

ICED Disability Symposium
6th November

Tackling stigma and
discrimination in the
home & community.
Building evidenced
based training
materials

Lessons learnt from
Burkina Faso &
Uganda

International
Centre for Evidence
in Disability

**Liliane
Fonds**

open the world
for a child
with a disability



MRC/UVRI and LSHTM Uganda Research Unit



Uganda
Virus
Research
Institute



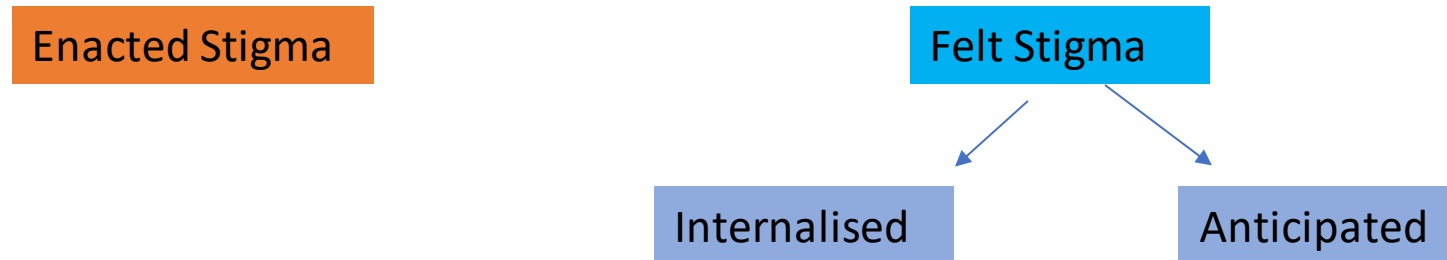
- **Burkina Faso- Groupe ACCES:** Félix Compaoré, Saïb Abou Coulibaly, Justine Kaboré Nébié, Lenie Hoegen Dijkhof
- **Medical Research Council/Uganda Virus Research Institute & LSHTM:** Ruth Nalugya, Carol Nanyunga, Ruth Naluga, Mercy Haumba, Jane Nansamba
- **London School of Hygiene & Tropical Medicine (LSHTM):** Maria Zuurmond, Tracey Smythe, Sarah Polack, Cally Tann

Overall Study Objectives:

1. To explore the experiences and impact of stigma & discrimination among children with cerebral palsy and their families in Uganda and Burkina Faso
2. To identify approaches and interventions addressing stigma related to childhood disability in different low and middle-income settings.
3. To develop a new training module on stigma and inclusion
4. To pilot test the new training module in Uganda and Burkina Faso

Stigma

“A social process, experienced or anticipated, characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a particular group”. Weiss, 2008



- Shaped by socio-cultural, historical, economic and political context

Enacted Stigma (social/public)

- Negative attitudes, prejudice, stereotype
- Discrimination
- Exclusion

e.g. enacted by the community towards child with disability and family.

- Those who stigmatize can:
 - **Enact:** actively engage in process of exclusion
 - **Endorse:** justify and support though may themselves refrain
 - **Accept:** disagree but do nothing to stop it.

Felt stigma

- Internalised (or self) stigma:
 - Affected individual internalises/accepts negative stereotypes/attitudes
 - negative feelings about self e.g. shame, guilt, withdrawal from social participation
- Anticipated stigma
 - Perception by the individual that stigmatization is likely to occur i.e. an anticipation/fear of the actual, enacted stigma

Process



Training Modules



TOGETHERNESS AND BELONGING

Tackling stigma and discrimination
at home and in the community

November 2019



SOLIDARITÉ ET APPARTENANCE

Lutter contre la stigmatisation et
la discrimination à la maison
et dans la communauté

Novembre 2019

**Systematic Literature Review-
Interventions to address stigma for children with disabilities**



Systematic review

- 2000-2018, 20 studies
- 65% of interventions targeted enacted stigma
- Most common intervention approach was education/training (63%)
- 54% interventions were delivered at the Organisational/ Institutional level and only 4 studies targeted more than one social level.
- Most common disability targeted was epilepsy (50%) followed by intellectual impairment (20%).
- Some evidence of reduction in a component of stigma,
- Overall poor quality design.

Scoping Review – Individual level interventions

- **Counselling**

- Rights Based Counselling (delivered by trained lay and peer counsellors)

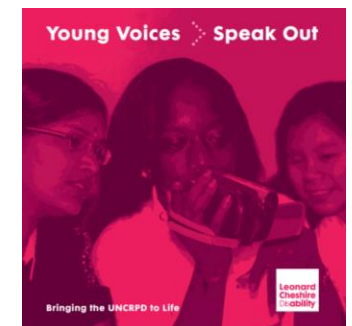
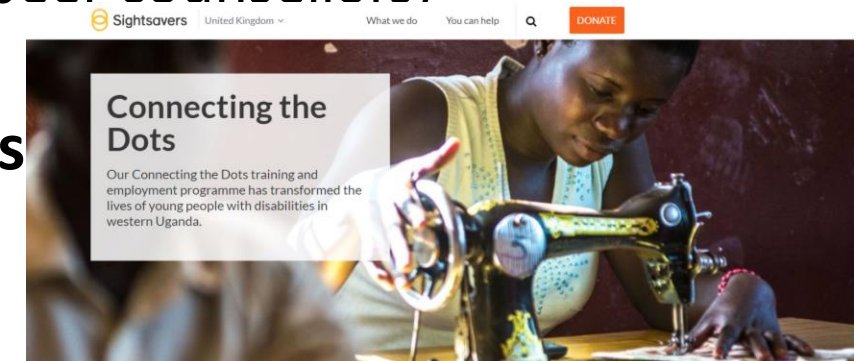
- **Peer support groups, parents and friends associations**

- **Skills and livelihoods trainings**

- Connecting the Dots (Sightsavers) - vocational training young people with disabilities

- **Disability activists, advocates, leaders, champions**

- Young Voices (Leonard Cheshire): build knowledge of young people on rights and using voice to advocate/influence policy.



Family level approaches

- Some examples (McConkey et al):
 - Nurturing development of child (e.g. GTKCP, EIP)
 - Promoting CONTACT e.g. community inclusion – interaction with other children, participation in school, play, community events
 - Providing information to dispel myths & improve understanding
 - Parental advocacy for rights of child

Community level approaches

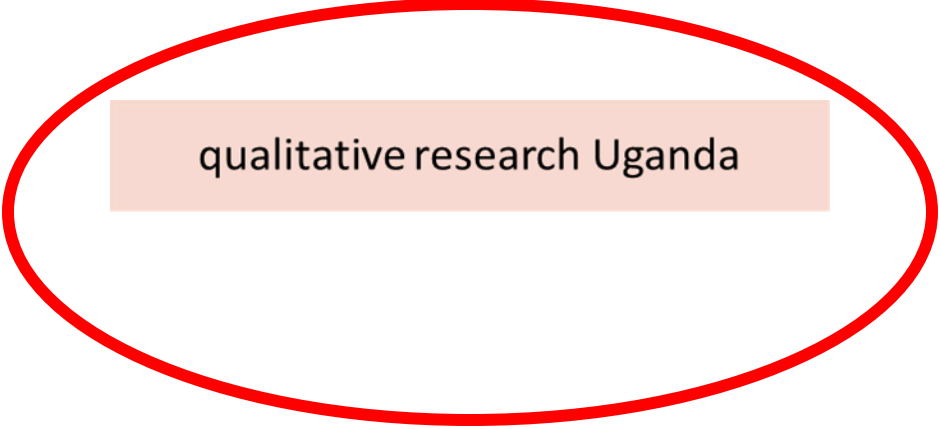
- **Education:** provision of factual information to dispel myths
- **Contact:** Interactions between public and affected persons: aim of improving attitudes, challenging stereotypes, reducing discrimination and exclusion
- ***Direct Contact + education shown promise in other fields***
- Intervention examples
 - Participatory video making
 - Community contact events: testimonials, film screening, comics (Indonesia, leprosy)
 - Films: Stepping out of the margins (intellectual disability), Purple Fields (Cerebral Palsy)
 - Arts based interventions(e.g. theatre, puppet shows) for mental health developed by community groups in India
 - Mass Media – radio shows, TV
 - Inclusive sports activities

Organisational level

- Training programmes addressing negative attitudes and/or exclusion
 - Teachers
 - Health workers
 - Students
- e.g. “Looking In - Looking Out” (LILO - Positive Vibes- HIV project)
 - LILO connect: training/facilitation workshop to address embedded prejudice and stigma within organisations through ***process of personalisation***

qualitative research Burkina Faso

qualitative research Uganda



Participatory workshops



Uganda workshop

Approaches

Home visits
Community engagement
All key gate keepers
Engage them as Consultants in child
Engage -
Find out what they know about disability
and then see how to bridge the gaps on
Myths and beliefs
Existing forms of care
Community Radio/PAs
Drama, Disability days (CP day, Fida day)
TO INVITE THE GATE KEEPERS
Parent Support Groups, Caregivers/DPOs
through the Local Council leaders
(Mukisa)
Main stream Schools
Rehabilitation Centers
Using the children with disabilities as role models to speak
Existing arrangements:
- Village meetings (However such meetings do not invite all the Key stakeholders)
Organizing events
- Women leadership retreats
- Charity walks
Use of short media clips

Home visits by local parents to ask them the time fathers be back at home. A local parent is identified when she has leadership skills.

Child

Dialogue Meetings

Inclusive games
Integrated out reaches (ANC, Child days)

Social media engagement



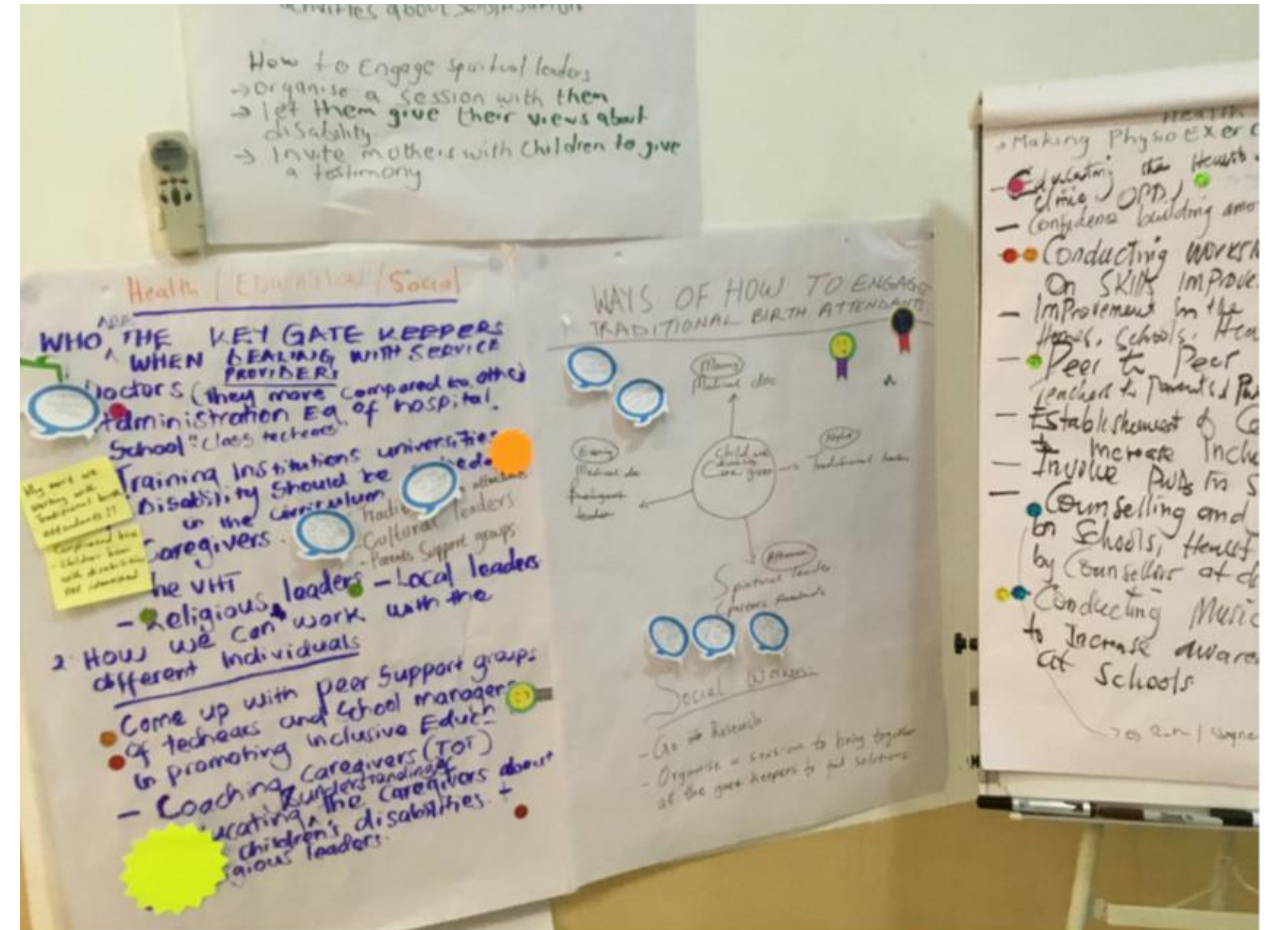
Workshop Aims

Share preliminary findings and validate

Explore ideas and experience from addressing stigma-related disability at:

- (1) Individual level
- (2) Family Level
- (3) Community Level
- (4) National level

Bring together researchers, NGOs/INGOS and parents



Development of draft training material

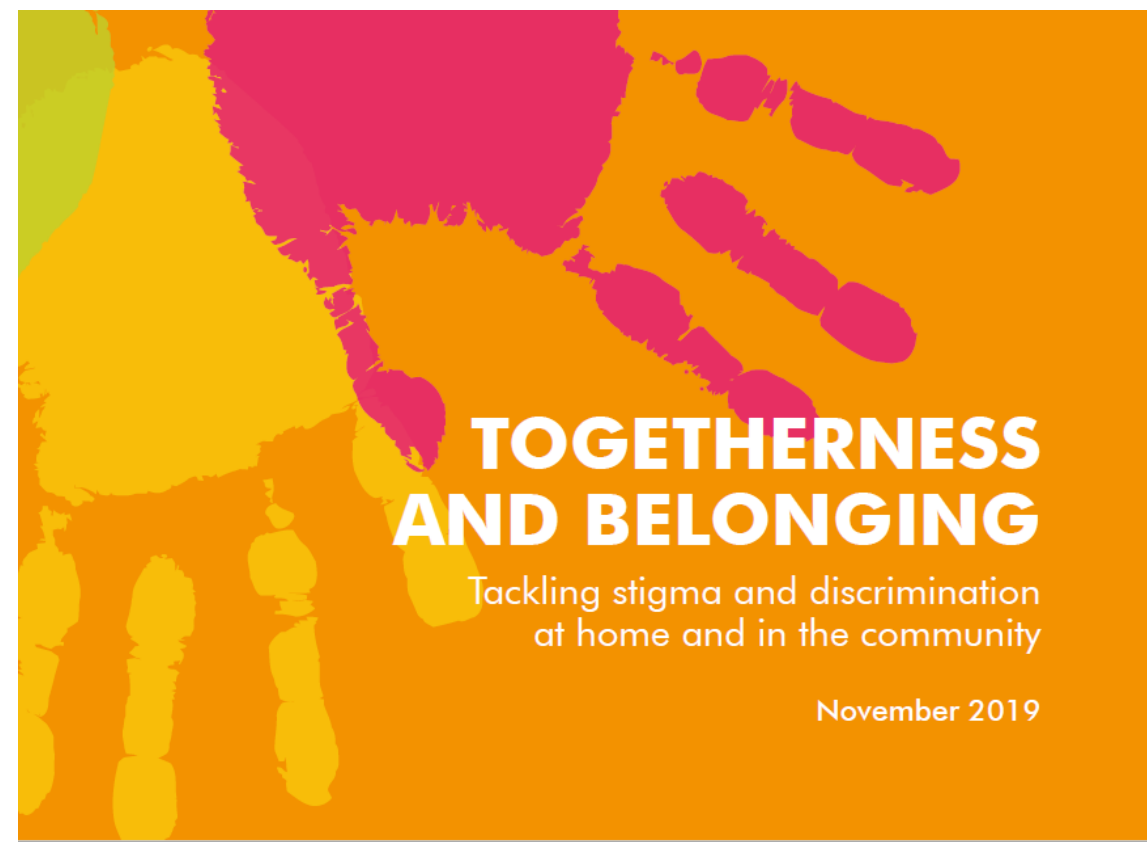
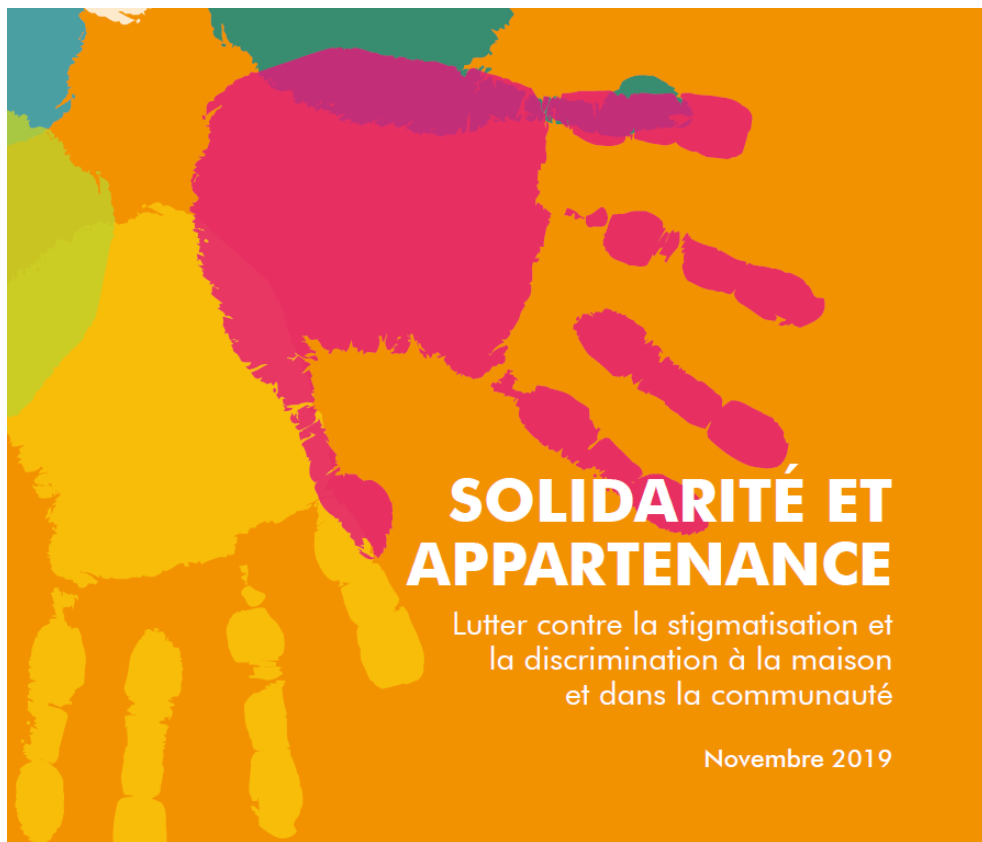
Field testing Uganda

Field testing Burkina

- Detailed structured feedback
- To test out comprehension & readability
- Ensure materials are locally relevant and/or adaptable to the local context
- Collect implementation process data
- Develop new case studies e.g. safeguarding
- Facilitated ownership for the materials



Training Modules



Thank you

- **Project teams**
- **Institute des Sciences des Sociétés,**
- **Burkina Faso:**
- Maxime Compaoré, Carole Bambara Congo,
- Mori Edwige Traoré and Adamo Kaboré
- **OCADES Caritas Burkina:**
- Simon Gniminou, Rita Zoungana and René
- Cyriaque Naré
- **Kyangina Child Development Centre:**
- Rachel Lassman
- **Kiwoko Hospital/Adara Development:**
- Christine Otai
- **Namutamba Rehabilitation Centre for Children:**
- Betty Nakafunvu

Workshop Participants

- **Uganda:** Carol Nanyunja, Ruth Nalugya, Mercy Haumba,
- Jane Nansamba, Maya Kholi-Lynch, Femke Bannink Mbazzi (MRC/UVRI &
- LSHTM), Betty Nyangoma, Lucy Mbazia (ABAaNA studies), Rachel Lassman (Kyangina
- Togetherness and Belonging_November19_Version1 | © LSHTM 14
- Child Development Centre), Margret Seela (Kiwoki Hospital/ABAaNA study), Anna
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- Nalumala, Betty Nakafunvu (Namutamba Rehabilitation Centre), Winnifred Nabikolo
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- DPPH), Florence Benao Ziba (Ministry of Health, Division prevention and control
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- Zoungana/Bamogo, Aicha Ilboudo, Marie Compaore and Ali Zaré (parents of children
- with disabilities), Wougo Kaboré, Agathe Zigani (ABF), Rafael B. Guibila (Humanité
- et Inclusion – Handicap International HI), Anne-Marie Wédraogo (CBM), Clémence
- Compaoré, APEE Parent Association of

www.ubuntu-hub.org

Resources – manuals, materials, community of practice, research, plans



Extra slides