Supporting young children with disabilities in humanitarian contexts

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Understanding Disability

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Convention on the Rights of Persons with Disabilities (CRPD)

Definition of Disability

"Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others"

(CRPD, 2006, p.4)



Broad Categories of Disability

Communication disorders

Ex: "speech delay"

Learning disabilities

Ex: Letter/number reversal, floating text/numbers

Sensory disabilities

Ex: Deaf, blind

Developmental disabilities

Ex: Autism Spectrum Disorder (ASD)

Mental health disorders

Ex: Anxiety, depression

Albinism (in certain contexts)

Intellectual disabilities

Ex: Down Syndrome

Physical disabilities

Ex: Cerebral Palsy (CP)



Broad Categories of Disability

Why do these categories matter?

- In humanitarian contexts, services are more common for people with visible physical or sensory disabilities, while others may be overlooked
- Effective interventions and program planning depend on meeting specific needs rather than taking a "one size fits all" approach



Common Models of Disability

Traditional Model

Medical Model Social Model Human Rights-Based Model



Common Models of Disability

Traditional Model

- Disability is viewed negatively, even as a curse
- Disability is viewed as the fault of the person with a disability or their parents
- People with disabilities are frequently excluded from society and/or hidden by their families
- Social stigma may be severe for the individual and family

Medical Model

- Disability is likened to having an illness: People are "afflicted with" or "suffer from" a
 disability
- Disability is considered a "deficit" that needs to be fixed through medical treatment, such as surgery, to make the person as "normal" as possible
- People with disabilities which cannot be corrected are pitied and not considered capable of full participation in society



Common Models of Disability

Social Model

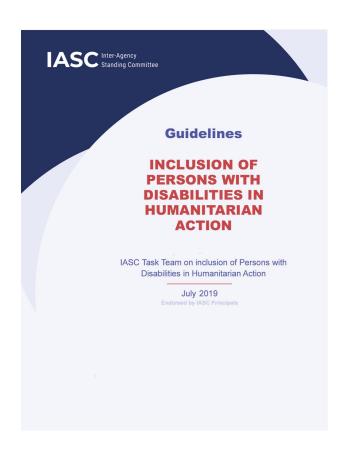
- Disability is defined by the interaction between the individual and society
- The environment can facilitate or hinder a person's abilities
- It is the responsibility of society as a whole to make sure all environments are as inclusive as possible

Human Rights-Based Model

- People with disabilities are entitled to all of the same rights and opportunities as people without disabilities
- It is the responsibility of society as a whole to make sure all environments are as inclusive as possible
- Governments are responsible for enacting and enforcing policies which protect people with disabilities and ensure their full participation in society



Inter-Agency Standing Committee Guidelines



Addresses the Inclusion of Persons with Disabilities in Humanitarian Action



Thank you!

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Community Capacity-Building for Disability in Low-Resource settings

Lessons from Uganda

Fiona Beckerlegge, Physiotherapist, co-founder and CEO Kyaninga Child Development Centre (KCDC)



Introduction

Disability in Uganda

- 2.6 million children (13%)
- Poor distribution of rehabilitation specialists only 20% have access to rehab services
- Poor access
- High cost of transport and services

High numbers of children with Cerebral Palsy

40% of children accessing services at KCDC





Introduction

Kyaninga Child Development Centre

- Multi-disciplinary therapy, education and assistive technology for western Uganda
- Community-Based Rehabilitation
- Training and capacity building
- VHT's and expert parents are the keys to success





Aims of the Parent Support Groups

- Promoting inclusion and participation of children with disability within the family and community
- Maximising a child's developmental potential, optimising health and quality of life
- Promoting empowerment of caregivers through information sharing and peer support
- Sharing maternal experiences and addressing stigma
- Promoting human rights of children with disability







Aims of the Parent Support Groups

- Facilitated by expert parents
- Community-based sessions
- Participatory learning approach

"The training helped me understand my child's problems and the thoughts of abandoning my child ceased and her life improved. I no longer feel stressed and sad"







Ubuntu-Hub







Getting Started

Eating and Drinking

Everyday Activities

Togetherness and Belonging

Know your child

Communicating

Learning to Move

Our Community

Positioning / Carrying

Play and Stimulation

Assistive Products

Next Steps





Practical applications







Thoughts of a parent

"Mothers never knew exercises were magical. It was not easy to convince them to just do exercises but with repetitive explanation, they got convinced and at least each child has achieved a milestone and we have not experienced any child that is still as they came" – expert parent

"We had a lot of fear and used to think they were "wasted" children but meeting other mothers has taught us a lot. Fellow mothers give us hope that our children will improve, and this kept us strong." - parent

"We have learnt how to feed him and care for him, so we help out when his mother is not around" – Grandmother





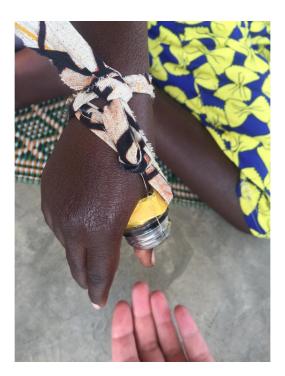
Thoughts of a parent





Useful resources











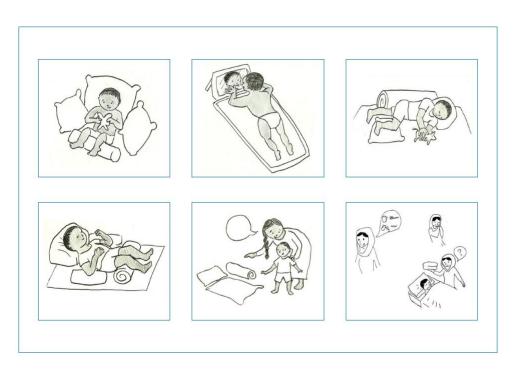






MAITS – training for community health workers

Example – resting and sleeping.





Caring for Children with Developmental Disabilities



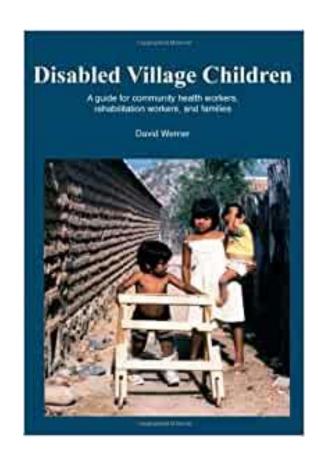
A Guide for Parents
living in low-resource settings





Resources

- <u>Disabled Village Children -</u>
 https://www.dinf.ne.jp/doc/english/global/david/dwe002/dwe00201.html
- www.ubuntu-hub.org/
- www.maits.org.uk







Thank you!

Fiona Beckerlegge fiona@kyaningacdc.org

Sesame Workshop and the Power of Representation in Media:

Using storytelling to reduce stigma against people with disabilities

Deborah Marie Rodríguez García Senior Manager, Education, Sesame Workshop









Why Ameera was created

- Challenge stigmas toward disability that is faced by many children
- Positive representation of children with disabilities
- Help children without disabilities learn about children with disabilities







Formative Testing with Syrian Family in Lebanon

"We tested some storyboards with Ameera and the mom here shared quite a bit of feedback after watching. Her 5-year-old son lost part of his left arm in the conflict and also has cancer so after she saw Ameera, she told the interviewer that watching it was the most special part of her day because she felt like her child would feel less alone.

She also mentioned it was the first time she saw anything on TV representing a child with a disability, so it was very close to her heart. It was so difficult to hear their story but so valuable to see how our content can help kids."





How Ameera was designed

- Multidimensional character
- Including disability experts from the start of the content creation process
- Choice of wheelchair
 representative of the children who
 do not have access to a variety of
 affordable AT







How Ameera was designed

 This photo demonstrates the reality of the insufficient access to adaptive equipment for people with disabilities, especially for people living in fragile contexts.



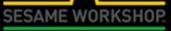
Photo: Image from Chad. Shared by S. Zuidema. Taken by F. Lee at iACT, an organization that supports refugee-led preschool programs (called Little Ripples) and soccer academies in refugee camps worldwide.



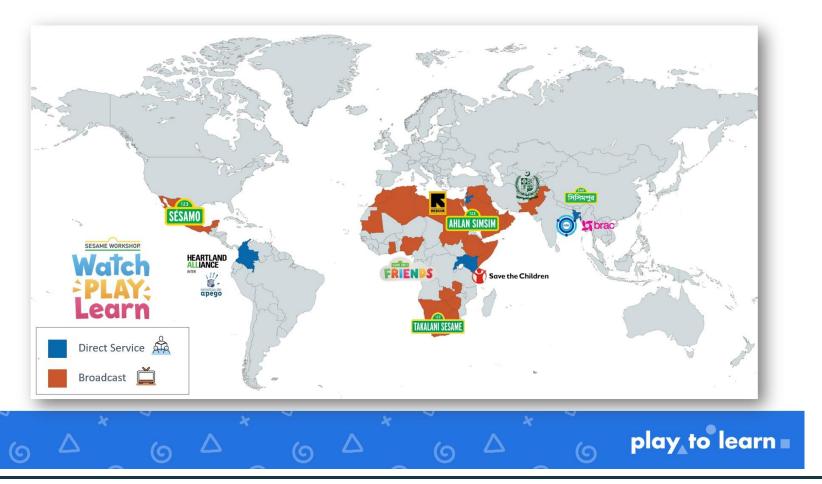


How Ameera was designed





Where Ameera will be featured







Thank you!

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