

Walking the Talk towards greater involvement of people living with NCDs

Language English



Christopher Agbega at NCDA Forum 2020

The NCDA's Walk the Talk webinar series Meaningful Involvement in Action highlights the importance of ensuring the meaningful involvement of people with lived experience in the NCD response. The second webinar in the series explored shifting the balance of power from top-down approaches to a shared balance of power in which people living with NCDs are equal partners in driving the NCD response. It also provided an opportunity to assess progress made in the two years since the launch of the [Global Charter on Meaningful Involvement of People living with NCDs](#) [1].

The webinar was chaired and moderated by Christopher Agbega, NCDA Our Views, Our Voices Advisory Committee member and Ghana NCD Alliance peer-trainer, and saw the unprecedented participation of a government representative, Dr Gladwell Gathecha, Ag Head Division of NCDs, Ministry of Health, Kenya. She provided an overview of the paradigm shift through which people living with NCDs have become meaningfully involved in the development of [Kenya's National Strategic Plan for the Prevention and Control of NCDs](#) [2] with the inclusion of lived experience representatives on the NCD Interagency Coordinating Committee. She credited the Kenya NCD Alliance, guided by its National Caucus of people living with NCDs, and their insistence on meaningful involvement as a major impetus for the shift.

Dr Gathecha made a powerful call to action for governments across the globe, naming some of Kenya's key drivers of success; for instance, ensuring that a diversity of socioeconomic status, gender, and cultural backgrounds are represented; providing training and support to enable people living with NCDs to make effective contributions; treating all members with respect through active listening and acknowledgment of contributions; and offering continual feedback to enhance communications.

Charity Muturi, NCDA Our Views, Our Voices Global Advisory Committee shared her experiences as an advocate with lived experience on the Kenya Mental Health Task Force. She began her journey as an advocate interested in changing the language and the narrative around what it means to live with mental illness. She recognized the challenges around inclusion in policymaking for people living with mental health conditions, as many are afraid to share their status due to stigma and adverse social and economic consequences. She described her own fears about speaking up in the Task Force and how support from the Our Views, Our Voices initiative enabled her to participate fully and to value her own expertise. She underscored the financial barriers faced by many advocates with lived

experience, and the challenges, especially among those living with mental health conditions, in completing their education, which places them at a disadvantage in securing employment and advocacy opportunities. “My call to action today is that after diplomacy let us choose activism, fearlessness, boldness...We have our documents in place, and we have our structures in place. And now it is about getting those [policymaking] seats...It starts with us,” said Muturi.

Camilla Williamson, Global Healthy Ageing Adviser, HelpAge International, spoke about HelpAge’s commitment to highlighting the voices of older people through a global network of 170 organisations across 91 countries, and to human rights-based strategies to engage older people in shared decision-making about their lives. The lessons learnt from HelpAge’s approach to meaningful involvement of older people can be applied to the NCD community. “To be meaningfully engaged and for our voices to be heard, we need to be engaged, we need to be informed, we need to be empowered... And we need mechanisms to ensure that our voices are heard by powerholders and are responded to...Today we are analyzing very deep-rooted power imbalances from the very personal level in families and communities, to the social and political,” said Williamson.

Christopher Agbega and Cristina Parsons Perez (Capacity Development Director, NCD Alliance) closed the session by reflecting on both the progress made and the deep-seated challenges remaining as the NCD community endeavors to put people first in the NCD response. Meaningful involvement of people with lived experience is now recognized as an essential part of policymaking, yet there is a long way to go before this is integrated into decisionmaking at global, national and sub-national levels.

Agbega remarked, “It is not an easy journey to live with an NCD and then become an advocate where people look to you to speak on issues and to fight to be in positions of power to balance the equation...We want the global community to recognise the power and importance of what it means to be a person living with an NCD as a resource. We are not to be taken for granted.”

NCD Alliance is grateful for the contributions of the speakers and remains committed to the meaningful involvement of people living with NCDs in decisions concerning their health. “We talk about putting people first in the NCD response and today’s webinar really illustrated the power and contributions of those with lived experiences...I think we will all remember from today the importance of providing support and an enabling environment to allow for participation,” said Parsons Perez.

This webinar was made possible thanks to NCD Alliance’s partnership with Access Accelerated.

Save the date: The third and final webinar of the series will be organised on Tuesday 14 December from 14:00-15:30 CET.

Post Date: Tuesday, 5 December, 2023

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Links

- [1] <https://ncdalliance.org/what-we-do/capacity-development/our-views-our-voices/global-charter-on-meaningful-involvement-of-people-living-with-ncds>
- [2] <https://ncdalliance.org/news-events/news/kenya-announces-new-national-strategic-plan-for-the-prevention-and-control-of-ncds>
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