Getting Research Into Households (GRIH) through the eBASE Family Centered Evidence Toolkit for Disability

Speakers:
Patrick Okwen, Nain Yuh, Alvin Lontum, & Aweh Akofu

Chaired by:
Siziwe Ngcwabe
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About The Africa Evidence Network

• Pan-African community
• **Vision**: end poverty & inequality
• **Mission**: evidence-informed decision-making in Africa
• **4 ways of working**
  • Informs e.g. newsletter
  • Connects e.g. Evidence 2020
  • Learns e.g. landscape maps
  • Advocates e.g. Africa Evidence Leadership Award
• Get in touch!
  @Africa_evidence
  ace@uj.ac.za
  www.africaevidencenetwork.org
Speakers

Patrick Okwen  Nain Yuh  Alvin Lontum  Aweh Akofu
Experimenting and Learning in Disability in Middle Africa

Patrick Okwen
Team Lead, eBASE Africa
Experimenting and Learning

• Two things that should happen together but usually don’t ...
The Four Waves of Evidence Revolution

Fig. 1 Four waves of the evidence revolution

White 2019: Palgrave Communications.
The Results Agenda
Impact Evaluations

The PIRL Project
Partnerships for Inclusive Research and Learning

CONSORT-Equity 2017 extension and elaboration for better reporting of health equity in randomised trials
We outline CONSORT-Equity 2017 reporting standards, an extension to the CONSORT (Consolidated Standards of Reporting Trials) statement that aims to improve the reporting of intervention effects in randomised trials where health equity is relevant. Health inequities are unfair differences in health that can be avoided by reasonable action. We defined a randomised trial where health equity is relevant as one that assesses effects on health equity by evaluating an intervention focused on people experiencing social disadvantage or by exploring the difference in the effect of the intervention.
Evidence Synthesis

“It is surely a great criticism of our profession that we have not organised a critical summary, by specialty or subspecialty, adapted periodically, of all relevant randomised controlled trials.” (Cochrane, 1979)
Evidence Synthesis

“Evidence-based practice is not exclusively about effectiveness; it is about basing practice on the best available evidence... the diverse origins of problems in health care require ...the utilisation of a diverse range of research methodologies to generate appropriate evidence.” (Pearson, 2004 p. 48)
Knowledge Brokering

Fig. 2 The evidence architecture  White 2019: Palgrave Communications.
Promising Big Data?

Single-Case Model
Geolocating SDH & SDG Indicators

CHWs pick up data (images, audios or videos + geolocations) and relays to eBASE/DHS

eBASE Team transcribes data, analyse, and export coded segments

Coded segments populated on GoogleMaps using Magpi

“\textit{In my last delivery, the nurse was very rude to me and did not listen to my complaints. Although he did his work well, I was not happy with the treatment, and it was my first delivery. I did not feel like going back there, especially because my neighbor had similar complaints and then successfully delivered at home}”

Code: - Community Delivery\Enablers\Healthcare Workers  \Weight score: 50

CHW Home Visit Bossa Woman 2 Position: 90 – 90  \GPS: 5°55'27.7"N 9°58'17.1"E

I do not sleep under a bednet because I don’t know how to use it

The bednet seems to be choking in the night

I am using the bednet for gardening
Power of Maps for Decision Making

Le Roi Njaya: 17eme Roi de Bamum

Circa: 1882
Understanding the Evidence Architecture

The JBI Model of Evidence-Based Healthcare

Overarching principles
Culture - Capacity - Communication - Collaboration
Tip: No Reinvention but More Learning
Thank you

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The eBASE Family Centered Evidence Toolkit for Disability Rights and Needs

Nain Yuh M.
Outline

• Background
• Objective
• Methods
• Results
• Discussions
Background

• Globally, the burden of disability is at 15% (WHO 2011). 80% of whom are in LMIC with 23% of children between 5 to 9 years having a disability in Cameroon (UNICEF 2015)

• Programs have been developed for PWD leaving out their voice & programs have been reported using quantitative data leaving out their stories and experiences.

• This Is inclusive of the evidence train
Objective

• We sought to improve livelihoods of PWD using innovation and best practices
Methods

• **Formative study**
• We conducted a formative study with families having children with disabilities (CWD) in Bamenda-Cameroon.
Geomapping

- We mapped out CWD in the city of Bamenda using Magpi and GoogleMaps using a data collection tool adapted from the Washington Group.
Methods

- Stakeholder engagement sessions
Evidence Search/synthesis

- We developed a PICO question to conduct a systematic search for best available evidence of what works for children with disability. We searched Cochrane, Campbell, JBI, Africa Evidence Network, and GoogleScholar for best available evidence. We also searched government and development agencies databases. We emailed authors and organizations working in disability.
  - Found=2000+
  - Eligible=150
  - Guidelines=6, 5 WHO & 1 local
  - NP=1
## Modelling the Toolkit

### Table 1: Mapping Evidence to Current Practice

<table>
<thead>
<tr>
<th>Axis</th>
<th>Current Practice</th>
<th>Evidence Based Practice</th>
<th>Clauses for Contributions to SDGs (based on CRPD SDG matrix)</th>
<th>Considerations for Training Modules</th>
</tr>
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</table>
| Rights of PWD | PLWD not attending schools | - PLWD should go to schools and schools should have adequate room for accessibility for PLWD.  
- Parents of CWD should assist them with homework, basic reading and writing. | By 2030, ensure that all men and women, in particular the poor and the vulnerable, have equal rights to economic resources, as well as access to basic services, | Train parents on importance of sending kids to school  
Explore reasons why kids don’t go to school  
Discuss with policy makers about investing in private inclusive education schools Modules: Rights & Education |
| Medical needs | Medical care when they go to HF  
- Needing assistive devices  
- Needing special diet  
- Needing physiotherapy  
- Expensive medical care  
- Lack of insurance  
- Not meeting hospital appointments | - CWD should be given good medical, nutrition and human contact  
- CWD in need of assistive devices should be provided with to facilitate accessibility  
- CWD need insurance scheme  
- Spend time bonding with CWD  
- Complete vaccination for CWD  
- Family should actively protect child against SGBV  
- Meet all hospital appointments | By 2030, achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all, (SDG target 3.8) | Train parents about importance of healthcare  
Train parents coping strategies – MHO, BEPHA  
Integrate insurance in IGAs Modules: Rights & Health |
Modelling the toolkit
The eBASE Family Centered Evidence Toolkit for Disability

9. Discussed health issues with child (No=0, Yes once in last week = 1, Yes more than once in last week = 2)
   - No
   - Monthly
   - Weekly
   - Daily
   - Not Applicable

10. Does the Child have a disability card? (No=0, Applied for and still awaiting = 1, Yes=5)
    - No
    - Applied and Waiting
    - Yes

11. Does the Child have a health insurance (No=0, Yes=5)
    - No
### Scoring_Families_for_Promoting_Rights_and_Needs_in_CWD_in_Cameroon

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<th>...TYPE_OF_DISABLE...</th>
<th>...DISCUSSHEALTH...</th>
<th>...CHILDDISABLE...</th>
<th>...CHILDHEALTHINS...</th>
<th>...BONDINGCHILD</th>
<th>VACCINATION_ST...</th>
<th>...PROTECTCHILD</th>
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Training
CHW
IGA
Beneficiary of IGA
Results

We developed 340 codes to describe the experiences of PWD in the communities. 29 Categories 90 sub categories, 340 coded segments. We identified 12 current practices, 47 barriers, 12 facilitators, 16 Coping strategies, and mapping of how conflict affects access for CWD. Our barriers category revealed 5 sub-categories and 16 coded segments.

We aligned them to the 5 CBR axis and developed guidelines for families for CWD.

Fig: Current Practices with regards to CWD
Source: MAXQDA
Results

• Barriers to accessing basic services

Fig: showing how the barriers impact on protection, financial access educational needs medical needs and entertainment needs

Source: MAXQDA
Results from Data analysis

Health variable change for CWD

Educational variable change for CWD
Results from Data analysis

Livelihood variable change for CWD

Livelihoods of CWDs

Social Wellbeing variable change for CWD

Social Situation of CWDs
Empowerment Variables

Empowerment of CWDs

- Participation in Comm. Hlth.: Round 1 = 13.3, Round 2 = 43.3
- Participation in Comm. Educ.: Round 1 = 20.0, Round 2 = 20.0
- Joined a Njangi: Round 1 = 20.0, Round 2 = 46.7
- Joined a Support group: Round 1 = 30.0, Round 2 = 43.3
Promising Result: Disability Card

- Disability card
- Access to basic services
- Engagement in evidence based practices
- Improved rights & needs
- Improved livelihoods for CWD
Discussion

• Use of computer assisted data collection, analyses, and further use to develop a family centered approach to improve lives of CWD in LMIC has not been reported in research literature to the best of our knowledge. Using the eBASE Family Toolkit enabled a more interactive and faster approach to understanding rights and needs of CWD in Cameroon and subsequently facilitated the integration of best practices in the process.
Thank you

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Left Behind: The Economics of Disability in Cameroon

How Can we Use Evidence to Create Market Channels for PWDs?

Alvin Lontum
Background

Economic security is the ability of individuals, households or communities to cover their essential needs sustainably and with dignity (ICRC, 2015)
Economic Security

Apart from Economic security variables, a source of income also allows families to:

• feed well,
• pay hospital bills,
• afford for education
• support children in vocational training
Economic Security and SDGs
Economic Security, SDGs and #WhatWorks

“From SDGs to using evidence within evidence portals to broker knowledge to households with PWDs, eBASE hopes to improve livelihoods for PWDs” eBASE Africa 2020
Economic Security and Community Based Rehabilitation

CBR MATRIX

- HEALTH
  - PROMOTION
  - PREVENTION
  - MEDICAL CARE
  - REHABILITATION
  - ASSISTIVE DEVICES

- EDUCATION
  - EARLY CHILDHOOD
  - PRIMARY
  - SECONDARY & HIGHER
  - NON-FORMAL
  - LIFELONG LEARNING

- LIVELIHOOD
  - SKILLS DEVELOPMENT
  - SELF-EMPLOYMENT
  - WAGE EMPLOYMENT
  - FINANCIAL SERVICES
  - SOCIAL PROTECTION

- SOCIAL
  - PERSONAL ASSISTANCE
  - RELATIONSHIPS MARRIAGE & FAMILY
  - CULTURE & ARTS
  - RECREATION, LEISURE & SPORTS
  - JUSTICE

- EMPOWERMENT
  - ADVOCACY & COMMUNICATION
  - COMMUNITY MOBILIZATION
  - POLITICAL PARTICIPATION
  - SELF-HELP GROUPS
  - DISABLED PEOPLE'S ORGANIZATIONS
Economic Security and Community Based Rehabilitation

- Skill Development
- Self employment
- Wage employment
- Financial Services
- Social Protection
- Source of income
- Bank Account
- Health Insurance
- Inheritance
- Legal Documents
- Njangi Group
- Disability Card

Source of income

Bank Account

Health Insurance

Inheritance

Legal Documents

Njangi Group

Disability Card
Objective

Improving livelihoods of PWD through use of research evidence and economic empowerment through income generating activities
Setting

Geographical Locations of CWDs
Methods

• stakeholders engagement
• Rapid reviews
• Developing audit and feedback criteria (including use of FAME concepts)
• Systems integration (use of CHWs and PTAs)
• Scoring households
• Incentivizing households
Economics Variables of Interests

I. Possession of a disability card
II. Adherence to health insurance
III. Ownership of source of income
IV. Adherence to inheritance
V. Ownership of bank Account
VI. Possession of legal Documents
VII. Joining a Njangi group
Snapshot Scoring: Economics Variables.

Round 1: Situation before the IGA
Results

- Disability Card
- Health Insurance
- Secured source of income
- Secured bank account
- Provides Inheritance
- Secured Legal Documents
- Joined a Njangi group

Round 1 vs Round 2
Evidence Informed Processes

- Inheritance
- Source of income
- Legal Documents
- Bank Account Njangi Group
- Disability Card
- Health Insurance
- Effective basic services

Economic Security

Source of income

Health Insurance

Disability Card

Effective basic services

Inheritance

Legal Documents

Bank Account Njangi Group
Poverty and Disability: A Vicious Cycle?

• According to (WHO, 2004), there is a strong correlation between disability and poverty.
• Providing an IGA with models for overcoming market barriers is an evidence based approach of creating channels for free market access for PWD.
Thank you

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Perspectives: Evidence and Disability for the Africa We Want

Aweh Annih Akofu
eBASE Africa
Background

How can this project contribute to the Africa we want?
Aligning Aspirations

• The #AfricaWeWant aspirations align with our disability project:
  1. A prosperous Africa based on inclusive growth and sustainable development.
  2. An integrated continent.
  3. An Africa of good governance and respect of human rights.
  4. A peaceful and secure Africa.
  5. An Africa with a strong cultural identity, shared values and ethics.
  6. An Africa whose development is people driven.
  7. Africa as a strong united and influential global partner.
Returns On Investments

• Funded by Stichting Wakka Foundation Holland and SSBK Holland with a 20,000 Euros grant (cash and kind).

• Directly impacting 30 households with persons with disability.

• Indirectly affecting over 100,000 children with disability through policy influences.

• Established a toolkit to get research evidence into households using existing structures.
Plans for the future

• More rigorous research.
  ❖ Engaging stakeholders.
  ❖ Research protocol design.
  ❖ Competing for grants.
  ❖ Seek global partners

• Scale out.
  ❖ Engaging policy makers in middle Africa.
  ❖ Engaging the African Union.
Thank you

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Questions/ Discussion
Thank you

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• All the speakers from e-BASE Africa
• All the participants
• AEN/ACE team
• Work stream 2: Enhancing Evidence Capacities working group led by Charity Chisoro and her team:
  o Frejus Thoto
  o Wiseman Ndlela
  o Enock Musungwini
  o Deo-Gracias Houndolo
  o Ndi Euphrasia Ebai-Atuh
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• Virtual: Sept 23-25, 2020

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