CBM UK Project Evidence Brief #7

An inclusive and holistic approach to supporting people affected by Neglected Tropical Diseases

The CiSKuLA Project in Nigeria

Photo: Amina, *(centre),* a woman affected by an NTD, has her community's support.

Project partners: Health and Development Support Programme (HANDS), CBM Global Disability Inclusion

Title: CiSKuLA
Location: Birnin Kudu, Jigawa State, Nigeria
Timeframe: Dec. 2022 – May 2025
Partnership between: HANDS and CBM Global - in collaboration with Jigawa State government and local government in Birnin Kudu.

Overview

Nigeria has the largest burden of Neglected Tropical Diseases (NTDs) in sub-Saharan Africa. While control and elimination of NTDs is occurring throughout the country, 100 million Nigerians remain at risk for at least one NTD.[1]

Efforts to prevent and control NTDs largely involve mass drug administration (MDA). This is an effective and essential treatment pathway for NTDs,[2] but does not address the substantial toll NTDs often take on many other aspects of a person's life and wellbeing.

The 2.5-year CiSKuLA[3] project was the result of years of collaboration between CBM and HANDS in Nigeria and was designed in response to evidence from the earlier Neglected Mind - Skin Link project, which revealed high levels of stigma experienced by people affected by visible skin NTDs. This stigma underscored multiple forms of discrimination and exclusion that impacted people's mental health and limited their ability to participate fully in economic and social life.

CiSKuLA tested a person-centred approach. It was purposefully designed to be inclusive and holistic, and to directly support the wellbeing of people affected by NTDs as a complement to the MDA approach. It focused on four critical areas of support: Inclusive Water, Sanitation and Hygiene (WASH), mental health, livelihoods, and morbidity management and disability prevention (MMDP).

This person-centred approach was embedded within a holistic model, which understood social stigma needed addressing for people to live full and dignified lives. CiSKuLA acted at family, community, and service provider levels, in collaboration with government, to improve the understanding of NTDs and acceptance of people affected.

CiSKuLA is part of a long standing partnership between CBMG and HANDS in Nigeria to support people affected by NTDs. It delivered a comprehensive, person centred and disability inclusive package of support combining integrated healthcare, economic empowerment, and inclusive Water, Sanitation and Hygiene (WASH) services.

From 2022 to 2025, CiSKuLA directly supported 205 people. It provided hydrocele surgeries, promoted self-care and better symptom management for long term wellbeing, self-help groups for peer support and better community awareness to reduce stigma.

The project also enabled livelihoods (e.g. goat rearing, farming, trading), and the establishment of inclusive WASH facilities, WASH committees and school WASH clubs.

This approach now informs other CBMG integrated NTD care projects in Nigeria.

[1] The End Fund, (2023) 'Ending the Neglect: Cost-Benefit Analysis of Eliminating Neglected Tropical Diseases in Nigeria by 2030'.
[2] Ibid.
[3] CiSKuLA stands for Cikkaken Shirin Kula Da Lafiyar Al'umma, a Hausa phrase meaning 'inclusive and holistic care'.

This CiSKuLA approach led to improvements in health and wellbeing, while also demonstrating the value of placing dignity and respect at the heart of NTD support.

Introduction

NTDs are diseases of poverty transmitted through human contact, insect bites, or exposure to contaminated water and soil containing worm eggs or larvae. This set of diseases results in chronic symptoms that devastate the quality and length of life of those affected - more than 1 billion people worldwide on current estimates.[4] Symptoms include persistent infection of the lower limbs, kidney damage, eye lesions which can lead to visual impairment and permanent blindness, anaemia, and infertility.

NTDs are a major public health concern in Nigeria, which accounts for around 25% of Africa's NTD cases. According to WHO, 165 million people in Nigeria (approximately 84% of the population) require preventive chemotherapy (through MDA) for at least one NTD. Nigeria's five most common NTDs are Lymphatic filariasis (Elephantiasis), Onchocerciasis (River blindness), Schistosomiasis (Snail fever), Soil-transmitted helminths (Intestinal worms), and Trachoma.[5]

NTDs particularly affect the most vulnerable and underserved communities in rural areas. Our earlier Mind - Skin Link project in Nigeria highlighted the impacts of exclusion, stigmatisation and discrimination on the lives of people affected by visible skin NTDs. It found that social stigma against people affected by NTDs led to their exclusion from their communities, disrupting their cultural and social lives and limiting their livelihoods.

CiSKuLA was implemented by HANDS in Birnin Kudu LGA, Jigawa State, Nigeria, in collaboration with the Jigawa State Government, and trialled a new and ambitious, person-centred, comprehensive approach to reduce the range of barriers affecting the lives of people affected by NTDs. By the end of the project, **88% of participants surveyed reported their sense of dignity had much or very much improved, alongside enhanced health and livelihoods.** Elements of the approach now inform new NTD integrated care projects, and this document summarises some of the key evidence and learning resulting from the approach.

Methodology

This project evidence brief draws from an independent evaluation of CiSKuLA conducted by Zebra Multiservices Limited. The evaluation combined secondary data analysis (project reports and monitoring data, the WHO NTD Roadmap[6], and the Nigerian Government's NTD Master plan[7]), with primary data collection, including site visits and case stories. 160 respondents were surveyed and 74 qualitative engagements (9 focus group discussions and 65 key informant interviews) were conducted, with

[4] The End Fund, 2023.

[5] For a full list of WHO-classified NTDs and a brief overview of each one, see https://www.who.int/campaigns/world-ntd-day/2025/brief-outline. Analysis from The End Fund (2023) put the productivity gains associated with eliminating these five NTDs in Nigeria by 2030 at USD 18.9 billion. The benefit of freed-up productivity of caregivers, for 2023-2030, for Schistosomiasis alone was estimated to be USD 5.79 billion.

[6] See https://www.who.int/publications/i/item/9789240010352.

[7] See https://espen.afro.who.int/sites/default/files/content/document/Nigeria%20NTD%20Master%20Plan%202023%20-%202027.pdf.

proportional and inclusive representation across communities. Major stakeholder groups were assessed, including state and local government representatives (across health, education, and WASH sectors), healthcare providers, people affected by NTDs, Organisations of Persons with Disabilities (OPDs), civil society and community-based organisations, traditional leaders, mental health professionals, and CiSKuLA project staff.

What the evidence tells us

1. WASH interventions are vital for tackling NTDs - but their success hinges on behavioural change, best achieved through peer support and active community engagement.

NTD-causing pathogens flourish where WASH is inadequate[8] and responding to this is essential. CiSKuLA has shown that improvements in the access to and quality of WASH infrastructure are essential interventions but are not the full picture. To achieve improvements in NTD management, attention must also be given to effecting and supporting behavioural changes. CiSKuLA has shown that this can be achieved within a supportive environment in which people are better informed about the relationship between hygiene, self-care and NTD management.

"People have understood the importance of sanitation, and there is unity in the community on hygiene issues." WASH Committee member

"We are very satisfied with the WASH project because they told us how to take care of our personal hygiene as well as how to keep our community clean." Community leader in Shungurum Ward

Water is essential for wound care and routine self-care for NTDs. So CiSKuLA improved WASH infrastructure: 95.6% of those surveyed confirmed boreholes had been rehabilitated in their communities, and 96.7% said their boreholes remained functional after the project ended.

The project improved access to water[9]. When asked *why* water access had improved so much in their Local Government Area (LGA), participants pointed to the community-focused WASH Committees and school-focused WASH Clubs as central to hygiene promotion and infrastructure oversight. These Committees and Clubs contributed to increased handwashing, reduced open defecation, improved toilet cleanliness, cleaner

Photo: Borehole repair training, including for people with NTDs, through the CiSKuLA project.

[8] For example: (1) Faeces and urine-contaminated water might contain worm eggs that facilitate transmission of schistosomiasis and soil-transmitted helminthiasis. (2) Poor quality latrines encourage the breeding of the Culex mosquito, which transmits filarial parasites, the cause of lymphatic filariasis, to humans. (3) Unclean water can severely complicate wound care and routine self-care for NTDs such as leprosy, lymphatic filariasis, mycetoma and rabies.

[9] 87.5% of those surveyed indicated a moderate or major improvement in water access, 83.8% rated the water quality as high or very high in terms of taste, and 82.5% were satisfied or very satisfied with the overall quality of the water (considering factors such as access to water point, availability, inclusion, and proximity).

school environments, and better hygiene and sanitation awareness in the community.

However, tackling underlying community stigma takes time and this remains a work in progress: only 52.6% of those surveyed said that they felt less stigma or discrimination when collecting water, with 36% responding that they felt no change yet. This suggests a need for further destigmatising interventions within the approach.

2. A systems approach underpins improved access to and quality of healthcare for people affected by NTDs

Health workers and Community Directed Distributors[10] (CDDs) played a critical role in the success of the CiSKuLA project. These health workers were trained to become more adept at understanding the effects and symptoms of NTDs, and to be empathetic to those affected. Healthcare workers trained on limb-care identification and management reported enhanced confidence and capacity in managing NTD-related healthcare. CDDs trained in limb-care identification and referral evolved from being basic drug distributors to conducting disease identification, counselling, limb-care education, and ongoing community follow-up.

"Before CiSKuLA, I only referred people. Now I follow up, distribute drugs, and remind them we are all human beings—no one should be ashamed." CDD from Wurno Ward

"The patient refused treatment, so I met with his family and explained the consequences. He later agreed to go." CDD from Sundimina Ward

"Before the training, I never knew that washing the limb regularly and performing exercises could help the limb return to its normal shape." Health worker

Project participants recognised that patient-facing interventions[11] were key to improving health seeking behaviour. 87.2% of people surveyed said that health workers now always treated them with respect during clinic visits and 55.3% reported a reduction in stigma and discrimination when accessing healthcare[12] - suggesting a higher likelihood of return visits for all-important clinical follow-up. Family awareness and support were also cited as key to opening accessing health care.[13]

Increased access to healthcare[14] potentially contributed to improved health seeking behaviours and health outcomes[15], including mental health. People surveyed linked access to Lymphoedema clinics, self-care kits, and mental health support to improved self-esteem and independence.

[10] CDDs work within communities to distribute drugs and refer patients for further treatment.
[11] 289 caregivers and people affected by NTDs were trained on limb-care management, 150 hydrocele surgeries were conducted, and lymphoedema case management was made possible across 38 primary healthcare facilities, which 88.1% of those surveyed said they attended, 88.7% of those at least twice.
[12] There is still work to be done, of course, 39.7% reported no reduction.
[13] Family / caregivers often act as gatekeepers to NTD care, sometimes withholding transport or opting for less effective solutions, like herbs and traditional healers. Better knowledge can help remove these barriers.
[14] 88.5% said it was easier or much easier to access health services compared to before the project started.
[15] 95.1% said their health had improved greatly or moderately and 95.1% said they had experienced reduction in infections or swelling since infection (swelling and infection of limbs are caused by some NTDs, especially Lymphatic filariasis).

3. Livelihoods are an important contributor to wellbeing

Of those surveyed, nearly half received livelihood support in the form of training in farming, goat rearing, or petty trading. 94.7% confirmed that their income had increased since receiving livelihood support, with an increase of 115% in average monthly income by the end of the project.

"When I started the business of frying and selling cakes, I was able to make a profit, from which I bought a goat and a sheep that I am rearing now." CiSKuLA participant

CiSKuLA set out to prove that a comprehensive, person-centred approach would support the physical health of people affected by NTDs *and* tackle the social isolation and mental health dimensions they experienced too. The livelihoods component of the project not only focused on income generation but also recognised that being productively engaged would improve participants' social status and enhance financial independence.[16]

For example, local people were trained to repair and maintain boreholes and improve water access for people with disabilities. This local artisan model meant that ongoing repairs could be done locally, promoting ownership and sustainability. CiSKuLA included people affected by NTDs in the repair and maintenance training, centring them within this community development and improvement effort. This shifted how they were perceived - now seen as valuable contributors to society.

"Before now, Anas was stigmatised but people no longer treat him with disgust because of his relevance in the community." A community leader reflects on the impact CiSKuLA training has had on the life of one young man, Anas, affected by NTDs

4. Community acceptance plays a critical role in supporting the mental health of people affected by NTDs

83% of respondents recognised that community stigma against people affected by NTDs affected their mental well-being.[17] CiSKuLA purposefully targeted interventions at sensitising service providers and the wider communities within which people lived. By the end of the project, 86.5% of those surveyed responded that they *now* felt confident or very confident about themselves and 88.1% reported their sense of dignity had improved.

"This project has given most patients confidence—they no longer feel low self-esteem; they feel inclusive too." Health worker

"Community sensitisation helped patients understand their conditions better, now many seek treatment rather than relying on myths." Health worker

[16] Approximately 80% of those surveyed reported improved ability to afford food, while over 65% noted better access to healthcare and medicines. But not just those: participants also reported improved ability to afford transport and school fees, enhancing their mobility and connectivity within the community and representing a meaningful step towards better educational access and opportunities for their children, respectively.

[17] Refer to CBM UK's documents on the Mind – Skin Link project and Understanding Stigma for further detail on the lived experiences of people with Leprosy and Lymphatic filariasis affected by high levels of community stigma in Nigeria.

CiSKuLA provided refresher training to 52 clinicians on NTDs and the WHO Mental Health Gap Action Programme[18], and conducted awareness-raising and community sensitisation activities, including for family members and carers in all 11 wards of Birnin Kudu LGA. 90.1% of those surveyed responded that their family had become more supportive of them since the project began, 88.7% noticed that the community treats them more positively, and 92.2% felt that they were more included in community activities.

Direct mental health support for people affected by NTDs complemented community sensitisation, providing 138 people with integrated mental health care services and establishing self-help groups that enabled additional peer to peer support for 64 people.

Learning from experience

Identification of lessons from CiSKuLA's comprehensive and inclusive approach supports the ongoing refinement of the CiSKuLA model of holistic support for people affected by NTDs. Key lessons include:

Lesson 1: Integrated approaches can generate important multiplier effects, but innovative projects require reflective management

The CiSKuLA project demonstrated positive improvements in the health, economic, and overall well-being of people affected by NTDs in Birnin Kudu. Health, WASH, and livelihood interventions worked together to provide person-centred NTD support. Each component was designed to complement the others for both individual and community level impacts. For example, investments in WASH infrastructure enhanced access to water and sanitation, which supported community hygiene practices and individuals' disease management. This same investment contributed to improved livelihoods, and wider community development. Separate components working together is the point of the integrated model.

"The project … has made them realise that being affected by such disease does not mean their lives has come to an end." CiSKuLA project coordinator

"I'm grateful to the CiSKuLA project because I now have my health back and my peace of mind as well." CiSKuLA participant

Achieving this integration, as CBM Global and HANDS did through CiSKuLA, requires innovative project management. Balancing the pace and sequencing of interventions to maximise the multiplier effects demanded continual reflection and prioritisation. Monitoring and adaptation were central to success.

Understanding how different components of the model interact remains a challenge. For example, did improved wellbeing stem more from livelihoods interventions or mental health support? Should one area receive greater focus or funding for optimal impact? While CiSKuLA did not generate evidence to answer these questions definitively, it strongly reinforced the value of a holistic approach: all components are important, even if their individual contributions are not yet fully understood.

[18] See https://www.who.int/teams/mental-health-and-substance-use/treatment-care/mental-health-gap-action-programme.

Lesson 2: Don't underestimate the transformative value of community awareness

One of the most powerful lessons from the CiSKuLA model is the transformative impact of community awareness-raising. Across all components, community engagement was essential to fostering visibility, reducing stigma, and promoting sustainability. Active participation from Organisations of Persons with Disabilities (OPDs) strengthened local advocacy and worked to embed inclusion into community norms. Local structures such as WASH committees (WASHCOMS), self-help groups, and clubs played a pivotal role in sustaining these efforts, demonstrating that when communities own the process, long-term change is more likely.

Stigma reduction was most effective when people with lived experience – champions – were actively involved in community activities. This helped normalise their presence and fostered greater acceptance and understanding. Social contact through peer support groups and livelihood initiatives helped bridge gaps, but culturally sensitive awareness strategies need prioritising and early planning. Involving community gatekeepers—such as religious and traditional leaders— amplifies outreach and ensures equitable access to services, especially in more remote areas.

Lesson 3: Livelihood support for people affected by NTDs must be tailored to be most effective

"The support matched what we do every day; it was not just given but connected to our lives." Person affected by an NTD

Effective livelihood support for people affected by NTDs hinges on tailoring interventions to individual needs and local realities. One clear lesson from CiSKuLA was the value of conducting individual needs assessments before offering support. This ensured that livelihood options aligned with people's interests, abilities, and daily routines, making the support more relevant and sustainable. The inclusive design—supporting both men and women—also fostered shared ownership of the intervention. Co-creation with relevant stakeholders, especially people with disabilities, gave people a voice in shaping the support they received, which in turn strengthened alignment with local contexts and empowered participants to lead better lives.

However, economic empowerment must also reflect prevailing economic conditions; even increased start-up capital[19] was insufficient for some petty traders due to inflation and market prices. Vulnerability to theft increased for some participants as they began earning and handling money, highlighting the need to promote secure savings schemes for financial security.

Lesson 4: Accessibility is not a side issue - it is central to equity and effectiveness

"Mobility aids will help us move freely and participate in community activities." Project participant with disability

Ensuring accessibility for people with disabilities requires more than general inclusion—it demands targeted support that addresses specific mobility and access challenges. People with disabilities living in Birnin Kudu LGA were involved in planning and decision-making for

[19] This was adjusted from 50,000 naira to 100,000 after feedback from participants.

key project activities.[20] Respondents emphasised the importance of assistive technology, such as tricycles and wheelchairs, which would enable individuals to move freely in their community. These aids are not just tools for movement; they support dignity, independence, and social inclusion, without which individuals may remain isolated and unable to engage in community development. Disability inclusion must be mainstreamed from the outset, embedding accessibility considerations into every component–from infrastructure and service delivery to livelihoods and health.

Lesson 5: Government ownership is key to sustainability

The CiSKuLA project demonstrated the value of aligning with existing government policies and structures, securing endorsement and participation at both state and local government levels. Activities were embedded within local systems, avoided duplication, and fostered ownership among government stakeholders. Collaboration with the Rural Water Supply and Sanitation Agency (RUWASSA), the State Ministries of Health and Education, and other ministries and relevant agencies helped integrate the project into broader WASH and education initiatives.

"This project has set the foundation; we now have the tools and knowledge to carry it forward." Government official, Jigawa State

The WHO NTD Roadmap emphasises that NTD interventions must be country-led, and CiSKuLA's experience reinforces this principle. Government ownership strengthened implementation and positioned government to scale successful models beyond the initial intervention. However, funding and capacity remain important considerations. Project funding needs to be structured to facilitate strong government engagement from the outset.

Recommendations

The CiSKuLA project was a small project that tested a new, holistic, comprehensive and inclusive approach to supporting people affected by NTDs in just one of the 27 Local Government Areas (LGA) of Jigawa State, Nigeria. The recommendations drawn reflect the operational lessons above to increase impact and sustainability, as well as actions to encourage replication beyond Birnin Kudu LGA.

Project Teams delivering holistic and inclusive approaches should:

- **Co-creation is key**. CiSKuLA included people affected by NTDs, government stakeholders, health professionals, and disability champions in co-creation workshops and design processes. This co-creation model should be adopted and promoted to encourage endorsement, participation, a strong sense of ownership and sustainability.
- **Integrate and sequence interventions thoughtfully to avoid imbalance and maximise multiplier effects**. In CiSKuLA, healthcare, mental health, and WASH components were essential to start straight away, while livelihoods support needed to progress in alignment with participants' readiness.

[20] In line with local realities, 50 people with disabilities were trained on and supported with farming, 70 people with disabilities were trained on and supported with goat rearing, and 30 women with disabilities were trained on and supported with petty trading.

- **Establish monitoring systems to assess the impact of each component and the intersectionality between them**. Develop clear theories of change to guide evaluation and project management. Use innovative digital field tools like Kobo Collect to improve longitudinal tracking of individuals – essential for a person-centred approach.
- **Increase visibility and community support for people affected by NTDs through sensitisation campaigns, stigma reduction methods and inclusive community activities**. Start this early and involve community gatekeepers (e.g., religious leaders) and disability champions.
- **Proactively identify people with disabilities and ensure inclusion and accessibility across all components, e.g. using accessible communications**. Include mobility needs assessments and provide assistive devices within the livelihoods package. Proactively map and engage people with disabilities in WASH activities; identify barriers to hygiene and sanitation and ensure inclusion in WASHCOMS and infrastructure (e.g. boreholes) assessments.
- **Conduct a local market assessment as a starting point for developing livelihoods initiatives and ideally promote savings and loans schemes to protect earnings, alongside tailored training and input supports**. Embed livelihoods within a graduation approach.
- **Integrate mental health and counselling services into existing health systems rather than relying on external consultants for supervision**. Conduct health system readiness assessments to identify entry points for this.
- **Support government capacity for co-ownership and leadership in integrated NTD responses**. Allocate funding for active and meaningful government participation.

Recommendations for National and State Governments:

- **Review data collection tools for MDA and lymphoedema management and align these with international standards, to fill gaps in disability-inclusive data**.
- **Prioritise finance models that enable government to lead without dependency on external incentives**.
- **Formalise partnerships among government, OPDs, and service providers**.
- **Advocate for funding for holistic and comprehensive NTD approaches that are person-centred – and not just for inclusive MDA**. Extend the approach to other LGAs with high NTD burden.

Conclusions

"The project didn't just treat illness; it helped heal the whole person."
Community leader, Birnin Kudu

The CiSKuLA project demonstrated the transformative power of integrated, holistic support for people affected by NTDs, affirming that addressing multiple dimensions of well-being (physical health, mental health, social life, and economic wellbeing) can

significantly improve lives and break the cycle of poverty and disability.[21] With 76.3% of participants affirming the value of receiving all services together, and 86.5% reporting increased confidence and self-worth, **the evidence underscores that treating the person, not just the condition, yields broader and long-lasting impact**. While the data does not rank the importance of each component, we can conclude that the combined approach led to improved healthcare access, reduced infection, reduced pain, improved mobility, some reduction in social stigma alongside improved mental health, economic empowerment, and an overall sense of dignity.

CiSKuLA was a small proof-of-concept project with a message that we want to spread to other areas with high NTD burden all over Nigeria: holistic, comprehensive and person-centred support enables people affected by NTDs to live full and fulfilling lives.

Acknowledgements

This evidence brief is produced by CBM UK, with reference to the reports written by the project team of the CiSKuLA project, in Nigeria and the independent evaluation of CiSKuLA conducted by Zebra Multiservices Limited. We would like to express our gratitude to all the participants in and authors and reviewers of these project outputs. We are particularly grateful to people affected by NTDs in Birnin Kudu LGA (especially the late Anas, whose natural exuberance shone through), as well as staff of the health system in Jigawa State, who so generously shared their experiences and insights with the CiSKuLA project partners.

Sincere thanks are due to HANDS (particularly Maureen Pali, Ameh Joseph, Jerry Atsi, and its late director Christopher Ogoshi, who believed in the person-centred holistic approach), CBM Global (particularly Professor Julian Eaton, Dr Danny Haddad, Philip Ode, Timothy Nnoruem, and Justina Agaji), JONAPWD, and the Jigawa State Government for their invaluable contributions to this project.

More information on CBM UK NTD programming, including our holistic support for people with NTDs, can be found on our website.[22] If you want to hear more from people with NTDs directly, you can view short films from the ISNTD Festival Showcase[23], including 'Renewed Hope - Anas' Story'.[24] You can also watch a short video explaining the unique CiSKuLA model.

For further information, please contact advocacy@cbmuk.org.uk.

[21] See https://www.endthecycle.info/.

[22] See https://www.cbmuk.org.uk/about-us/who-we-are/areas-of-work/neglected-tropical-diseases/ and https://www.cbmuk.org.uk/about-us/dream-big/holistic-support-for-people-with-ntds/.

[23] See https://www.isntd.org/isntd-festival-showcase-film.

[24] See https://www.isntd.org/isntd-festival-showcase-film/renewed-hope---anas'-story.