Faith Actors Destigmatizing Disability to Improve Community-based Rehabilitation

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Christian Connections for International Health

Capacity Building  Networking  Fellowship  Advocacy

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Faith Actors, Communities and People with Disabilities
Housekeeping

- Put questions in Q&A Box
- Recording on www.ccih.org > Events > Webinar Recordings
Our Panel Today

**Cynthia Bauer** is US Executive Director and Co-Founder of Kupenda for the Children. Her work as a wildlife biologist brought her to Kenya, where she was inspired to start Kupenda. As a person living with a disability, Ms. Bauer was especially motivated to help children with disabilities overcome discrimination and stigma. She has over 10 years of experience as a wildlife biologist with multiple nonprofit and government agencies. She has also taught biology classes for over a decade, and has a Master’s degree in Biology and Ecology and a Bachelor’s degree in Wildlife Conservation.
Our Panel Today

**Abdulgafoor Bachani, PhD, MHS** is Associate Professor in the Department of International Health at the Johns Hopkins Bloomberg School of Public Health, and Director for the Johns Hopkins International Injury Research Unit (JH-IIRU). Dr. Bachani has a particular interest in strengthening health systems to enhance access to rehabilitation services in low-resource settings; and applying new and innovative information and communication technology approaches to injury prevention, disability, and rehabilitation.
Current status of disability and response in low-and-middle-income countries

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jhsph.edu/IIRU
Key issues

- Why consider disability?
- Current status and issues
  - Conceptualization of disability
- Disability and rehabilitation

Sources:
*https://www.istockphoto.com/photos/special-needs*
Why consider disability?

- Globally, 1 in 7 people live with some form of disability
  - Short-term vs long-term, temporary vs permanent vs relapsing

- Changes in disease patterns – chronic conditions including COVID19

- Individuals, caregivers, families, society is impacted

- Consequences
  - **Health**: physical limitation, rehabilitation needs, chronic conditions,
  - **Social**: caregiving needs, stigma, marginalization, limited educational opportunities, living standards, exposure to violence
  - **Economic**: exposure to shocks, asset ownership, health expenditures, multidimensional poverty

Sources:
- World Report on Disability, 2011
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5739437/
Why consider disability?

Global Goals

- **UN Convention on the Rights of Persons with Disabilities (CRPD)**

- Universal Health Coverage

- Disability-related Sustainable Development Goals:
  - Inclusive education (Goal 4)
  - Inclusive employment opportunities (Goal 8)
  - Social, economic and political inclusion (Goal 10)
  - Accessible cities, transport services, and public spaces (Goal 11)
  - High quality, reliable and timely availability of disability data (Goal 17)
Disability: Current Status & Issues

- Estimates for disability historically problematic due to a variety of reasons:
  - Conceptualization:
    - Medical & Social models: interaction of health, environmental, social, and cultural factors (2-6)
    - Identification of disabled individuals – social stigma
  - Measured through 1-2 questions in national censuses or, cross-sectional studies to meet specific needs
  - Measures lack comparability and for many LMICs, simply unavailable
  - Efforts to standardized measurement

Source:
Linear Medical Model

Health condition

Body function and structure

Activity

Participation

Environmental factors

Personal factors

Contextual factors

Sources:
• Adapted from: IOM (Power and Tarlov), 1991
• International Classification of Functioning, Disability and Health, 2001
Response: Efforts to understand the burden of disability

- Disability Data Initiative
- Analysis of disability questions in national censuses and household surveys between 2009 and 2018
- Internationally comparable questions on functional difficulty were found for only 47% of countries and 16% of household surveys and censuses under review, despite impetus towards standardizing disability measurement
- Any type of question about disability was lacking for 24% of countries and 65% of reviewed datasets
- Opportunity for measuring disaggregated data to impact policies and interventions

Sources:
https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(21)00312-0/fulltext
Response: Inclusive Health Systems

- Universal Health Coverage & SDGs
- Health systems currently not designed to be inclusive for people with disability
- Barriers:
  - Physical access, attitudinal, financial
  - Training
  - Equipment
  - Socio-cultural
- Some efforts underway to address these issues
Learning, Acting, and Building for Rehabilitation in Health Systems
An estimated 2.4 billion people are living with a health condition that would benefit from rehabilitation; less than 10% have access to the care they need.
Challenges

- Lack of data
- Inadequate government investment
- Weak policies
- Fragmented health system
- Limited capacity
- Stigma and marginalization
- Lack of prioritization
- Dependence on private sector
- Insufficient regulatory bodies
Global Efforts

• Increasing number of policies and programs for rehabilitation and AT
• Growing investment in data collection and research
• Creation of rehabilitation and AT-focused divisions within government ministries
• Increasing the number of workforce and examples of successful service delivery models
• Guidelines developed to standardize care
Development of health systems that are responsive to growing needs for rehabilitation across the lifespan

- Improve the health and well-being of the population
- Provide down-stream benefits in terms of future health care costs, increased productivity, and social inclusion
Anticipated Impact

Health systems strengthened through a sustainable approach

- Expanded Capacity
- Inclusive Engagement
- Integration
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Our Panel Today

Earnest Kioko serves as CURE International’s Senior Director, Spiritual Ministry. In this position, Mr. Kioko provides functional support and guidance to the Spiritual Ministry teams across the CURE network and oversees the development, dissemination and organization of CURE’s Christian ministry resources. He previously served as the Spiritual Director of CURE Kenya and is an ordained Reverend with the Africa Inland Church, Kenya and is currently pursuing a PhD in Theology and Development at Africa International University in Kenya.
Our Panel Today

Leonard Mbonani is Kenya Executive Director and Co-Founder of Kupenda for the Children. He has over 40 years of experience working in disability programs as a special needs assessment officer for the government, a disability researcher for an internationally funded nonprofit organization, and an educator at special schools and units throughout Kilifi County, Kenya. His compassion for people with disabilities began within his own family, when interacting with relatives who were deaf and unable to communicate due to lack of sign language training. He holds certificates in Secondary Education and Primary School Management and Diplomas in Special Education and Learning.