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

Lessons learnt from Burkina Faso & Uganda

ICED Disability Symposium
6th November
• 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

ICED Disability Symposium
6th November
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

- Enacted Stigma
- Felt Stigma
  - Internalised
  - Anticipated

• 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

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

- Qualitative research Burkina Faso
- Qualitative research Uganda

Participatory workshops

- Burkina - 25th April 2019
- Uganda – 29th May 2019

Development of draft training material

- Field testing Burkina
- Field testing Uganda
Training Modules

TOGETHERNESS AND BELONGING
Tackling stigma and discrimination at home and in the community
November 2019

SOLIDARITÉ ET APPARTEANCE
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 sigma within organisations through *process of personalisation*
qualitative research Burkina Faso

qualitative research Uganda
Participatory workshops
Uganda workshop

- Home visits
- Community engagement
- All key gatekeepers known as consultants in child protection
- Dialogue meetings
- Existing terms of care
- Parent support groups
- Mainstream schools
- Rehabilitation centers
- Women leadership forums
- Use of short radio ads
- Organizing events
- Promote beer for social gatherings

Social media engagements

Early childhood awareness
- Media awareness
- Disability day
- CP day
- Disability month
- COVID-19

Promote the GATE VET

GATE-VET

- Women leadership forums
- Media awareness
- Disability day
- CP day
- Disability month
- COVID-19

Use of short radio ads

Organizing events

Promote beer for social gatherings

Child protection

Dialogue meetings

Existing terms of care

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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
Field testing Burkina

Field testing Uganda

- 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
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Workshop Participants

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- INSS Institut des sciences des sociétés
- MCRC/UVRI and LSHTM Research Unit
- Uganda Research
- Inclusion
- Handicap
www.ubuntu-hub.org

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

[Images of resource icons: Resources for providers, Research reports & journals, Support for families & carers]
Extra slides