

MRC/UVRI and LSHTM Uganda Research Unit



The impact of COVID-19 measures on children with disabilities and their families in Uganda

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Disclosure of speaker's interests



I declare I have no conflict of interest

Background

- Since March 2020 Uganda has confirmed cases of COVID-19
- Lock down March – June 2020, ease of restrictions Jul – Sep 20
- First wave starting in October 2020, further ease of restrictions Oct 20 – Mar 21
- Second wave started end of May 2021



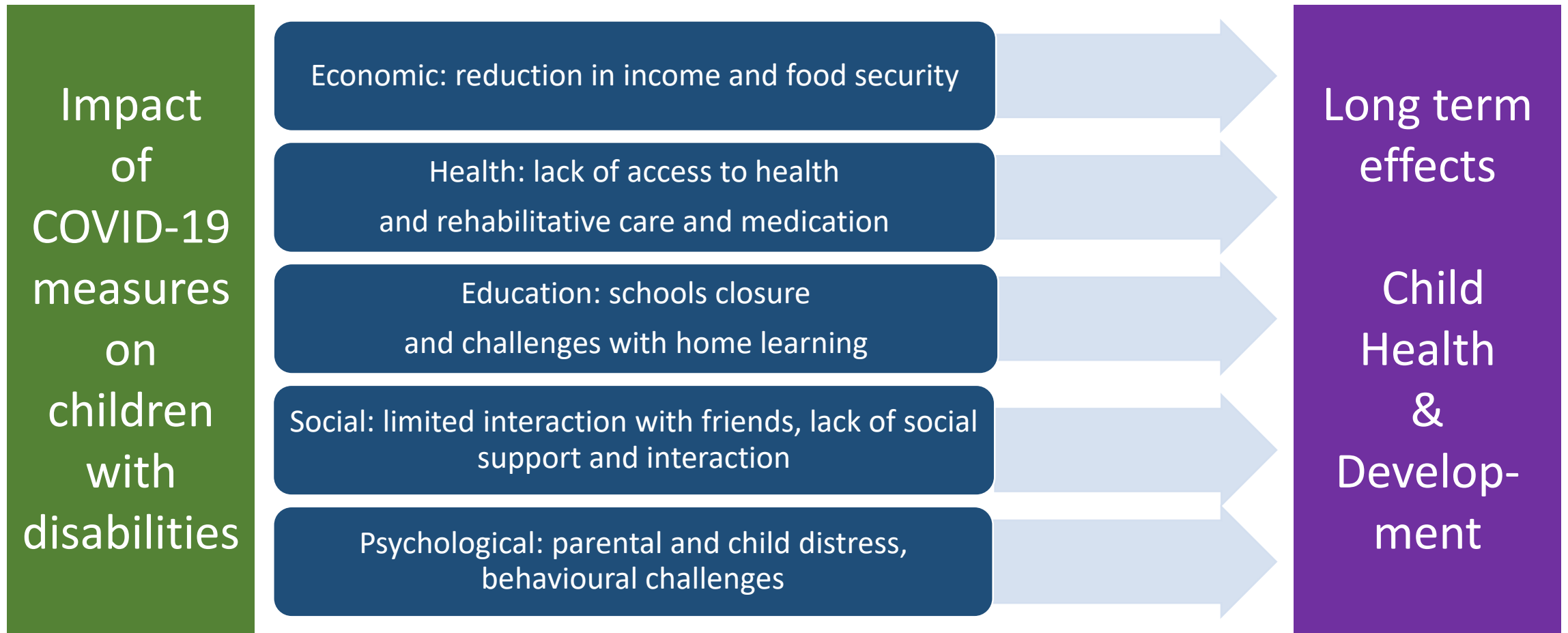
Objective and methods

- Within an ongoing disability inclusion study we conducted a nested COVID study
- Objective: study the impact of COVID and related measures on inclusion and quality of life of children with disabilities and their families in Central Uganda
- 4 rounds of interviews: May, July, October 2020, February 2021, ongoing...
- Phone and in person interviews: guide, recorded, transcribed
- Thematic analysis

Study population (N=125)

Variable	Description	Number (%)	Variable	Description	Number (%)
Caregiver	Father	22 (17.6%)	Gender child	Female	51 (40.8%)
	Mother	83 (66.4%)		Male	74 (59.2%)
	Grandfather	1 (0.8%)	Age child	Median (range)	11 (8 – 14)
	Grandmother	19 (15.2%)	Class child	Primary 1 - 4	
Marital status	Married	75 (60.00%)		Primary 5 - 6	
	Separated	20 (16.00%)	Disability child	Autistic Spectrum Disorder	3 (2.4%)
	Widowed	16 (12.80%)		Cerebral palsy	2 (1.6%)
	Single	14 (11.20%)		Epilepsy	4 (3.2%)
Education level caregiver	University	4 (3.2%)		Hearing impairment	12 (9.6%)
	Post-secondary	6 (4.8%)		Intellectual disability	39 (31.2%)
	Secondary school	33 (26.4%)		Specific learning disorder	6 (4.8%)
	Primary school	81 (64.8%)		Physical disability	12 (9.6%)
	None	1 (0.8%)		Speech impairment	5 (4.0%)
Average net monthly income	< 50 USD	71 (56.8%)		Visual impairment	15 (12.0%)
	50 – 100 USD	25 (20.0%)		Other impairment	4 (3.2%)
	100 – 150 USD	20 (16.0%)		Multiple impairments	23 (18.4%)
	> 150 USD	9 (7.2%)			

Themes identified



Economic effects

- All families were unable to work during the lock-down, and measures have negatively affected their income over the past 12 months.
- All parents mentioned experiencing food shortages and rationing food, a few skipped meals. The situation was worst in the first 6 months of the pandemic:
“There is a very big change/challenge because earlier [...] the children had breakfast, lunch, evening tea and supper but now, there is nothing. All they have is only one meal a day”.
- During the lock down some families received food distributions
- After some of the lock down measures were released participants raised concerns about increased transport costs, having to pay rent, and schoolfees that would need to be paid when schools reopen.

Effects on health and rehabilitative care

- Challenges in accessing regular health and rehabilitation services and medication
- No access to emergency care during lock down
- Regression of child's development due to absence of care:

“My boy has not been able to go for his reviews and therapy for over two months, he is regressing and beginning to self-injure again, we are not able to take him to the hospital as we cannot move. I cannot carry him on my back and walk, he is very heavy and it's too far”

- Negative effects of rationing medication and self medication
 - some children experienced frequent seizures, had issues with their bladder, and others were said to have become very forgetful.

Effects of school closure and home learning

- Parents initially encouraged children to study from home, both lost motivation :
- Home learning difficult for children with neurodevelopmental disabilities

“She has class work at home but she cannot do it as the book gets covered in saliva and I cannot help her. Teachers at school tell me she is able to learn but I don’t know how [...].”
- Learning materials for sale at the local councils, most could not afford to buy these
- Difficulties accessing lessons on TV and radio due to electricity outages and inaccessibility of lessons: *“The font size of the TV words is too small for him to read.”*
- Missing learning together, daily structure, and play with peers
- Worries about exams and repeating a year: *“I feel so bad because I consider this a dead year”*
- Concerns about safe school re-opening, and school fees payment

Social effects

- Parents missed social interaction and support from others (in person / on phone)
“I have not met with anyone, I just stay home [...]. The money you would use to buy airtime you use to buy pancakes for the children, or water, or charcoal, so I have not communicated [...].”
- Most parents also reported finding it difficult not to be able to attend funerals during the lock down and worried about COVID spread at funerals.
- Children reported missing their friends from school, most played together with neighbours, some during and the majority again after the lock down.
- A few children were kept indoors by parents to prevent them getting infected, parents explained that their social skills regressed due to isolation.

Psychological effects

- Emotional distress related to lack of food and finances, and home learning.
“Children are crying saying the situation is difficult. They are unhappy because they see us sad.”
- A few parents were concerned about their children’s behaviour
“We can’t control the boy, he goes away with friends [...] he can’t settle, we need help”
- Some parents (8%) were concerned about girls and the risks they may be exposed to now they are home without structured education for too long.
“[...] children are getting pregnant [...] we can’t protect them as much as they do at school.”

Study limitations

- Small group sample in Central Uganda only
- Phone interviews had various challenges:
 - Sensitive to response bias
 - Missing the non verbal communication
 - Leaves out those who are not available on phone
 - Phones 'go off' due to network and electricity supply difficulties
 - Recordings of the interviews are susceptible to noise and recording difficulties
- In person interviews had to be carried out wearing masks:
 - Difficult to read facial expressions and non verbal cues
 - Recordings of the interviews are hard to hear and transcribe

Conclusion and recommendations

- The COVID-19 measures have had a marked impact on the inclusion and quality of life of children with disabilities and their families in Central Uganda.
- Consider children with disabilities and their families when developing and communicating responses to the COVID-19 outbreak
- Prioritize vulnerable children with disabilities and their families for food distribution and health and rehabilitative care interventions.
- Home learning approaches need to take into consideration the absence of learning support staff, and develop creative support systems through phone calls, and where possible parental, peer or sibling support at home.

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