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# STIGMA STUDY ICED CONFERENCE LSHTM

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# Stigma study



Building the evidence and understanding on experiences of stigma related to children with cerebral palsy in two LMIC and to develop and pilot test a training module on stigma which can be included in participatory training programmes for caregivers of children with neurodisabilities.

## Study Objectives:

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

# Stigma study

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## **Study Setting:**

Rural : Luwero and Nakaseke

Urban: Kampala

## **Methods:**

4 FGD (2 per site) with primary care givers

16 IDIs (8 per site) with primary and secondary care givers.

8 IDIs (4 per site) with community members i.e TBA, LC chairmen, Health workers, VHT, social worker

**Data Analysis:** Thematic coding

**Ethical Approval:** UK: LSHTM, Uganda: UVRI SEC and UNCST



# Study Outcomes

## **Triggers of Stigma** (Across three levels: caregiver, family/household, community)

- Moral beliefs that disability is a consequence of moral actions.
- Societal negative attitude and perceptions about disability
- Beliefs that disability is related to cultural practices such as human sacrifice for blessings
- Common failure of fathers to accept the child with disability.
- Lack of readily available medical services
- Nature of the disability and perceived inability of the child to change.



# Quotes

- *“The community members look at the children as outcasts and abnormal which pushes the mothers to keep these children hidden and not love them. Some treat them just like a disgusting thing wishing they could die. (male, social worker)*
- *“My husband came to tell me that in his family, no one has ever given birth to a child like this, so what I've given him is a curse”. “...my in-laws told my husband that I committed adultery by having sex on our marital bed with another man. He couldn't accommodate this at all so, he abandoned us” (FGD, Caregivers)*
- *“When people see a drooling child they say; the person gave birth to “mugogo kyona kili bwe kityo , tekitegelekeka kwegamba meaning a strange thing, difficult to understand .It's just a complicated thing, hard to understand.” (IDI, community leader)*

# Wider Impact of stigma at individual, family and community level:

## ❖ Individual level

### A) Emotional and psychosocial effect

- Feelings of self-stigma and Blame
- Social withdrawal
- Failure to sleep/emotional stress
- Aggressiveness
- Loss of hope

*I can't leave this child with any one, I can't go with her at my work place because no one can buy groceries from me since people think that you have poor personal hygiene according to the way the child looks. like the child can be drooling people can lose appetite to buy eats. We just persist but we are sorrowful, (FGD care giver*

### B) Physical impact

- loss of sleep,
  - stomach upsets,
  - headaches,
  - weight loss;
  - Daily fatigue
- . Physical abuse, such as being beaten by their partners over a child's disability.

## OUTCOMES CONT'D

### 2) At the family/household level-

- Threatened economic survival of the household,
- Relationship break-ups,
- Social isolation of families
- Segregation among siblings

However, some family members are still supportive especially grand parents and a few husbands and they are a strong source of support and resilience.



### • Quotes

- *My husband came to tell me that in his family, no one has ever given birth to a child like this, so what I've given him is a curse ((FGD care giver)*
- *Because of my child's condition I am always there lacking, I am not hand capped but I cannot work to get money for survival since I cannot leave my child with anyone. If we fail to get food, we sleep and we wait for another day (primary caregiver, 32 years mulago)*
- *my family treats the child really well especially my husband that even when I am very frustrated by the child's condition, my husband encourages me not to give up on the child.*

## Out comes Con't

### 3) At community Level

- Community/social detachment
- Denial to access to services
- Delayed Referrals



### Quotes

*I found when the clinician who knows about my child's condition was not around, another clinician worked on my child, he tried to look for the blood veins but didn't find them, he asked me what happened to my child, I told him that the child got tired during birth, he answered that children like my child don't grow, he didn't attend to her, he held his equipment and left to his room and sat down, (FGD care giver)*

*cerebral palsy is a life long condition which makes the child require fulltime attention of the caregiver. This in turn weighs on the caregivers and by the time they come to me, they are very frustrated which makes my work difficult because I am always tasked to work with frustrated people and are not willing to put into practice what I tell them,*

*(community member, physiotherapist)*



# Coping mechanisms

- Emotion-focused/acceptance such as seeking God through prayer/meditation, behaving well towards others, aggressive behaviors, accepting who their children were and ignoring negative comments, relaxing while listening to music and avoiding others by locking themselves and the child indoors or self-excluding themselves from family and community activities were common practices.
- Action oriented: participating in disability intervention based activities at the hospital, rehabilitation centre or within the community, mobilizing both social and physical resources to meet the increasing needs for their family and for the CWD.

# Acknowledgement

- 1 . Study Teams
2. Study Participants
3. Funders

# Conclusion

- Disability related stigma is experienced widely, and it affects the general well-being of the majority of families particularly the care givers
- The stigma is fueled by lack of knowledge, and traditional beliefs about the causes of stigma. And some factors related to the condition of cerebral palsy, such as drooling and poor self-care, also appear to trigger fear about contagion.
- Caregiving is gendered, and the stigma associated with the disability is also reinforced by social gender norms.
- The impact is at all levels, and as a result, stigma and exclusion contribute to the vicious cycle of poverty, gender inequality, and disability.

# THANK YOU



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