’s not just patients who have nothing to contribute.

We want to be recognized as people with rights, needs, hopes, responsibilities and aspirations. We are ready to share our lived experiences and drive change. We call for an enabling environment that fosters our active involvement and gives us an opportunity to speak up.

We people living with NCDs in Malawi, we call for:

- The involvement of people living with NCDs in policy making and accountability processes that affect our daily lives, to play an active role in NCD governance and to be on the front line of NCD advocacy.
- People living with NCDs to share their experiences with the general public so that the communities know and appreciate what it means to live with NCDs.
- The establishment of networks for people living with NCDs to have support groups, share experiences and speak in one voice.
- Training, mentoring and support to improve our knowledge, skills, and strengthen effective participation in health promotion, policy development and advocacy.

- Support in establishing partnership with government and other key stakeholders including community to develop and scale up activities led by people living with NCDs, improving dialogue between people living with NCDs and health service providers.

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- Greater access and up-to-date information about diseases and risk factors, prevention and treatment to strengthen various interventions.

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- Strengthening of civil society organizations (CSOs) and formation of NCD support groups to amplify the needs of people living with NCDs.

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- Involvement of people living with NCDs in the formulation, implementation and evaluation stages of policies related to NCDs.

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“We are the Voice of the Voiceless”