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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

Housekeeping

- To keep the technical process simple, we will not be using webcams for this session;
- Organisers will keep your microphones “**Muted**” while listening to a presenter to avoid background noise during the session;
- Please submit your questions and comments through the **Chat Box** which is visible in the GoToMeeting control panel. You can submit questions at any point during the webinar;
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- **Mission:** evidence-informed decision-making in Africa
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 - Connects e.g. Evidence 2020
 - Learns e.g. landscape maps
 - Advocates e.g. Africa Evidence Leadership Award
- Get in touch!
 - @Africa_evidence
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**AFRICA
EVIDENCE
NETWORK**



Picture: Africa Evidence Network



Speakers



Patrick Okwen



Nain Yuh



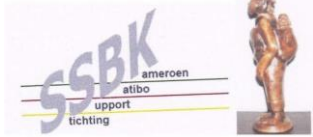
Alvin Lontum



Aweh Akofu



Working together to make
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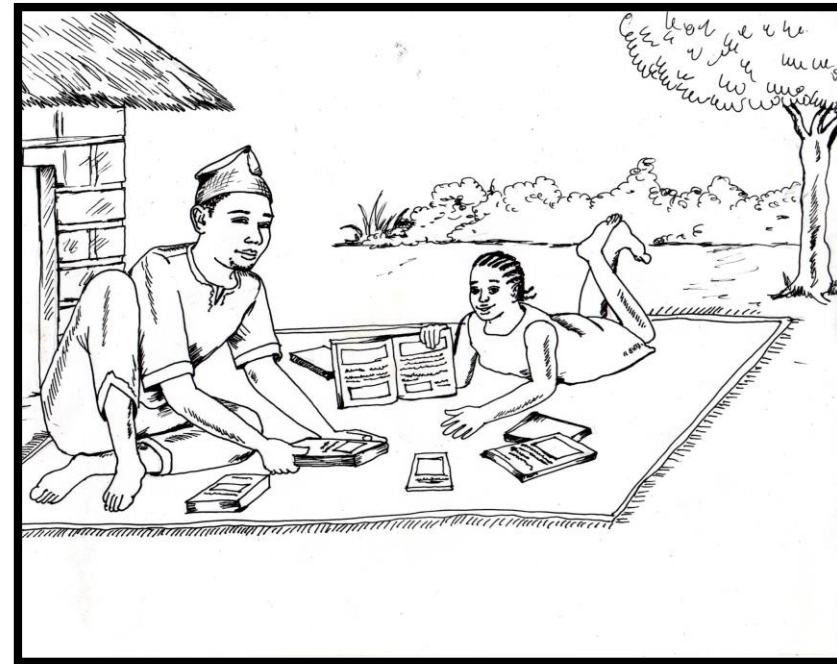


Experimenting and Learning in Disability in Middle Africa

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

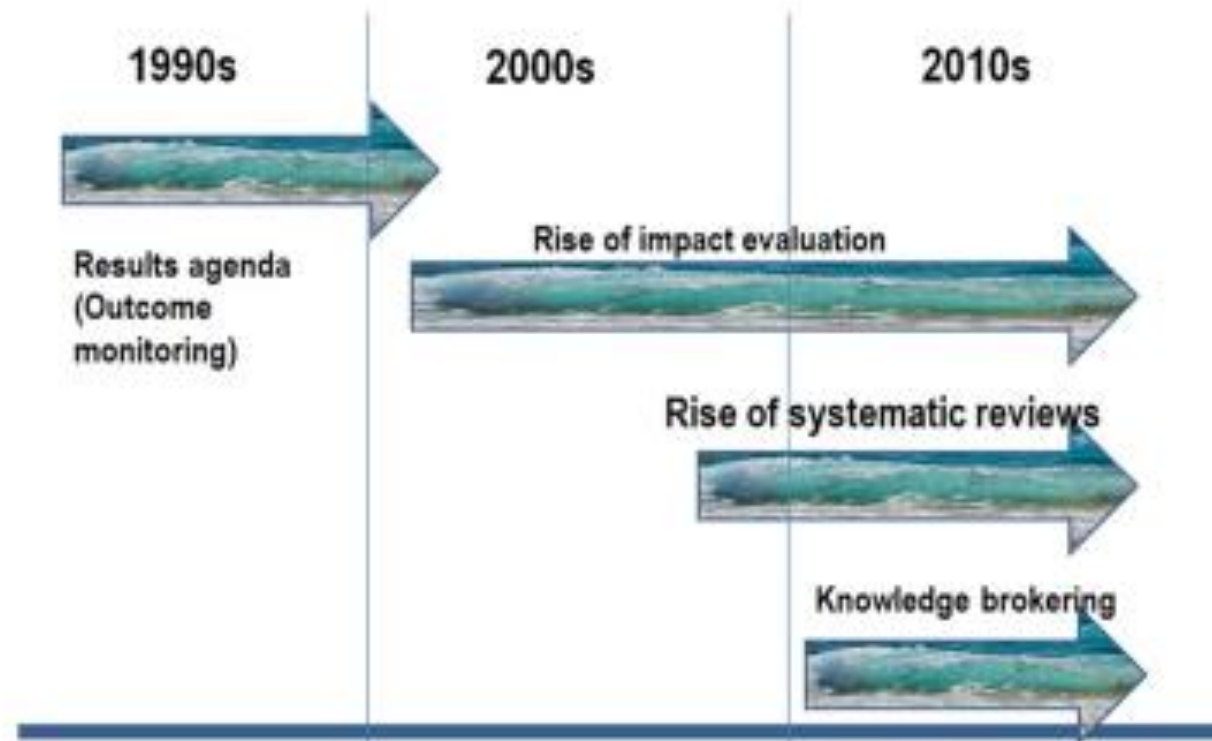
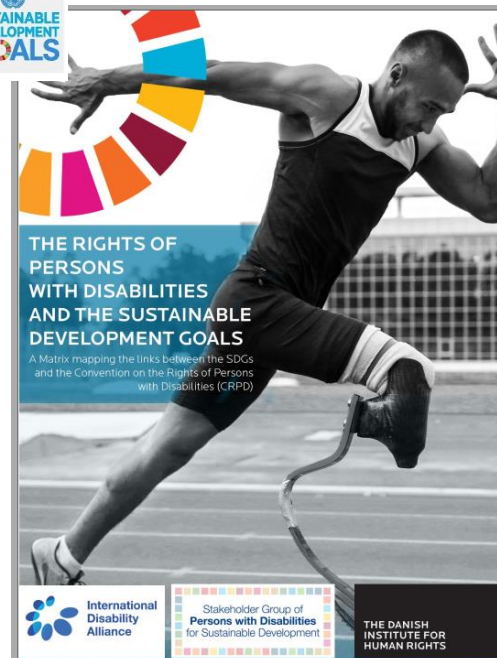


Fig. 1 Four waves of the evidence revolution White 2019: Palgrave Communications.

The Results Agenda



Impact Evaluations

The **PIRL** Project













Partnerships for Inclusive Research and Learning

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

	Permanent	Temporary	Situational
Touch	 One arm	 Arm injury	 New parent
See	 Blind	 Cataract	 Distracted driver
Hear	 Deaf	 Ear infection	 Bartender
Speak	 Non-verbal	 Laryngitis	 Heavy accent

Evidence Synthesis



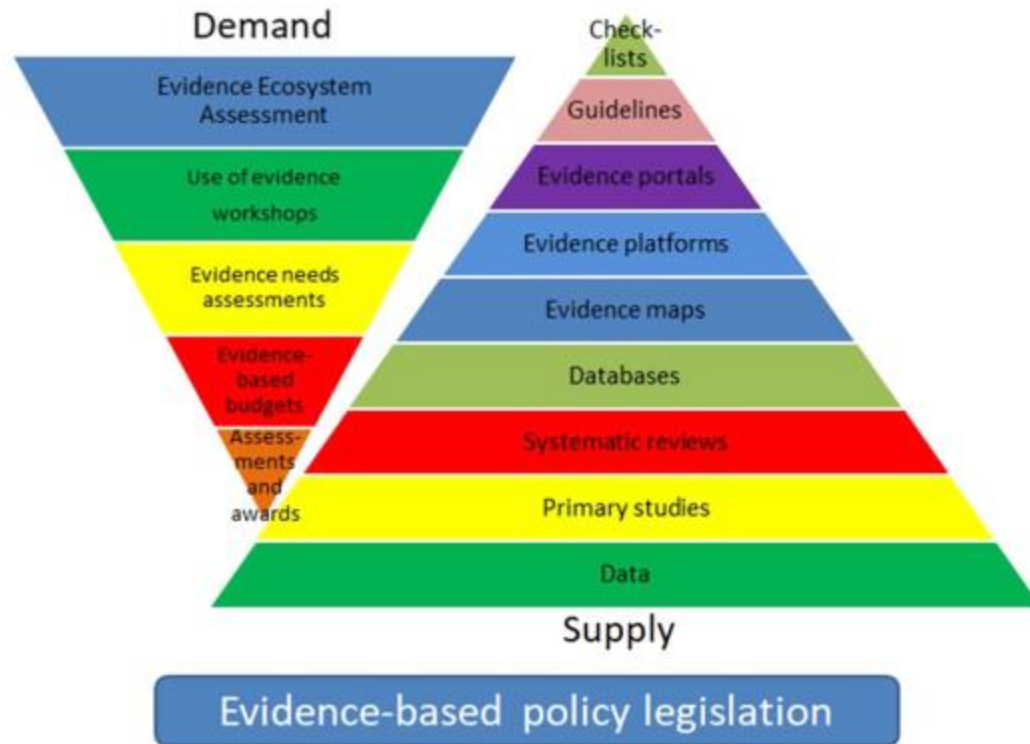
“It is surely a great criticism of our profession that we have not organised a critical summary, by specialty or subspecialty, adapted periodically, of all relevant randomised controlled trials.” (Cochrane, 1979)

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



MTN 3:26 PM 45%

← 2 Scoring Families for Promoting... Save

8 Health

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

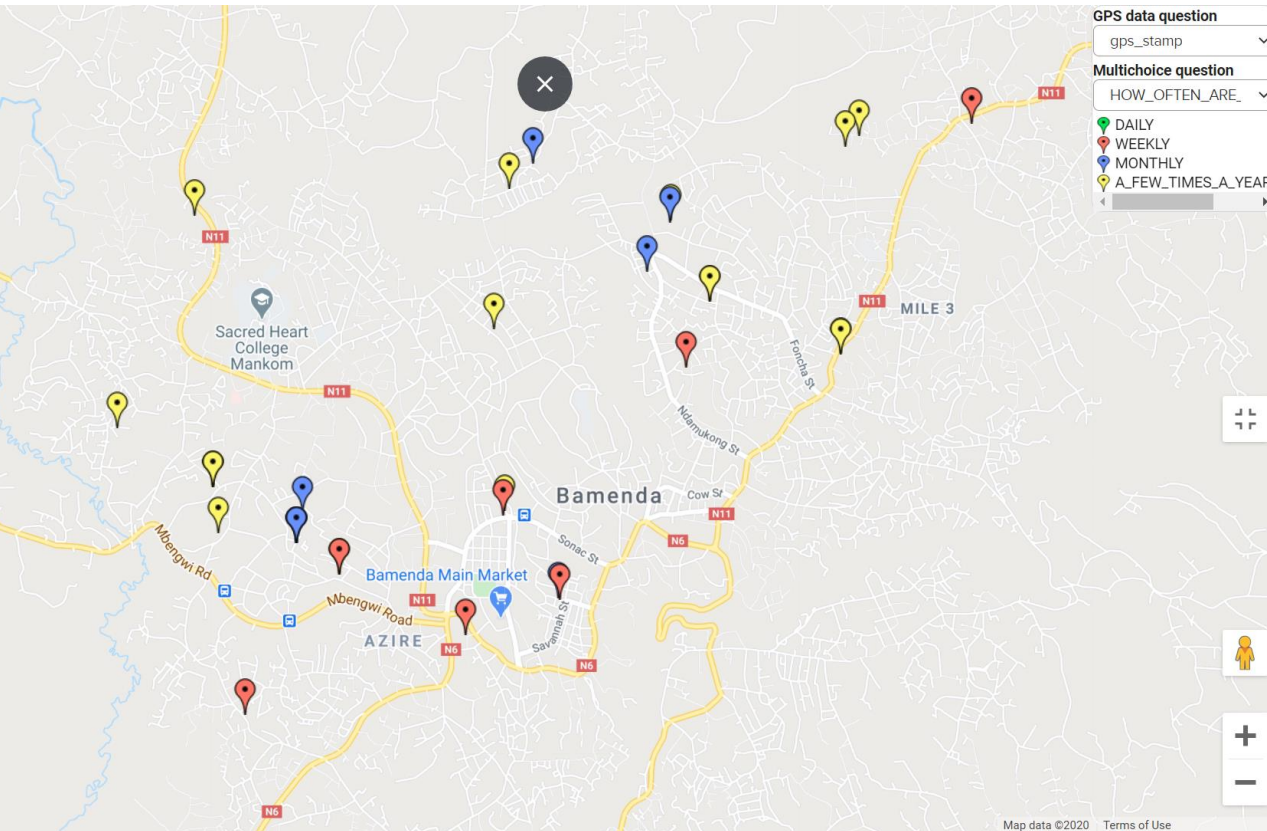
11 Does the Child have a health insurance (No=0, Yes=5)

☐ No

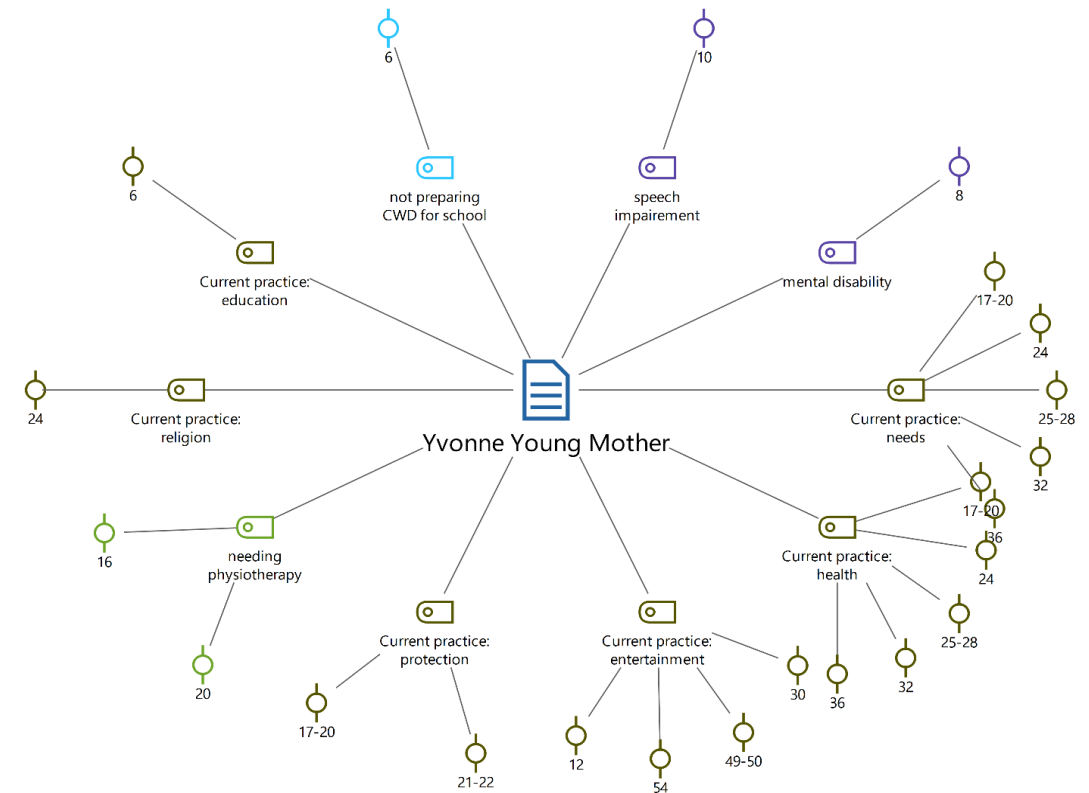
Fig. 2 The evidence architecture

White 2019: Palgrave Communications.

Promising Big Data?



Single-Case Model



Geolocating SDH & SDG Indicators



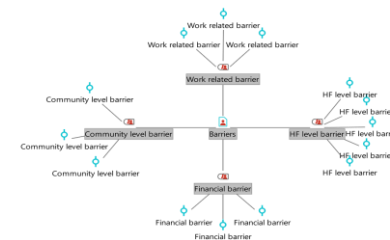
CHWs pick up data (images, audios or videos + geolocations) and relays to eBASE/DHS

eBASE Team transcribes data, analyse, and export coded segments

Coded segments populated on GoogleMaps using Magpi



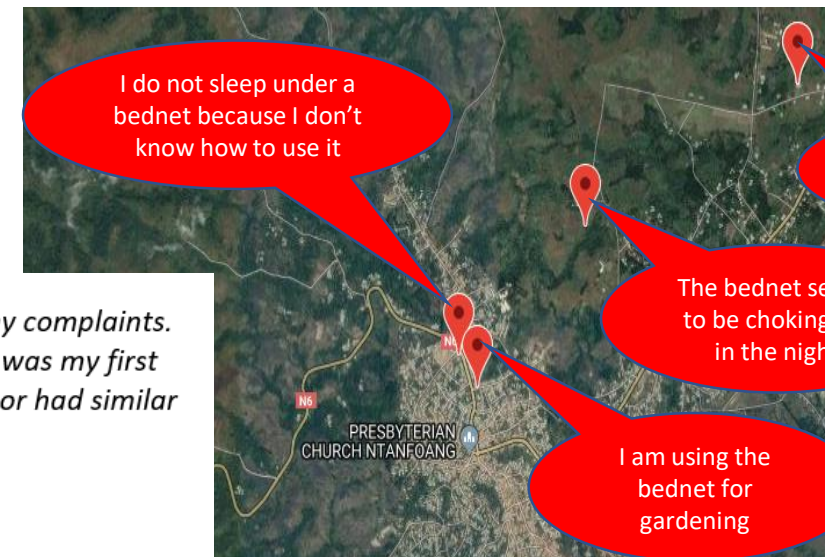
Code-Subcodes-Segments Model: Barriers to Healthcare



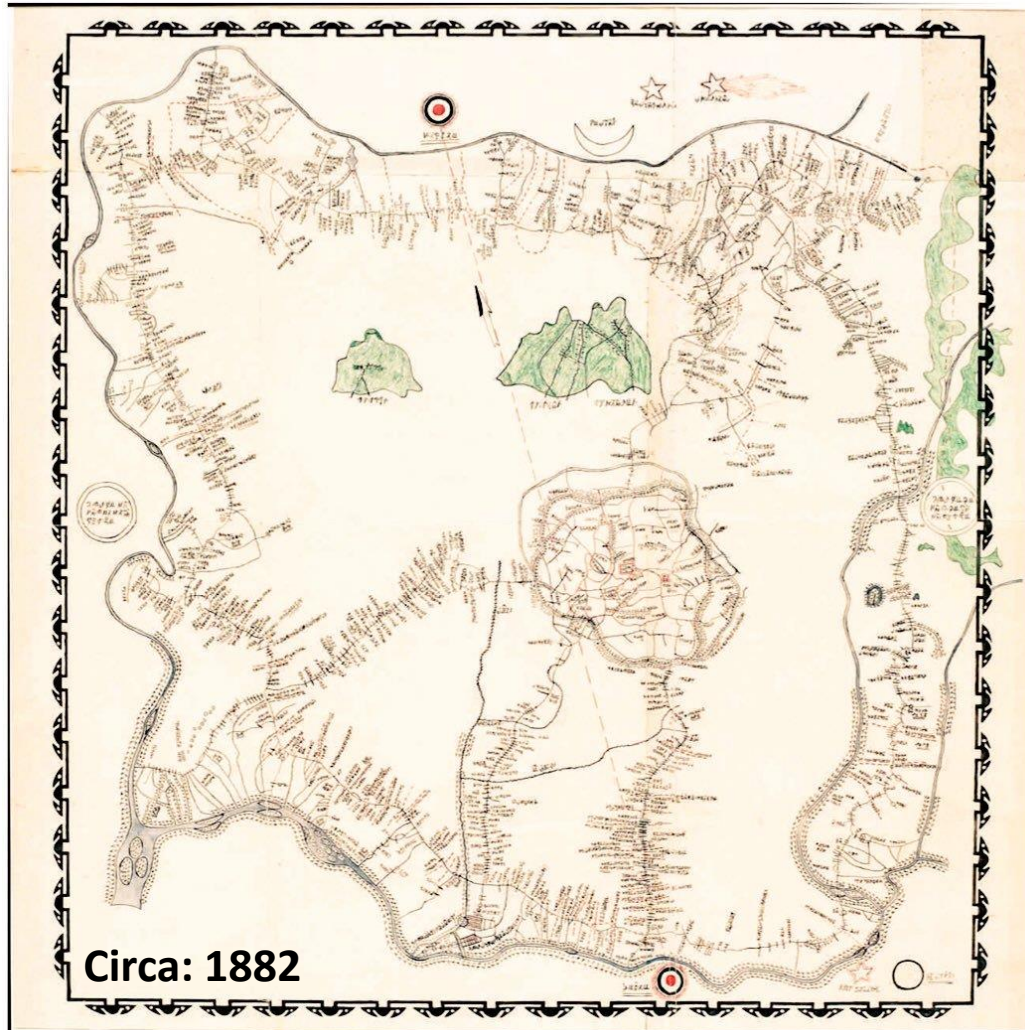
"In my last delivery, the nurse was very rude to me and did not listen to my complaints. Although he did his work well, I was not happy with the treatment, and it was my first delivery. I did not feel like going back there, especially because my neighbor had similar complaints and then successfully delivered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



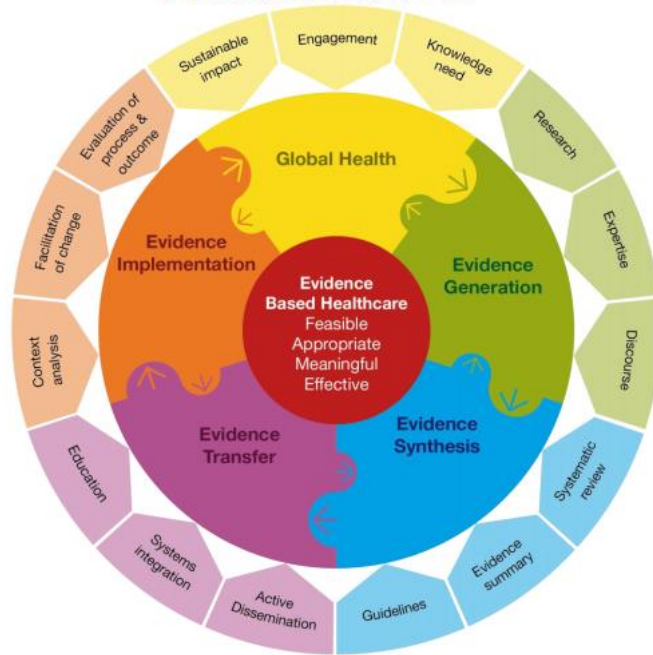
Power of Maps for Decision Making



**Le Roi Njoya: 17eme Roi de
Bamum**

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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Effective Basic Services (eBASE) Africa



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Questions? Email okwen@ebaseafrica.org



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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.

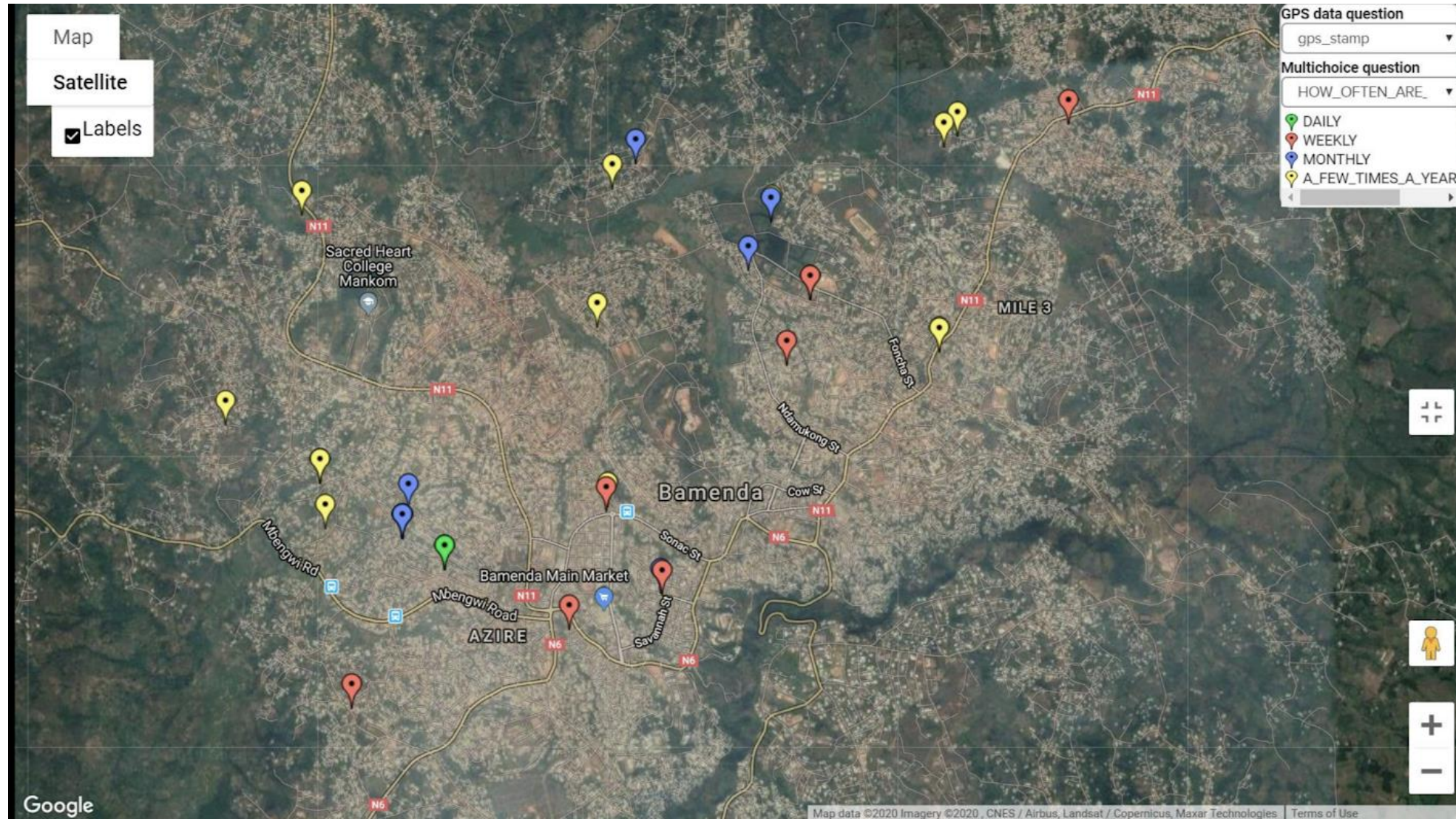


Picture: Source name.



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



Source name.

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

BEST PRACTICE GUIDELINES FOR IMPLEMENTING FAMILY- CENTERED CARE FOR CHILDREN WITH DISABILITIES IN THE NORTH WEST REGION OF CAMEROON

PREPARED BY

THE BEST PRACTICES IN FAMILY-CENTRED CARE GROUP

BAMENDA COORDINATING CENTRE FOR STUDIES IN DISABILITY AND
REHABILITATION

BAMENDA, NORTH WEST REGION, CAMEROON

AND

INTERNATIONAL CENTRE FOR DISABILITY AND REHABILITATION
UNIVERSITY OF TORONTO, CANADA



Picture: Source name.



Modelling the toolkit

Table 1: Mapping Evidence to Current Practice

Axis	Current Practice	Evidence Based Practice	Clauses for Contributions to SDGs (based on CRPD SDG matrix)	Considerations for Training Modules
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 schools Discuss with policy makers about investing in private inclusive education schools Modules: Rights & education
Medical needs	-NO 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

Mbah Okwen

1. Cameroon National P

Nain Yuh

5. Tirussew 1999

Nain Yuh

7. Richter 2004

Nain Yuh

WHO 2010

Nain Yuh

Henderson, 2008; Eva, 20

Nain Yuh

Kristina, 2003; Ichirotsvi, 2

Nain Yuh

Van Cleave 2007, Nam 200

Nain Yuh

New, 2016

Nain Yuh

Van der Maas, 2007;

Nain Yuh

Meer, 2015; Wirtz et al, 20

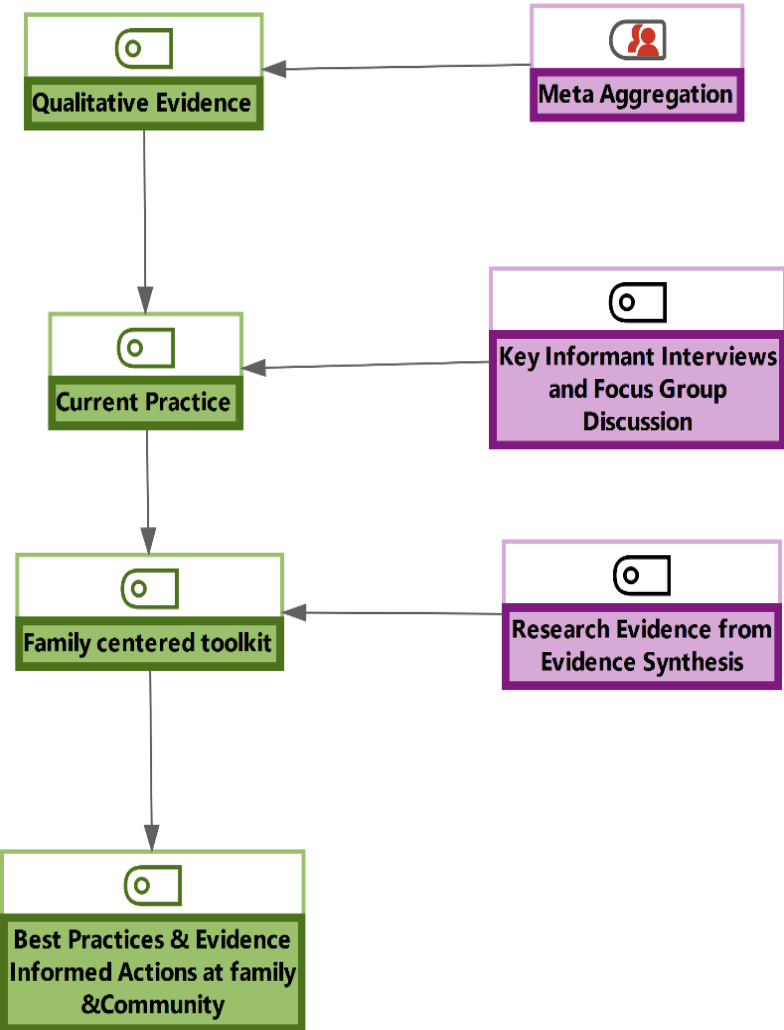
Nain Yuh

WHO global disability acti



Modelling the toolkit

Developing Best Practices for Children With Disability



Picture: Source name.

The eBASE Family Centered Evidence Toolkit for Disability

MTN 3:26 PM 45%

← 2 Scoring Families for Promoting... Save

8 Health

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

Picture: Source name.



The eBASE Family Centered Evidence Toolkit for Disability

DesignDataMapAnalysisShareRespondProperties

Scoring_Families_for_Promoting_Rights_and_Needs_in_CWD_in_Cameroon

Last edited date from: 2020-02-01to: 2020-06-21All Dates...All Users...Type search terms

AddEditExportPublishImportDelete

L...TYPE_OF_DISABIL...	DISCUSSEALTHI...	CHILDDISABILITY...	CHILDHEALTHINS...	BONDINGCHILD	VACCINATION_ST...	PROTECTSCHILD	RESPECTAPPOINT...	ASSISTIVEDEVICES	SCH
Yes	5	No	0	5	5	5	5	3	5
Yes	5	1	0	5	5		5	3	5
Yes	5	No	0	5	5	3	5	Not_Applicable	5
Yes	Not_Applicable	No	0	5	5	3	5	No	0
No	1	No	0	1	5	3	3	No	1
Yes	3	No	0	5	1	5	5	No	0
Yes		5	5	5	5	3	3	No	Not_
No	3	No	0	5	5	3	5	3	Not_
Yes	5	1	0	5	5	5	5	3	5
Yes	5	No	0	5	5	5	5	3	5
Yes	5	No	0	5	5	5	5	No	5
Yes	1	No	0	5	5	5	5	No	5
No	0	5	0	3	5	5	5	No	0
Yes	3	No	0	5	5	3	3	3	0
Yes	3	No	0	5	5	3	5	3	Not_

Training CHW



name.



Evidence



IGA



Picture: Source name.



Beneficiary of IGA



Picture: Source name.



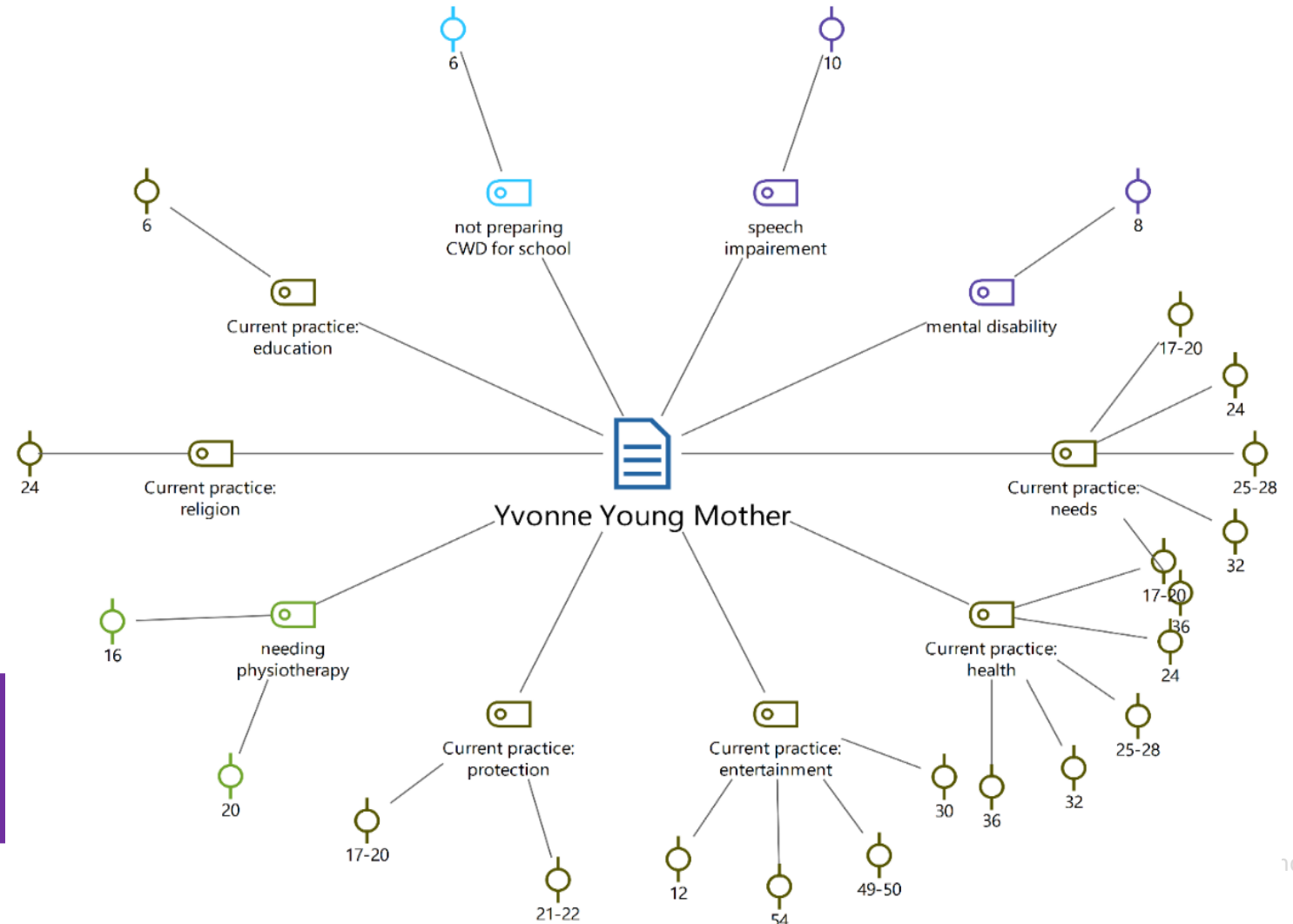
Results

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

Single-Case Model

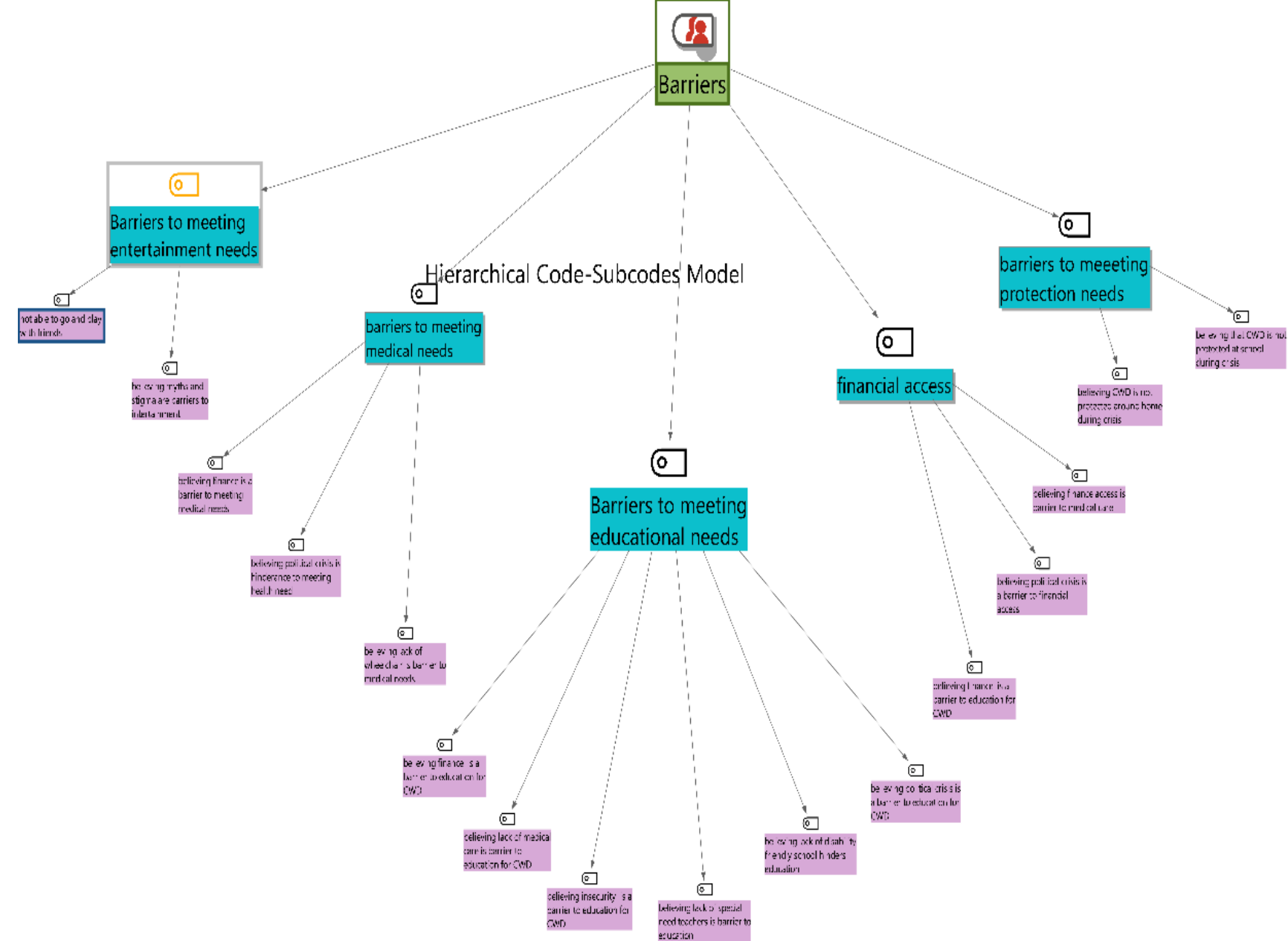


Results

- Barriers to accessing basic services

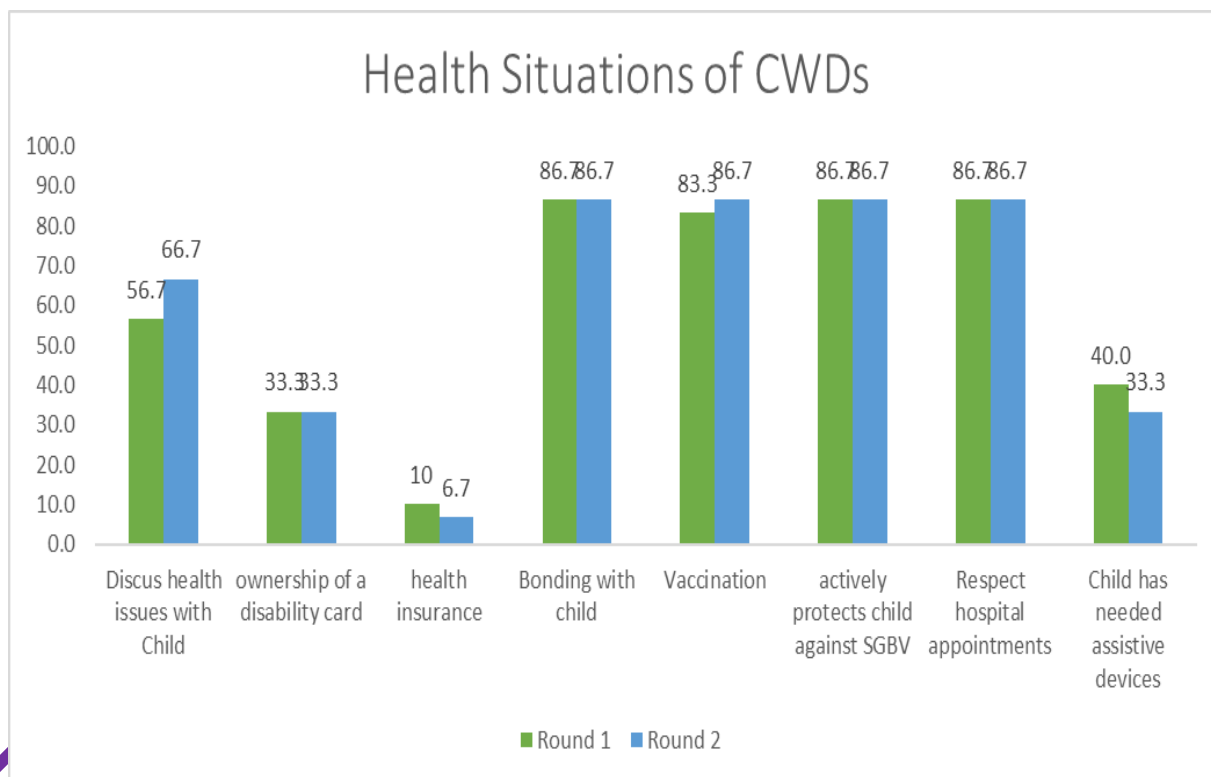
Fig: showing how the barriers impact on protection, financial access educational needs medical needs and entertainment needs

Source: MAXQDA

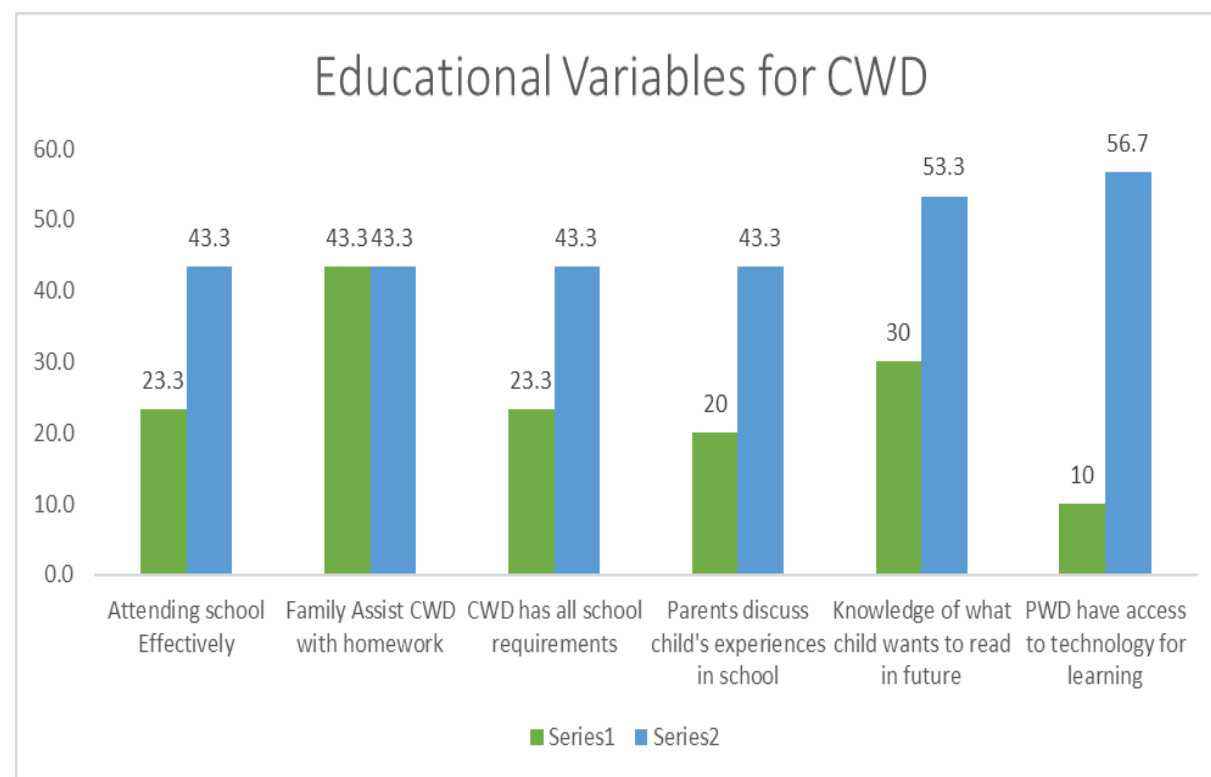


Results from Data analysis

Health variable change for CWD

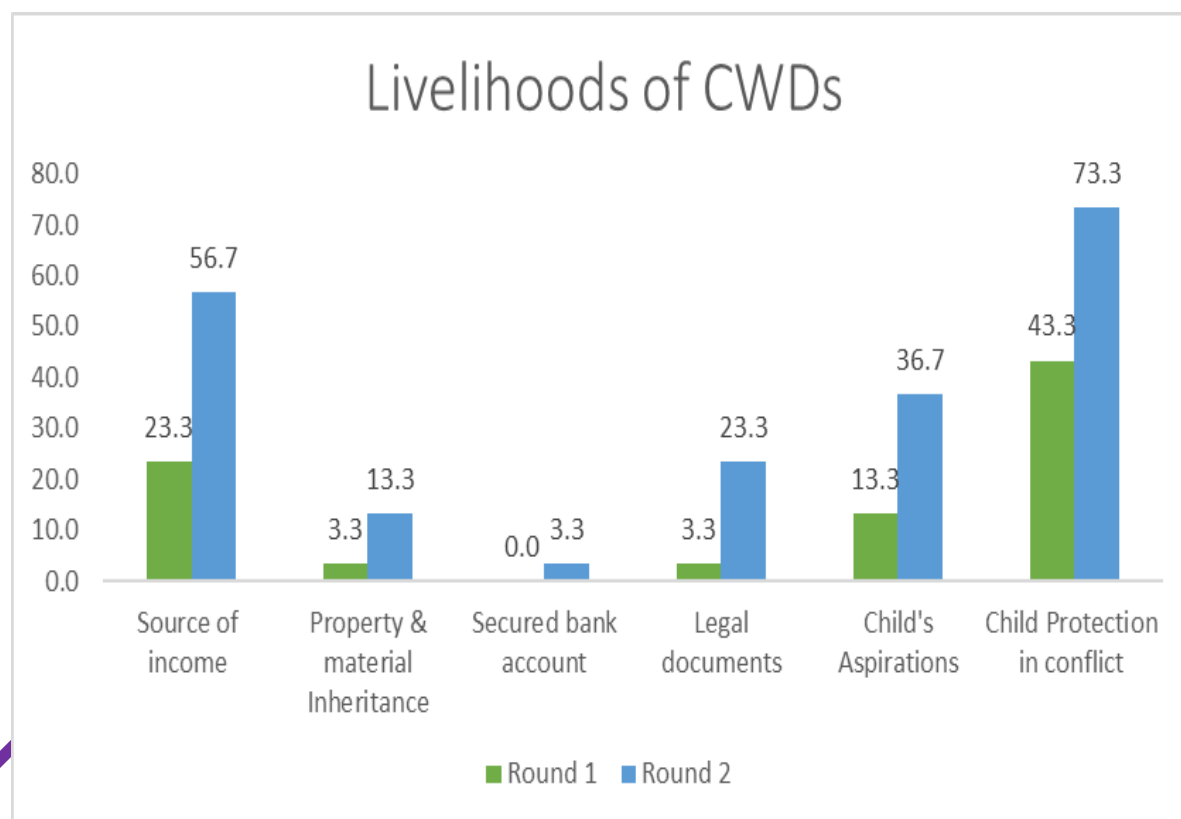


Educational variable change for CWD

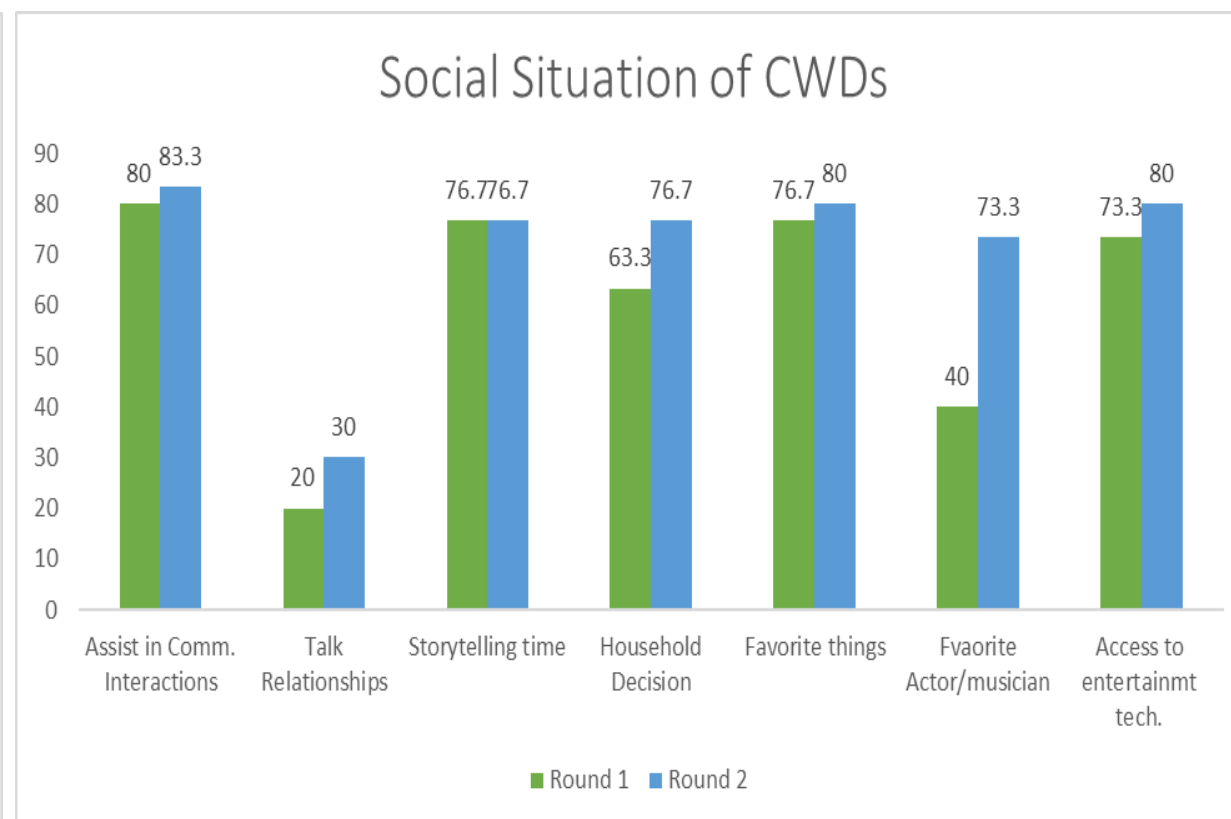


Results from Data analysis

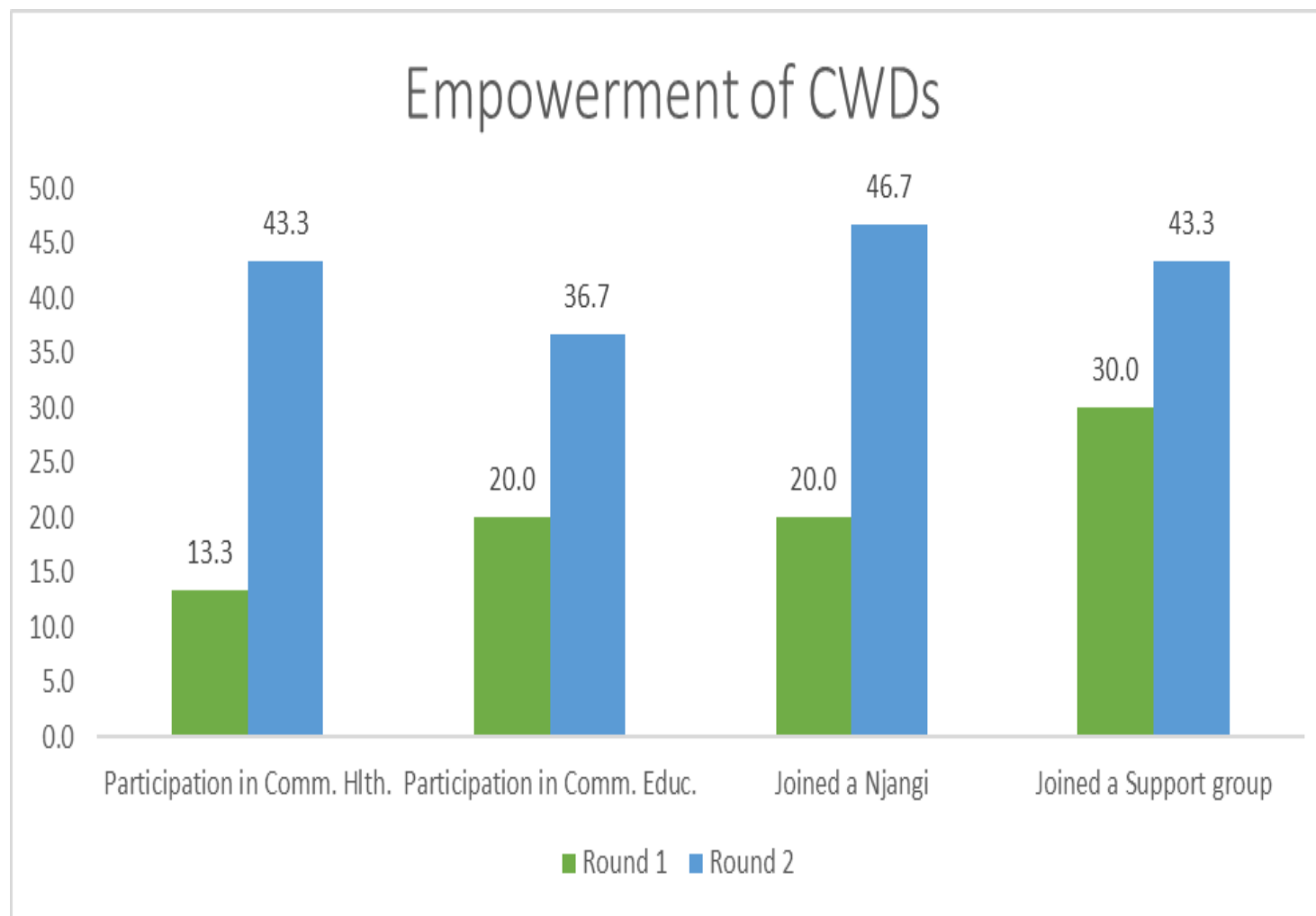
Livelihood variable change for CWD



Social Wellbeing variable change for CWD



Empowerment Variables



Picture : Source name

Promising Result: Disability Card

Disability card

Access to basic
services

Engagement in
evidence based
practices

Improved
rights & needs

Improved
livelihoods for
CWD



Source name

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.

Picture : Source name



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



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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



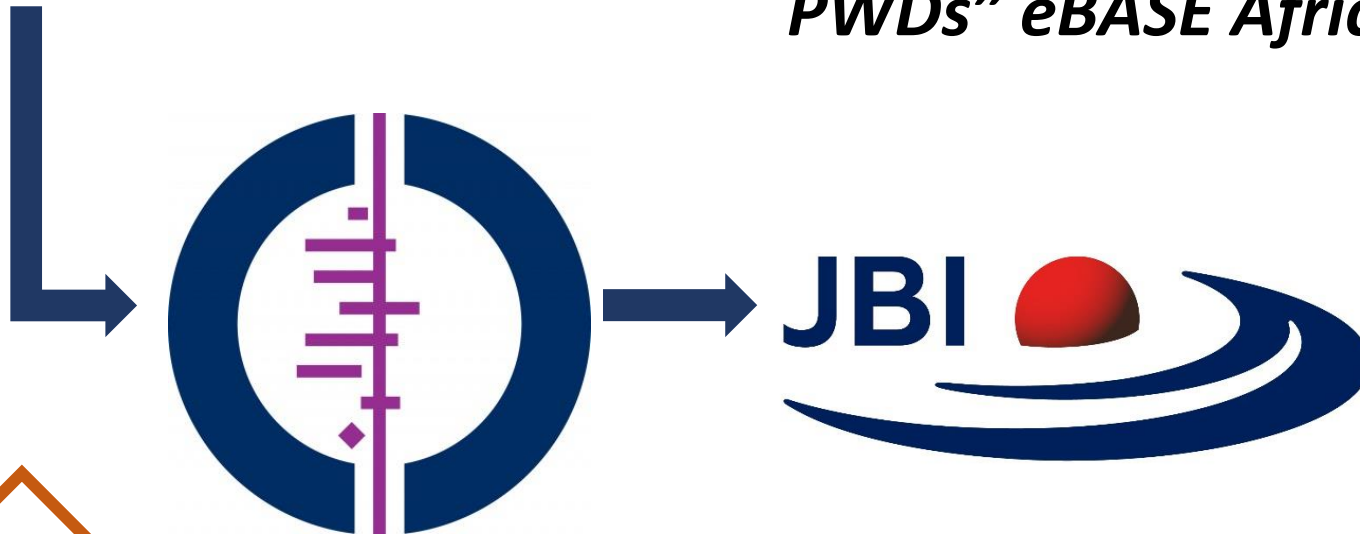
Economic Security and SDGs



Economic Security, SDGs and #WhatWorks



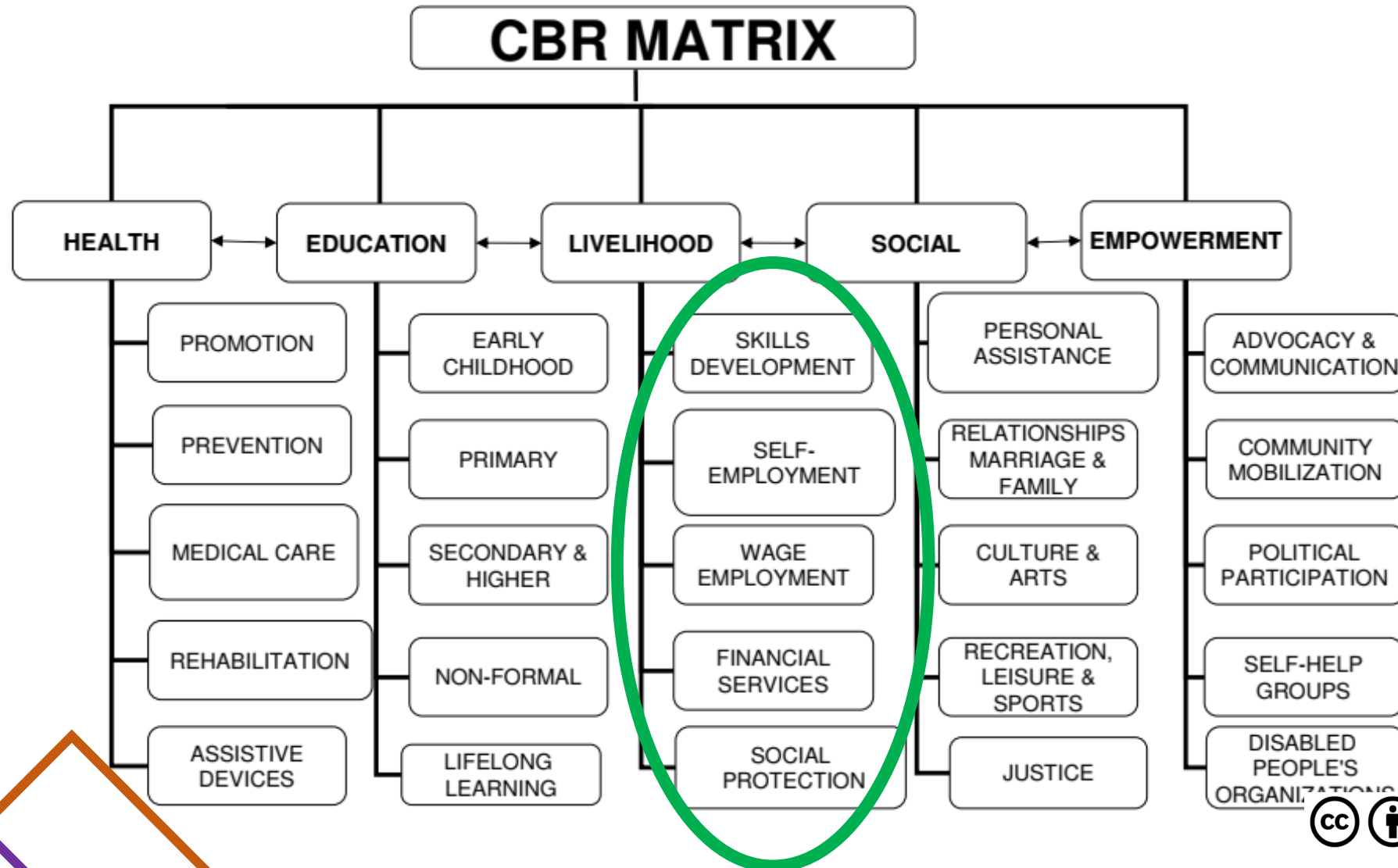
“From SDGs to using evidence within evidence portals to broker knowledge to households with PWDs, eBASE hopes to improve livelihoods for PWDs” eBASE Africa 2020



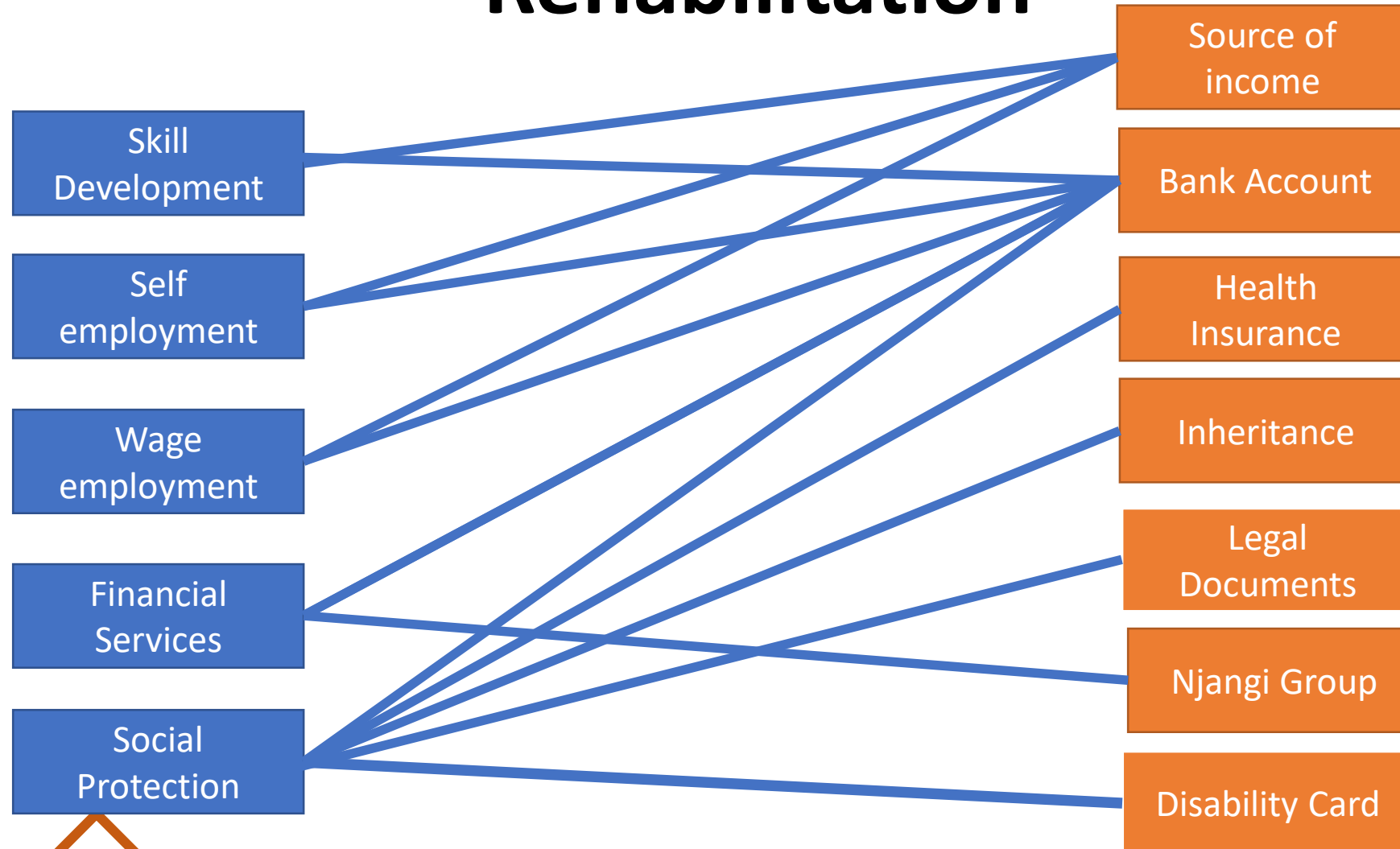
Effective Basic
Services Africa
A JBI Affiliated Group



Economic Security and Community Based Rehabilitation



Economic Security and Community Based Rehabilitation

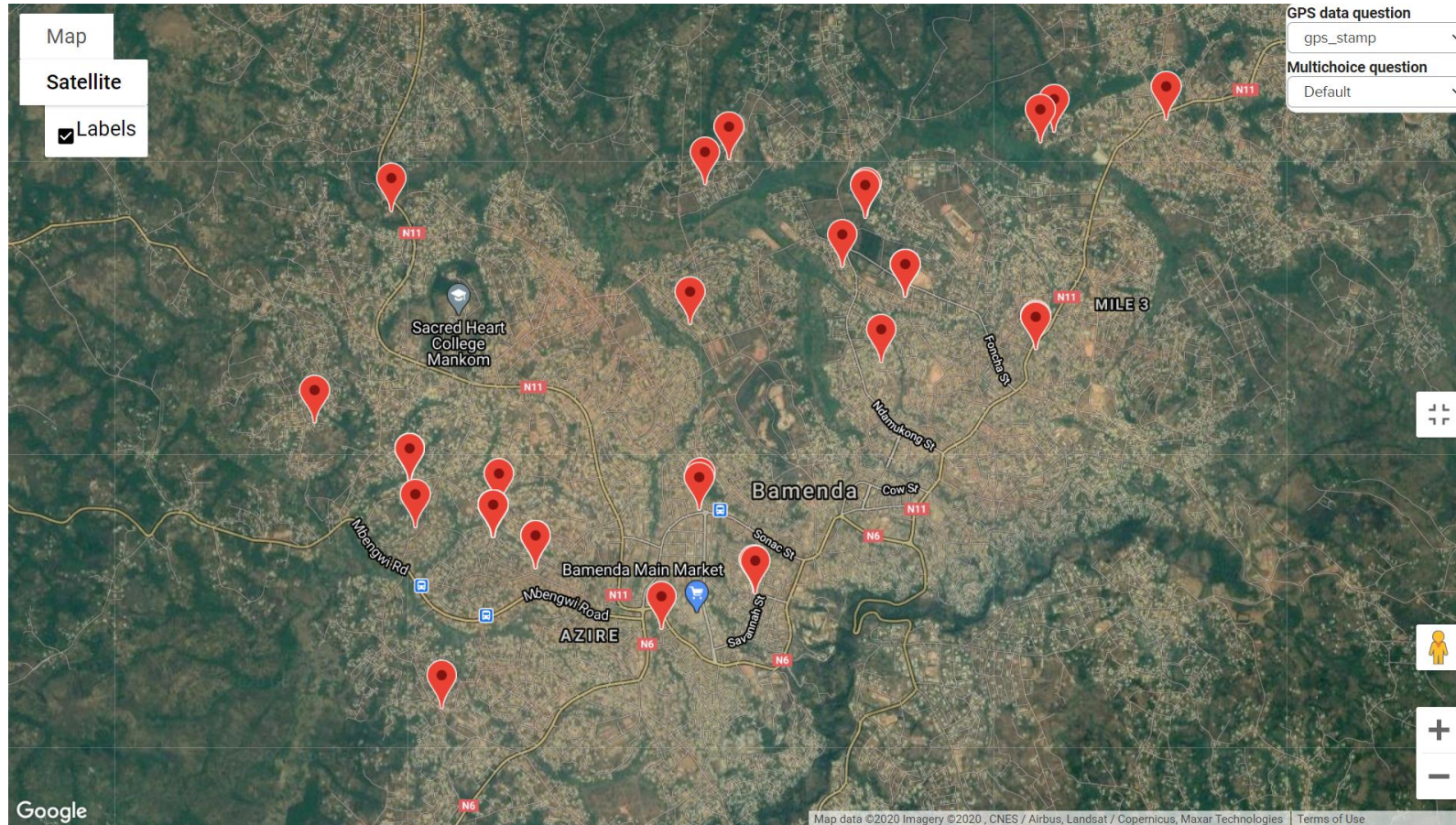


Objective

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



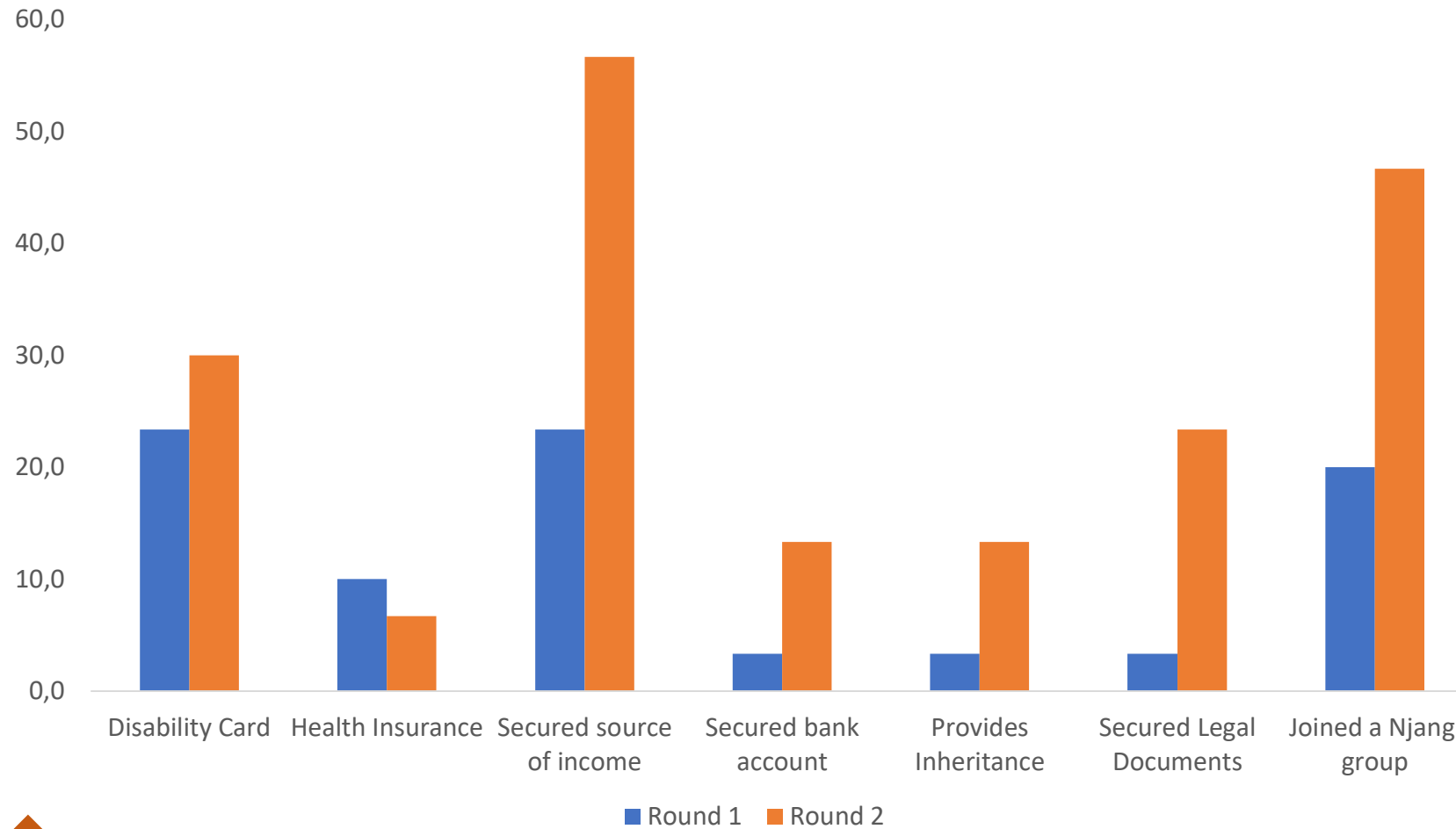
Snapshot Scoring: Economics Variables.

Round 1:
Situation
before
the IGA



	Disability Card	Health Insurance	Income Source	Provides Inheritance	Bank Account	Legal Documents	NjangiGroup
1	5	0	0	0	0	0	0
2	5	1	0	0	0	0	0
3	1	5	0	0	5	0	0
4	5	0	0	0	0	3	0
5	0	0	0	0	0	0	0
6	0	0	3	0	0	0	3
7	0	0	0	0	0	0	3
8	0	0	0	0	0	0	3
9	5	0	0	0	0	0	3
10	0	0	0	0	0	0	3
11	5	0	0	0	0	0	0
12	5	0	0	0	0	0	0
13	5	0	0	0	0	0	0
14	0	0	0	0	0	0	0
15	5	5	3	0	1	0	1
16	1	0	0	0	0	0	1
17	0	0	0	0	0	0	0
18	0	0	3	0	0	0	1
19	0	0	3	0	0	0	1
20	0	0	0	0	0	0	0
21	0	0	3	0	0	0	0
22	0	0	0	0	0	0	0
23	1	0	0	0	0	0	0
24	0	0	3	3	0	0	3
25	5	5	0	0	0	0	0
26	0	0	0	0	0	0	0
27							

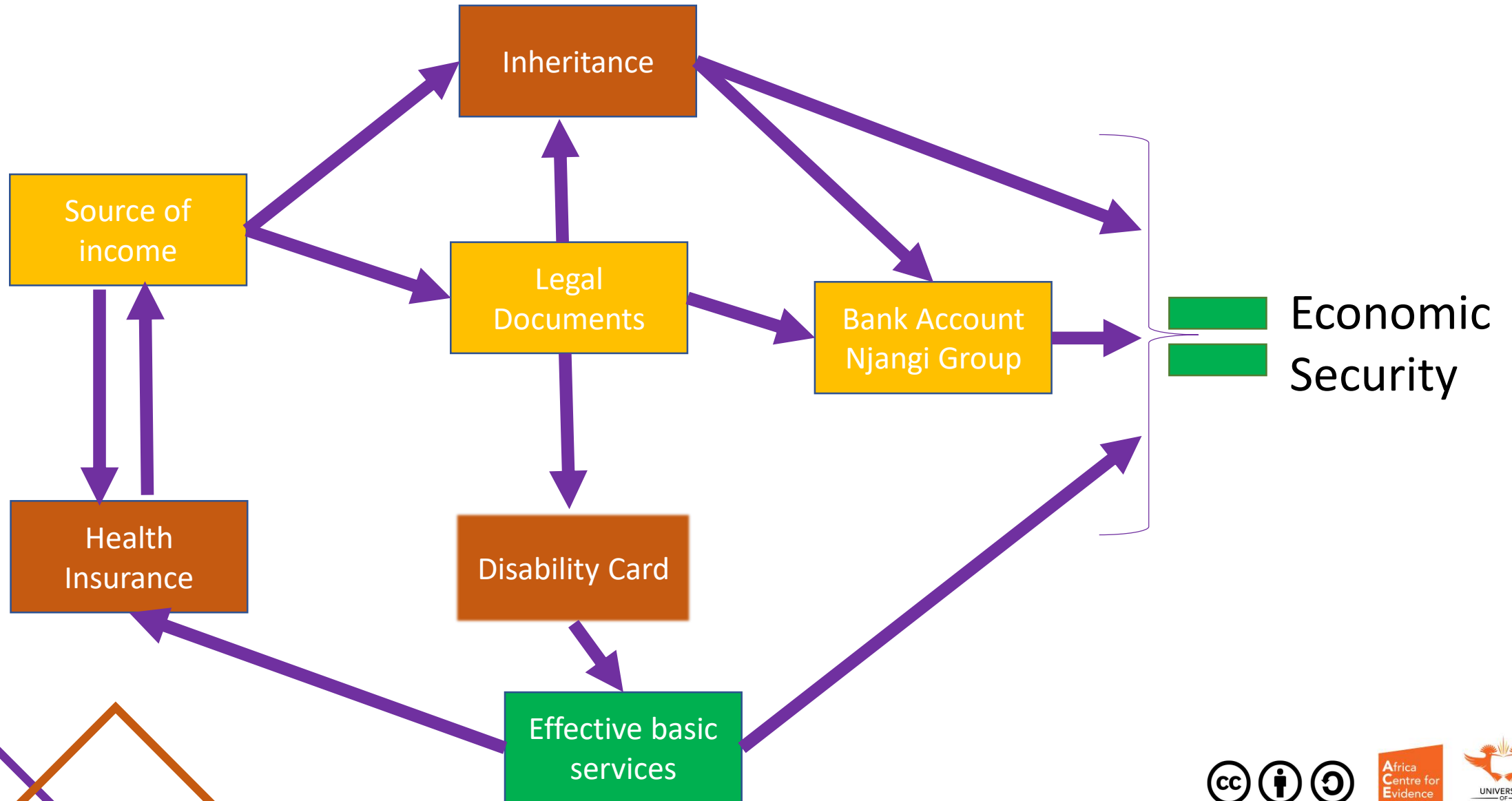
Results



Picture: Africa Centre for Evidence



Evidence Informed Processes



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

Thank you to:

- 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:**
 - Frejus Thoto
 - Wiseman Ndlela
 - Enock Musungwini
 - Deo-Gracias Houndolo
 - Ndi Euphrasia Ebai-Atuh



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- Virtual: Sept 23-25, 2020
- Learn more:
- <https://confsa.eventsair.com/evidence-2020-conference/about/>



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