



NEGLECTED TROPICAL DISEASE  
NGO NETWORK

A global forum for nongovernmental organizations  
working together on NTDs

# Welcome to the NNN Conference 2020

Accelerating to 2030:  
Building Resilient NTD  
Programmes in a  
Changing World

With thanks to our  
sponsors



Virtual Event

8<sup>th</sup> – 10<sup>th</sup> September 2020

Billy Weeks (2016, Chikwawa, Malawi)



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# Workshop Agenda

- Introduction and Housekeeping: Martin Kollmann
- Presentation of best practices
- Persons affected by Chagas: Javier Sancho and Jenny Sanchez
- Podo Network: Gail Davey and Fikre Hailekiros
- Persons affected by NTDs and People with disabilities: Suresh Dhonge
- Persons affected by leprosy during Covid 19: Alice Cruz
- Questions and comments: Martin Kollmann and Speakers
- Small group discussion: Speakers and Facilitators
- Report to plenary: One rapporteur per group
- Conclusion: Geoff Warne



# Breakout groups

- Participation of persons affected in the fight against NTDs: Javier Sancho, Elvira Idalia Hernández and Geoff Warne
- Building capacity of persons affected for advocacy: Gail Davey and Fikre Hailekiros
- Participation of persons affected in advocacy for human rights: Mathias Duck and Alice Cruz
- Participation of persons affected in community based inclusive development: Suresh Dhonge and Martin Kollmann



# Patient Advocates: Experience within the Podoconiosis Network

Fikre Hailekiros and Gail Davey

September 10<sup>th</sup>, 2020



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**National Podoconiosis  
Action Network (NaPAN)**

"Together for healthy feet." ለጤናማ እግር ቢጋራ እንስራ"



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# Background: the need and the challenges

Like many other NTDs, podoconiosis is found in remote, rural settings, in communities far from the 'seats of power'.

Affected people experience physical, social and psychological barriers to participation.

They are less likely to have had formal education and more likely to be food insecure than unaffected people in the same community.





# How have patient advocates been identified and prepared? – the NaPAN perspective



- Understanding of the disease and its self-care practices
- Treatment adherence and progress gained
- Ability to articulate self-story related to the condition and socio-economic impact
- Passion to support other, particularly housebound cases



# How have patient advocates been identified and prepared? – the NaPAN perspective



- Capacity building on communication skills and corporate business management
- Inclusion and participation in various community conversation sessions
- Equipping with the required infection prevention materials while giving care to housebound patients
- Providing messaging flyers and leaflets to use in community awareness-raising activities



# How can patient advocate training be supported? – the *Footwork* perspective

Identify (and create!) opportunities to participate



Identify budget lines to support –

- Language training
- Communication skills training
- Travel for visa application
- Flights, visas, accommodation, subsistence and conference registration expenses for advocate **and** supporter





# Footwork – support for patient advocates

Research funding budget lines

- Public and community engagement/involvement
- Dissemination

Specific fundraising

Unrestricted funds

Developing patient advocates is a long-term process



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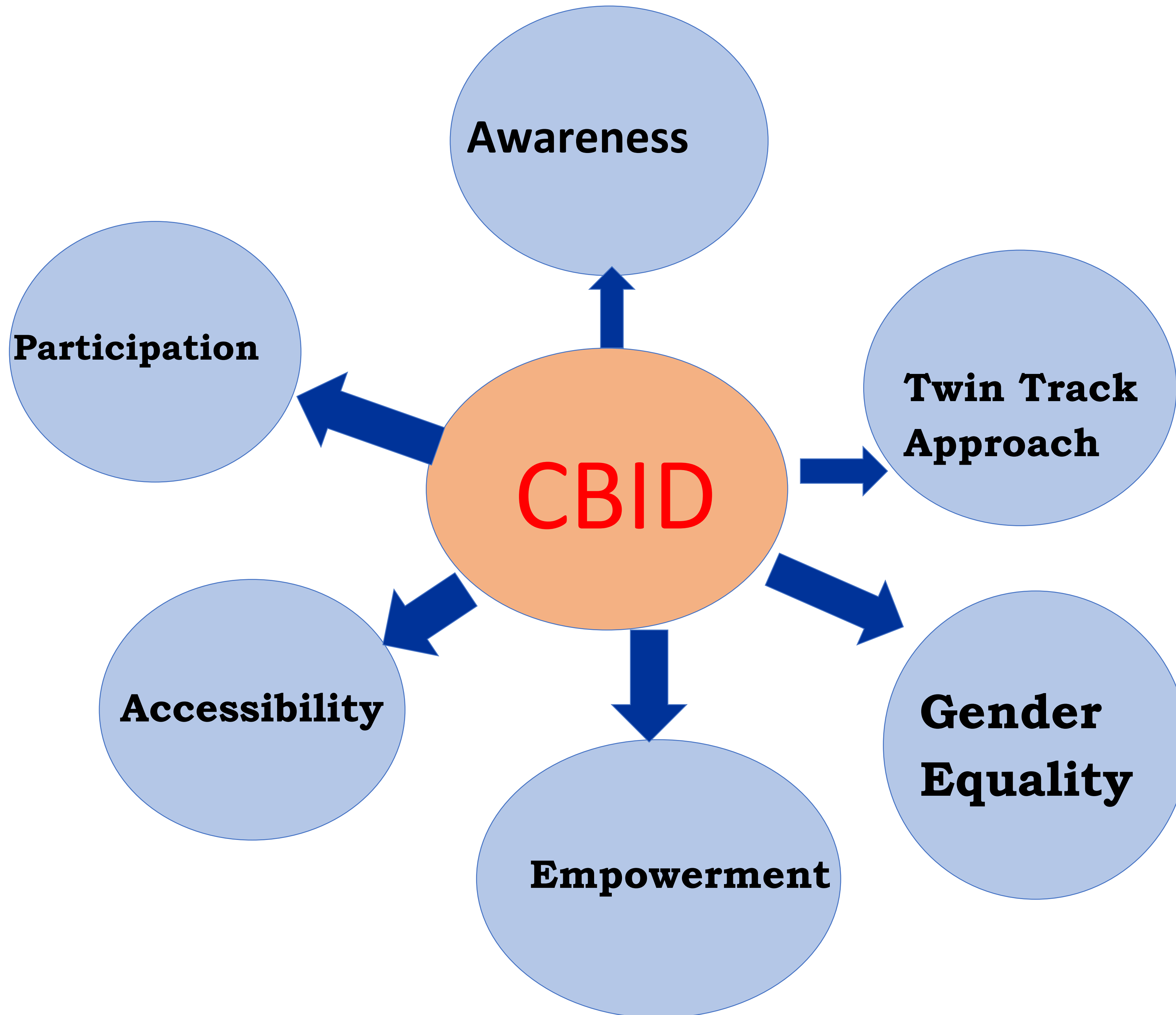
# Community Based Inclusive Development:

for inclusive, equitable & resilient communities





# Community Based Inclusive Development





## Break out group discussion (25 minutes)

- What are the lessons learned when it comes to participation of persons affected? (From the presentations, but also from other experiences we have made)
- What are the challenges/obstacles we face when it comes to increasing participation of persons affected? How can we address these challenges?
- What are the next/first steps? Thinking especially about NGOs who are starting to think about participation of persons affected? Which actions can be implemented?





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