

# Early Care and Support for Young Children with Developmental Disability in East Africa:



African Regional Convening to Support Parents & Caregivers  
21<sup>st</sup> – 23rd June 2022

LONDON  
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MEDICINE



**Dr Cally Tann, on behalf of the Baby Ubuntu team**

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# BACKGROUND

- Facilitated group participatory programme for young children with developmental disability and their caregivers – co-facilitated by expert parents

## Themes running throughout the programme

- 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 particularly addressing stigma
- Promoting the human rights of children with disability





- ‘Ubuntu’ is a Zulu term - “humanity towards others” - a nonprofit research and educational hub
- Aims is to improve the lives of children with developmental disabilities, and their families
- Shared also through a community of practice spanning >300 members and 70 countries
- <https://www.ubuntu-hub.org/>



Developed as a group programme that empowers families, Ubuntu (version 2 of ‘getting to know cerebral palsy’) places emphasis on a participatory approach to learning at community level. Ubuntu focusses on children with developmental disabilities, aged approximately 2-7. Please contact us on the form at the base of this web page if you wish to translate version 2: Ubuntu – working together with families and children with developmental disabilities. Materials are available in English and include:

- A facilitator manual
- Images and display materials

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The Baby Ubuntu Programme was developed in response to a recognised need to support families of very young children (0 to 2 years) with an evolving developmental disability (e.g. following birth asphyxia). It was developed from both the original GTKCP and the Juntos programmes, and focuses on supporting children and their families in the first 1000 days of life. Baby Ubuntu material is available in English and Kinyarwanda and include:

- A facilitator manual
- Images and display materials

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Juntos was developed for children with congenital zika syndrome and their families in Latin America. Children with cerebral palsy and their families have also attended these groups. It combines content from Ubuntu and ABAaNA, and is a ten-session programme. An innovative psychosocial component is included. Juntos materials are available in Portuguese, Spanish and English and include:

- A facilitator manual
- Images and display materials
- Videos

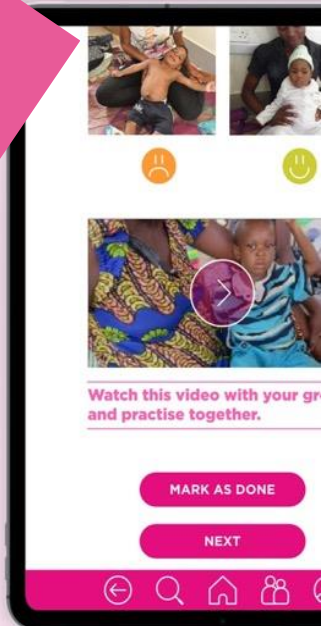
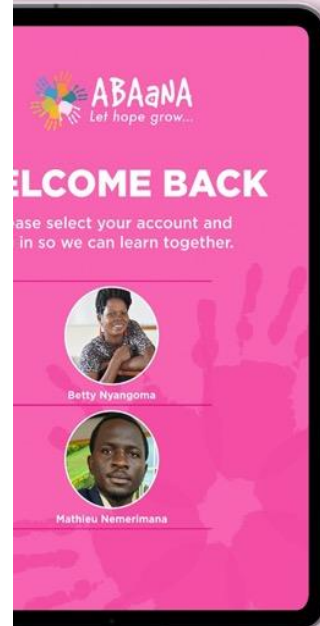
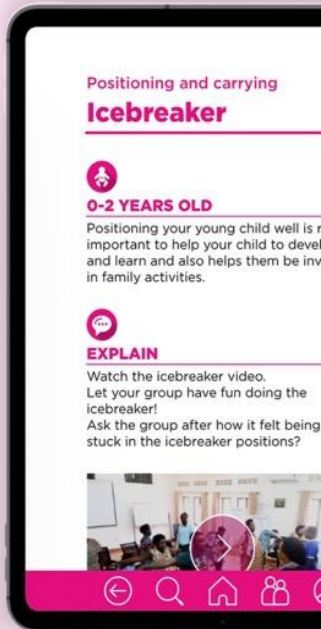
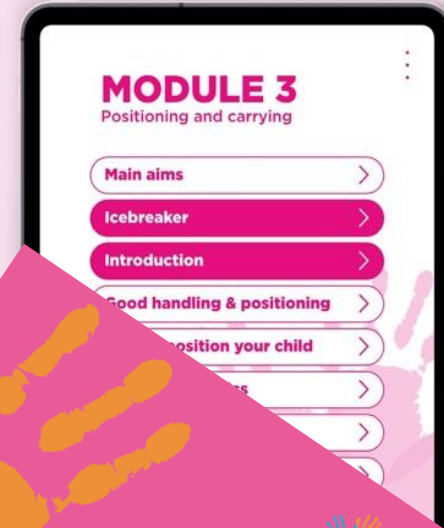
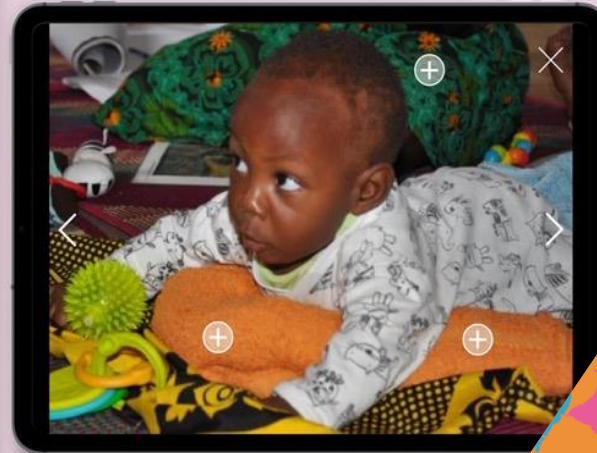
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# CONTENT



- Manual (free online download)
- Access to the Ubuntu shared learning platform and resources
- 3-day implementation facilitation workshop
- 5 day training course and ongoing supervision and mentorship delivered by 'Master Trainer'
- Tablet application under development to support fidelity

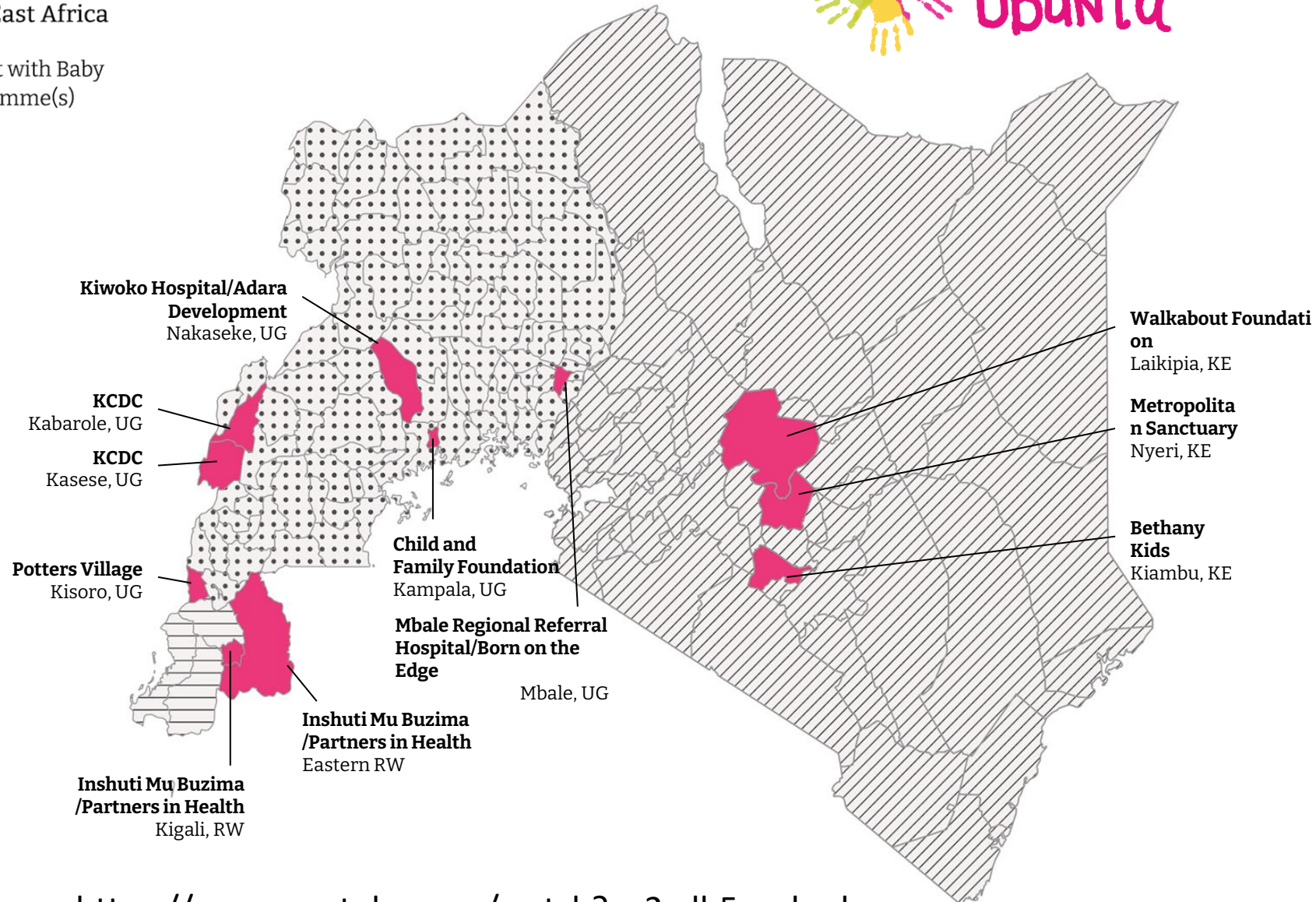


# Programme reach: East Africa and beyond



## Baby Ubuntu in East Africa

- County/District with Baby Ubuntu Programme(s)
- Uganda
- Rwanda
- Kenya



## Beyond....

**Africa:** Burkina Faso & Malawi in early phase

**Fiji:** Adapting to meet the specific needs of a high-risk preterm population (collaboration with the University of Melbourne)

**Afghanistan:** Adapted for humanitarian settings 'Mighty Children'

Strong collaborative links within the UK leading to adaption for a UK setting

<https://www.youtube.com/watch?v=2vdb5yeyhmk>

# Transitioning to scale...

## Public engagement

Tweets & replies Media Likes

Pinned Tweet

Cally Tann @CallyTann · 10m

Wonderful celebrating #WorldCPDay today holding art workshops for children and their families from #ABAaNastudy #earlyintervention to address #stigma and promote #inclusion. Much love & laughter shared! Watch this space for deets of #LetHopeGrow exhibition early next year!



MRC Uganda and 9 others

## Feasibility trial & cost of intervention

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ADARA GROUP  
- BRIDGING WORLDS -



Cerebral Palsy ALLIANCE RESEARCH FOUNDATION



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## Mixed-methods evaluation of programme roll out in Rwanda & Uganda

Partners In Health Inshuti Mu Buzima



Kyanninga Child Development Centre  
Helping children reach their full potential



## Transitioning to scale for low-resource settings

- Package of training, mentorship, monitoring & evaluation
- Tablet application for enhanced accessibility, fidelity, monitoring
- Sustainable scale-up strategy
- Add livelihoods component



Cluster-randomised trial inclusive of process & economic evaluation

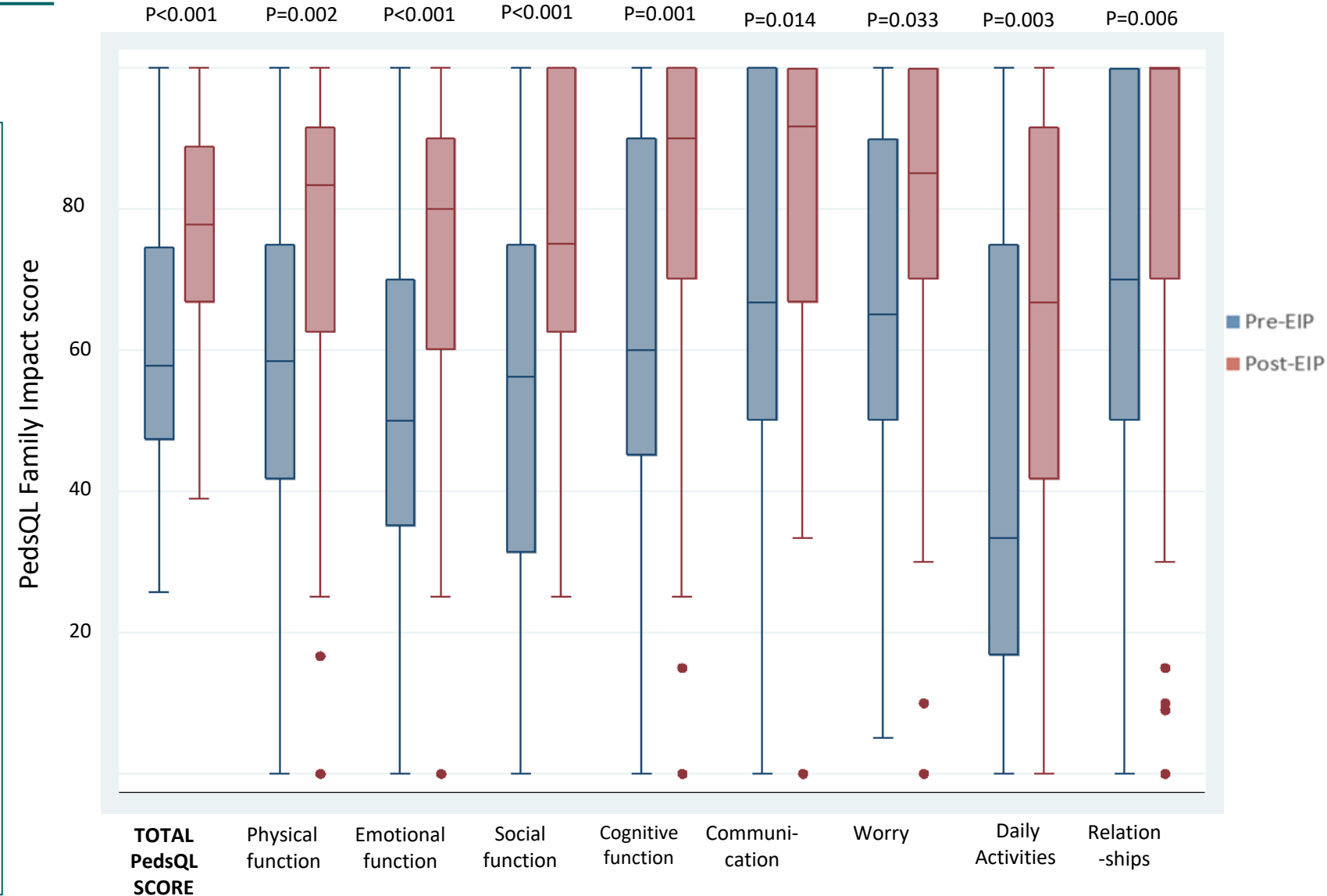


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# Early piloting and pre- / post-evaluation

- Developed in Kampala 2015-16
- Participants 6-12 months with moderate-severe impairment
- Kampala: 25% improvement in total Peds QL family impact (median difference +15.6,  $p=0.001$ ) (n=28)<sup>1</sup>
- Western Uganda: Significant improvement in total quality of life score (21%) and most sub-domains (n=48)<sup>2</sup>
- Improved caregiver knowledge and skills, and reducing stigma



<sup>1</sup>Tann et al. *Infants and young children* vol. 34,1 (2021): 17-32

<sup>2</sup>Sadoo et al. *BMC Pediatr.* 2022 Mar 26;22(1):158.



**Aim:** Conduct a feasibility trial to evaluate feasibility, acceptability, early evidence of impact and provider costs (mixed methods)

**Participants:** Infants with moderate-severe neurodevelopmental impairment & their caregivers

- Median 9.5 months (IQR 7.5 – 10.2)
- 51% boys
- Median DQ 28.7 (IQR 14.2 – 42.6)
- HINE median 32.5 (IQR 22 – 46)

## OUTCOMES

- **Feasible: 126 infants recruited and randomised**
- **Acceptable: 68% satisfactory attendance**
- Piloting of outcomes measures to assess early evidence of impact: *Inconclusive with wide CI's reported, high impact on qualitative evaluation*
  - Quality of life,
  - Child functioning, nutrition, mental health and well-being
- Provider costs: *Total \$142.03 USD per participant*
  - Set-up: \$27.31
  - Running: \$114.72
- All mixed-methods including qualitative component



Photos: Karen Martin

**Knowledge, skills and confidence:** *“[My child] doesn’t look the way he looked before. He has improved in his health. He was so small since I didn’t know how to feed him but ever since I was taught.., I practiced.. and now my child is healthy”*

**Stigma & exclusion:** *“Health workers are now supporting her in case she takes her child for treatment. No longer judge them for their children’s weight/appearance”*

**Daily activities:** *“I had given up with work since no one could accept to stay with my child but because I learnt to feed him and how to make him calm, I have returned to work leaving [him] with one of my relatives.”*

# Factors important for scale

- **Demand:** Stakeholders reported a very high demand in the community as very few organisations and services targeting children with disability
- **Integration:** Integration of programme into community health systems substantially supports accessibility and therefore acceptability
- **Community engagement:** Enhanced community engagement crucial to reduce superstition and self-stigma, and promote inclusion
- **Paternal engagement:** Engagement of fathers and wider family members critical for mothers accessing care and support
- **Poverty:** Financial impacts of child disability and poverty are key barrier to access and improved quality of life
- **Manage expectations:** Managing caregiver expectations in terms of progress in development, functioning and growth
- **Capacity:** Important to consider capacity of healthcare systems and staff



# Integrated, tiered approach to early care and support

- Integration with existing community health services in a tiered approach is crucial for scale-up and sustainability
- In Uganda VHTs trained to identify at risk infants and refer for developmental assessment in line with current national strategy
- Referral to specialist services (tier 2) integrated through community service mapping
- Vertical and horizontal scale-up models being evaluated in partnership with MoH and iNGO/NGO partners



# Future vision at scale...

- **Integrated:** An integrated approach to early child development and disability, harmonized with government community health systems
- **Transformative:** Community transformation increasing social inclusion and participation for children with disabilities and their caregivers, that promotes access to health, developmental care and education for all
- **Sustainable:** Robust learning and delivery platform for high fidelity implementation of Baby Ubuntu with a network of Master Trainers
- **Accessible & adaptable:** Accessible programme that is able to adapt to diverse settings and contexts promoting global reach

## Challenges

- Maintaining quality & fidelity at scale
- Simplicity vs effectiveness vs cost



# Conclusion

- **Baby Ubuntu is a community-based, participatory group rehabilitation programme, co-facilitated by expert parents,** that aims to provide a cost effective solution to providing early care and support for caregivers.
- Our feasibility trial found the Baby Ubuntu programme to be **feasible and acceptable to families** in both urban and rural settings in Uganda.
- Mixed methods evaluations have provided **strong qualitative evidence of impact on family knowledge, skills, attitudes and quality of life, however this was less clear on quantitative evaluation**
- Clear need to **embed identification, care and support within existing tiered community health systems.** Facilitating factors included **community level engagement and sensitisation around child disability**
- Important **barriers included stigma, poverty, limited capacity of existing health care systems** and highlighted the need to **manage expectations around the child's progress.**
- The **cost estimate represents a feasible intervention for this vulnerable group,** encouraging financial sustainability at scale, however full economic evaluation warranted.



# Thanks / Mwebale

## Stakeholders & Partners

- Partners in Health/Inshuti mu Buzima
- Adara Development Uganda
- Mulago University Hospital
- Kiwoko Hospital
- Hope Uganda
- Saving Brains Learning Platform
- Kyaninga Child Development Centre
- Uganda Society for Disabled Children

## Investigators & Collaborators

- Karen Martin
- Rachel Lassman
- Frances Cowan
- Miriam Martinez-Biarge
- Maria Zuurmond
- Angelina Kakooza
- Tracey Smythe

A special thank you to our Baby Ubuntu families and expert parent facilitators



## Sponsors:



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