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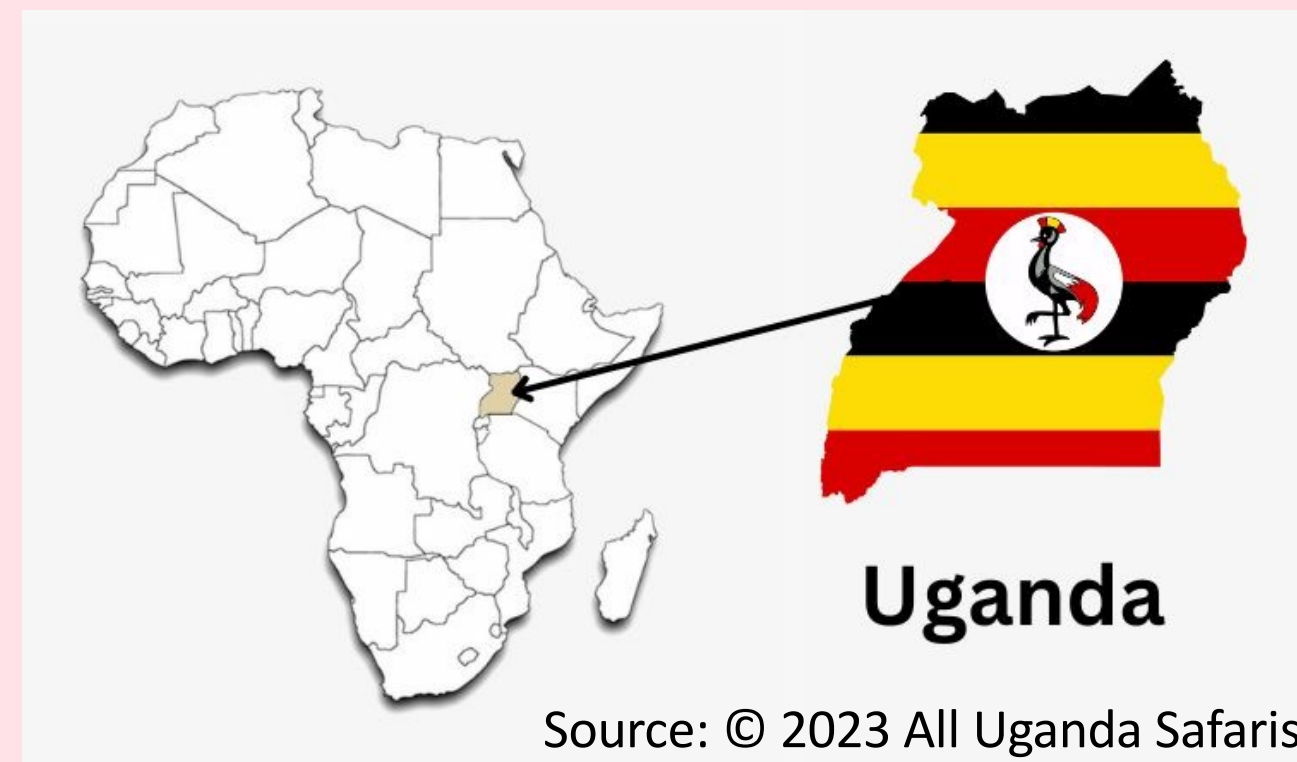
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Adapting a participatory intervention for caregivers of children with complex neurodisability from low resource to high income settings: Moving from “Baby Ubuntu” to “Encompass”

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The adaptation is underpinned by the ADAPT guidance (Moore et al., 2021) and MRC complex intervention development framework (Skivington et al., 2021)

What is Baby Ubuntu?

1. A community-based
2. Participatory
3. Caregiver training programme
4. Facilitated by an 'expert parent' and a health professional
5. Works through a different module per session

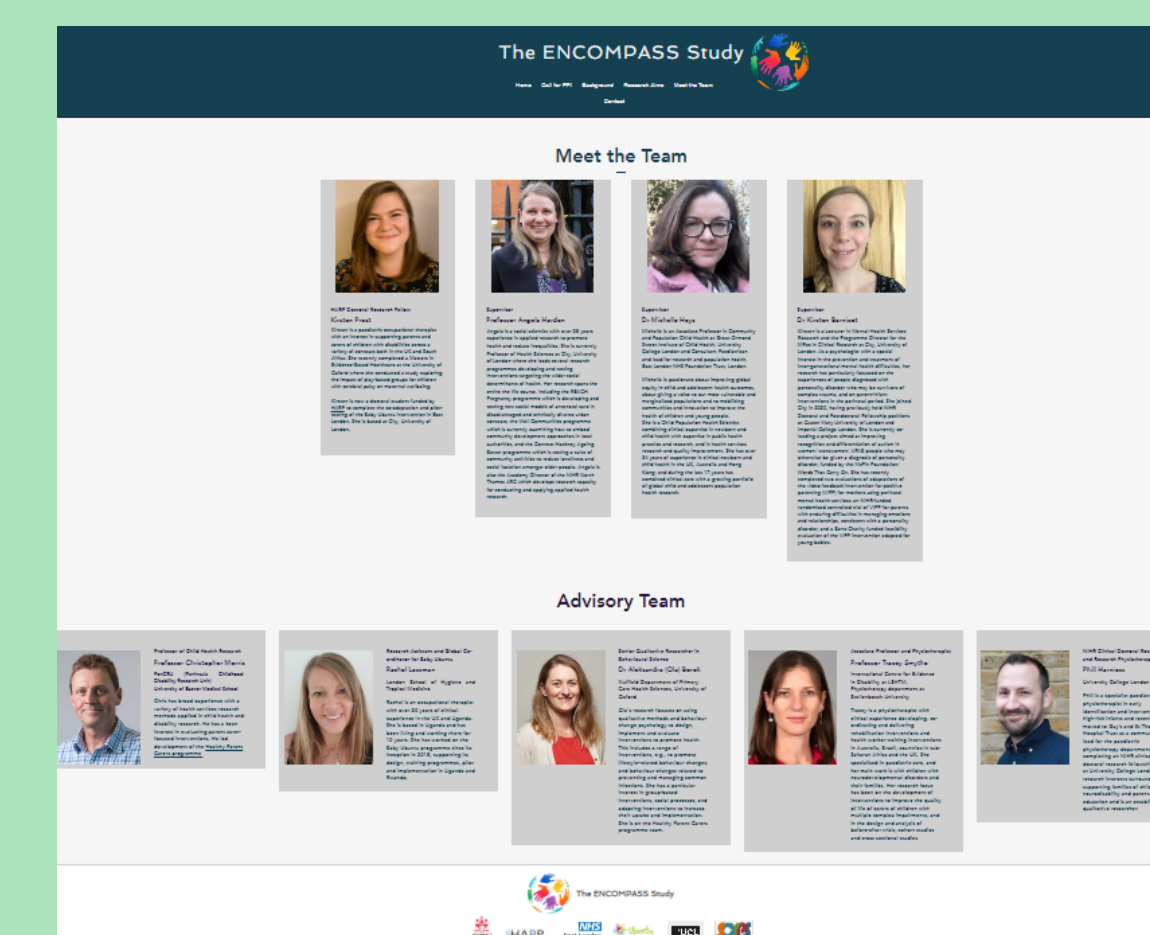
The Importance of an Adaptation Team

Research Team

- PhD fellow
- Supervisors

Advisory Group

- Original creators of the intervention
- Methodological expertise
- Expertise with the clinical population



PPI Group

- Parents from Newham and Tower Hamlets who have a child with a complex neurodisability
- Parents from Uganda who were involved in the development of Baby Ubuntu

Context Mapping

The PhD fellow was able to visit the Baby Ubuntu team in Uganda and meet with programme implementers, researchers and parents.

During PPI groups, similarities and differences were mapped out between Uganda and East London, UK



Similarities: Feelings of isolation, mothers being the primary caregiver, difficulties sharing mental health struggles, sharing stories helps parents to feel less alone

Differences: More opportunities for adaptive equipment, schooling and support from doctors (UK), at times more opportunities for therapies (Uganda), differing cultural ideas about disability and the reason for it.

Qualitative Data Collection

Semi-structured interviews were conducted with 12 parents and 6 healthcare professionals who care for children with complex neurodisability, with a focus on cerebral palsy, in Newham, UK. The aim was to explore recommendations for the adaptation of Baby Ubuntu to a UK context.

It was felt that content should include greater emphasis on **caregiver mental health and well-being**, signposting to third sector organisations, **simplifying** medical terminology, and support with **schooling**.

Key programme delivery recommendations included joint facilitation with health specialists and expert parents, and considerations of language and cultural diversity

Developing a Programme Theory

Realist methodology was used to develop a programme theory along with the knowledge and experience of the adaptation team. It is expressed through the following context, mechanism (resources and responses), outcome configuration:

Context: National Health Service, ethnically diverse, deprived London areas

Resources: "Encompass" intervention (10 modules) delivered in groups

Responses: parents learn new skills, peer support

Outcomes: Improved empowerment, parent skills and health literacy

Next Steps:

1. Complete the adapted "Encompass" manual
2. Pilot test the intervention in the East London boroughs



Two East London Boroughs



ENCOMPASS