Ubuntu-Hub programmes
A global need

• > 50 million children live with developmental disabilities
• Main carers for children with disabilities are their family
  • Limited family and clinical support
  • Increased strain.
• Large and growing need to empower and strengthen families
  • maximise health and well-being of their children.
How we can help

• Identify themes for research that give an increased opportunity to thrive
• Caregiver groups - put the results into practice at community, health service and health system levels
• Strong collaborative research partnerships
• Bring together world-class scientists, families, NGOs, OPDs, and established research organisations
What do we do?

RESOURCES for providers

RESEARCH reports & journals

SUPPORT for families & carers
What are Ubuntu, Baby Ubuntu and Juntos?

• 3 programmes
  • harness peer psychosocial support
  • help improve carers’ skills in caring for their child
  • modular session programme, which offers practical advice for care (e.g. feeding, movement, disability rights)
  • each session is 3 – 4 hours long
  • facilitators encourage learning through participation (facilitators and carers work together, and carers’ learn through sharing their own experiences about topics that are important to them)
• around 10 children and their carers
Our platforms

• Website – manuals, videos, parent posters, blog, publications, webinars
• Facebook - https://www.facebook.com/UbuntuHubProgrammes
• Community of practice
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• Community of practice
Ubuntu hub is a non-profit research and educational team.

Our aim is to help improve the lives of children with developmental disabilities, and their families. We are a nonprofit research and educational hub based in the International Centre for Evidence in Disability at the London School of Hygiene & Tropical Medicine.
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The Ubuntu programmes are caregiver support groups for the families of children with developmental disabilities, which are run by a trained group facilitator. These groups enable you to:

**Meet together:** Meet other carers of children with disabilities  
**Share together:** Share ideas, questions, concerns and experiences of caring for your child, and yourself  
**Learn together:** Learn about wellness, child development, health, education and your rights  
**Talk together:** Talk about your experiences and how you are feeling  
**Practice together:** Practice with the help of trained facilitators  
**Discover together:** Discover how to create an effective support community

For practical advice and information, please use the materials provided below.

**Group information**

- Download in colour
- Download in black and white

**Our videos**
All children have the right to live happy and healthy lives

- Support your child’s posture to encourage independence
- Keep your child stimulated so they can learn how to think and play
- Feed your child well so they will grow strong
- At our community groups, we will help you support your child’s growth and development at home. Together, we will learn how to:
- Keep your child safe if they have a seizure
- Help your child wash and stay clean
- Develop our communication skills to help your child make friends and take part in the community

We will also support you as parents and caregivers to raise awareness in your community, advocate for your child’s rights, and access local services to support your family.
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Would you like to join a global community to share ideas, access the latest research, find solutions, meet new people and collaborate on innovative and exciting projects?

We share ideas and exchange knowledge through:

• Lessons learned
• Sharing best practices
• Discussing common problems
• Collaboratively creating solutions
• Working together for more coordinated state or regional efforts

And more!

Our purpose is to strengthen collaboration and exchange learning between groups of people who share similar interests. We aim to support and facilitate discussions on topics that fit within this community and through a series of webinars, blog posts and case studies. Members can use the platform as a way of sharing lessons learned, best practice and seeking help, advice and support.

Join our community
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Updating GTKCP
What did we do?

• Interviews in April/May 2020 - understand use of GTKCP and inform next steps for updating.
• Direct providers for trainers, facilitators, or caregivers (75%)
• Co-ordinators of programmes (25%)
• Africa - Nigeria, Zambia, Rwanda, Uganda, Tanzania
• Middle east - Iraq, Iran
• Latin America and the Caribbean - Brazil, Honduras, Guatemala, Nicaragua, Colombia, and Bolivia.
What did we do?

- Key findings were presented at a steering committee meeting on 14th June 2020 to prepare for online dissemination meeting
What did we do?

• Online dissemination meeting was attended by 41 participants on 22nd July 2020 and the recording of the interactive meeting was uploaded to: https://www.ubuntu-hub.org/updating-getting-to-know-cerebral-palsy/
What did we do?

• A reference group - provide feedback on updates and changes to the manual.
What did we do?

• A second dissemination meeting to update stakeholders on our progress and to seek feedback on changes to date was attended by 32 participants.
Updates and changes

• Language of the manual was simplified and repetition removed
• Copy editing July - August 2020
• Information that has been requested from country programmes on emotional wellbeing – through modules
• Management of seizures
• Infant eating and drinking – module 4
• Caregiver agency (for community engagement) – through modules, and in ‘our community’ module – access to health and education
• Stigma and discrimination – separate module now included
Update and changes

• Our name and logo
• Layout – summary of information that the module will cover
• Developmental disabilities not just CP
• Personal stories and introducing close friends and families (with posters) module 1, 2, 10 and 12
• Sharing thoughts and emotions – through all modules
• Module 2 – developmental charts
• Module 2 – managing seizures
• Positioning – eating and drinking – learning to move
• Module 9 – togetherness and belonging
• Module 10 – our community – barriers to inclusion, negative attitudes and exclusion, using education and health care
• Module 11 – assistive products
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LIST OF MODULES

- Ubuntu
  - Let's get started
  - Know your child
  - Positioning
  - Eating and drinking
  - Learning to move
  - Communicating
  - Play
  - Everyday activities
  - Togetherness and belonging
  - Our community
  - Assistive products
  - Next steps
Update and changes

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This module covers the following information:

Let’s get started
What are developmental disabilities?
Our children
Our family and support
Monitoring progress
Update and changes

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Last week you told us a little bit about yourselves and your child. This week we’d like to hear about other people who make up your close family and friends.

Using the second circle of the chart, draw some of the people who are involved in your day to day life and tell us a little bit about how they contribute to helping look after your child.
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SHARING EMOTIONS AND FEELINGS

**Ask**

“How did this session feel? Did it raise any emotions or feelings that you did not expect? How have you been feeling this week?”

Allow time for discussion and interaction with each other.
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These circles show what Joseph can do already. He can lift his head and sits with support.

The next step is circled in red. Joseph’s mum would like to help him learn to sit.
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- In groups of 3-4 separate statements into correct and incorrect
- Sharing experiences – do any of your children have seizures? What happens?
- What should you do when your child is having a seizure?
- Practice in pairs placing each other in this position
- Information that could be useful when consulting a health professional
- Additional general advice

| Seizures are caused by evil spirits                |
| My child can get help and early treatment from health workers for her seizures |
| If my child has a seizure it is because she is cursed |
| Medical treatment can help my child’s seizures |
| Other children can catch seizures from my child |
| Uncontrolled seizures can affect my child’s development |
| A seizure is an electrical overload in the brain and my child can lose control of her muscles when she experiences a seizure |
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NOW PRACTICE WITH YOUR CHILD

Part 1: Lying Down Positions

Ask
Ask someone to volunteer to lie on the floor and copy the position of the child in picture (3.02a).

The rest of the group should observe and change this position to make it more helpful, using pillows or blankets. Encourage discussion as changes are made.

Return to the smaller groups.

Return to sitting together with children on caregiver’s laps.

Ask
“How is your child sitting with you now? What should you change?”

Now practice with your child

Encourage caregivers to work together to change the position of their child and
Activity 6

Give everyone a sieve, a spoon, and a bowl. Place some bean / vegetable soup with liquid into the sieve and show how to crush the bits into a smooth puree as seen in the pictures below.
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  • **Module 8 – cartoon for translation**
• Module 10 – our community – barriers to inclusion, negative attitudes and exclusion, using education and health care
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Activity 2

Act out a role play of the two picture strips below, using a doll. Either the facilitators or a few of the caregivers can act out the role play.
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This module covers the following information:

- Togetherness and belonging
- Reflection on changing your individual beliefs
- Family and community inclusion
- Inclusion in Services
- Group action plan
- Sharing emotions and feelings
• James the investor
• Our stories
• Role plays and treating with dignity
Update and changes

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This module covers the following information:

Our community
Rights of people with disabilities
Focus on the right to health
Focus on the right to education
Community mapping
Sharing community maps
Sharing common barriers
Mapping our communities
Finding community solutions
Monitoring progress
Sharing emotions and feelings
End of session
Update and changes

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• New Branding for the ABAaNA Early intervention programme

• Early care and support

• New module – Togetherness and Belonging

• Future plans to further harmonise with Ubuntu (more inclusive to a wider range of disabilities)
BABY UBUNTU TABLET APPLICATION

• Developing a simple tablet application to provide an interactive resource for both facilitators and families with dynamic accessible content (even if network difficulties)

• Information in spoken and video format for improved accessibility

• Clear tracking of progress

• Reporting and data analytics on usage

• Links to support and mentorship for all contributors

• Processes for monitoring, evaluation & learning
Inclusive families and communities supporting young children with disabilities to thrive

Transition to Scale

Training for fidelity

Training package
- Road map for implementation
- Updated training materials with facilitator guide with media-based training aspects

Literacy, accessibility & fidelity

Tablet Application
- Interface for facilitators & families
- Short-film clips with visual core content
- Monitoring, evaluation and learning built in

Financial impacts

Livelihood Component
- Scoping review and online survey of livelihoods programs
- New livelihoods module

Demand

Scale-up strategy, & business model
- Scale-up strategy developed using existing framework
- Policy brief & stakeholder engagement

Inclusive families and communities supporting young children with disabilities to thrive
What next?

• Community - monthly webinars, email community of practice
• Feedback on materials
• Guest blogs
• Programmes that use Ubuntu
Ubuntu: Launching version 2 of ‘getting to know cerebral palsy’
Aug 3, 2021 | News
We have updated GTKCP to ‘Ubuntu – working together with families and children with developmental disabilities’. The manual includes information for

Handouts for parents and caregivers
Dec 4, 2020 | News
Together with caregivers, group facilitators and programme coordinators, we have produced a resource for parents that is both a handout and a poster. Having a poster displayed at home is great.

Animations: child development and developmental disability
Nov 26, 2020 | News
Download and use these animated videos from ICED on child developmental and developmental disability, with versions in English, Portuguese and Spanish. The
Thank you!