



Ubuntu



Baby
Ubuntu

Juntos

Ubuntu-Hub programmes

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



ICED
International Centre
for Evidence in Disability

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

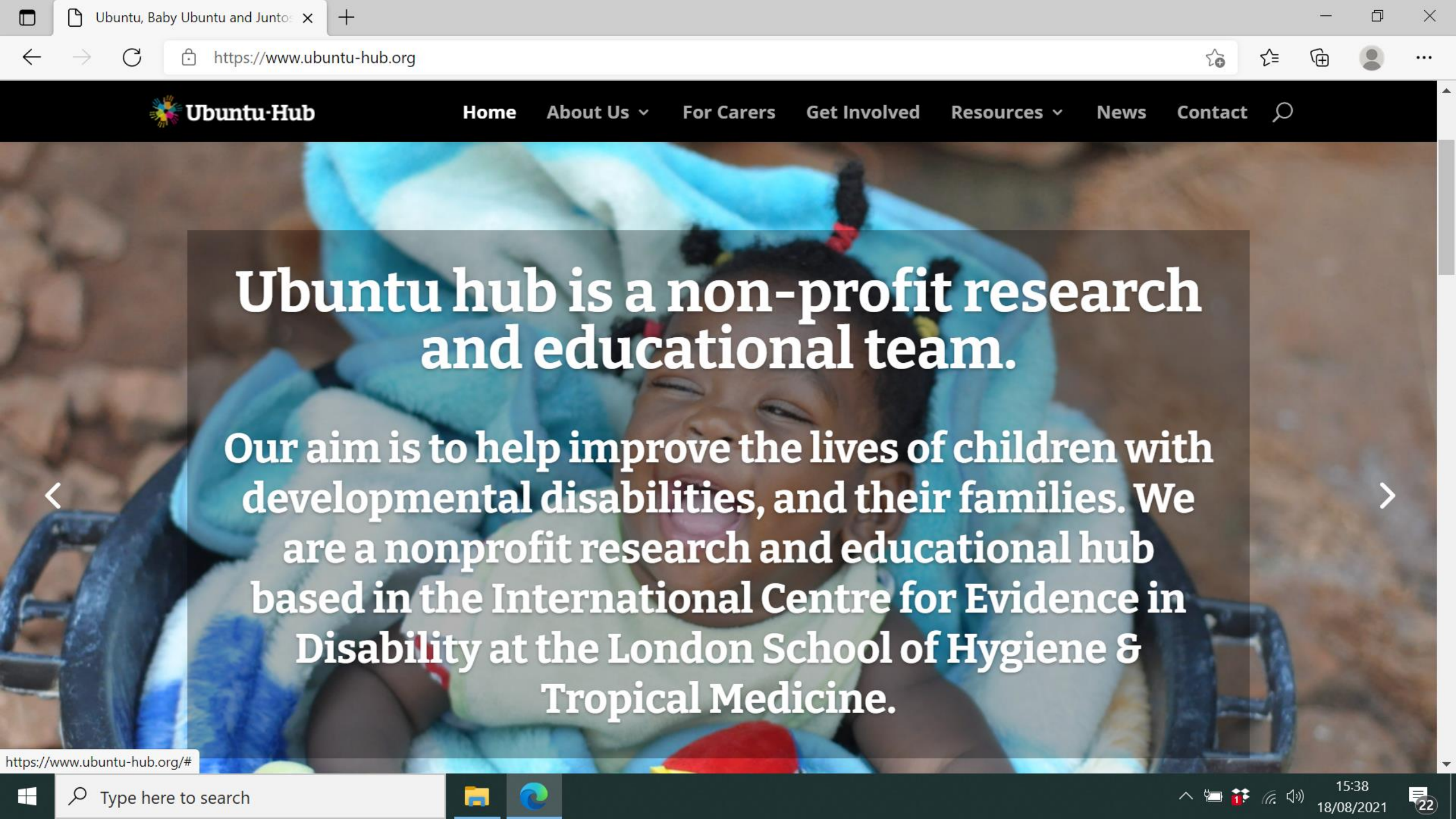


Our platforms

- Website – manuals, videos, parent posters, blog, publications, webinars
- Facebook - <https://www.facebook.com/UbuntuHubProgrammes>
- Community of practice

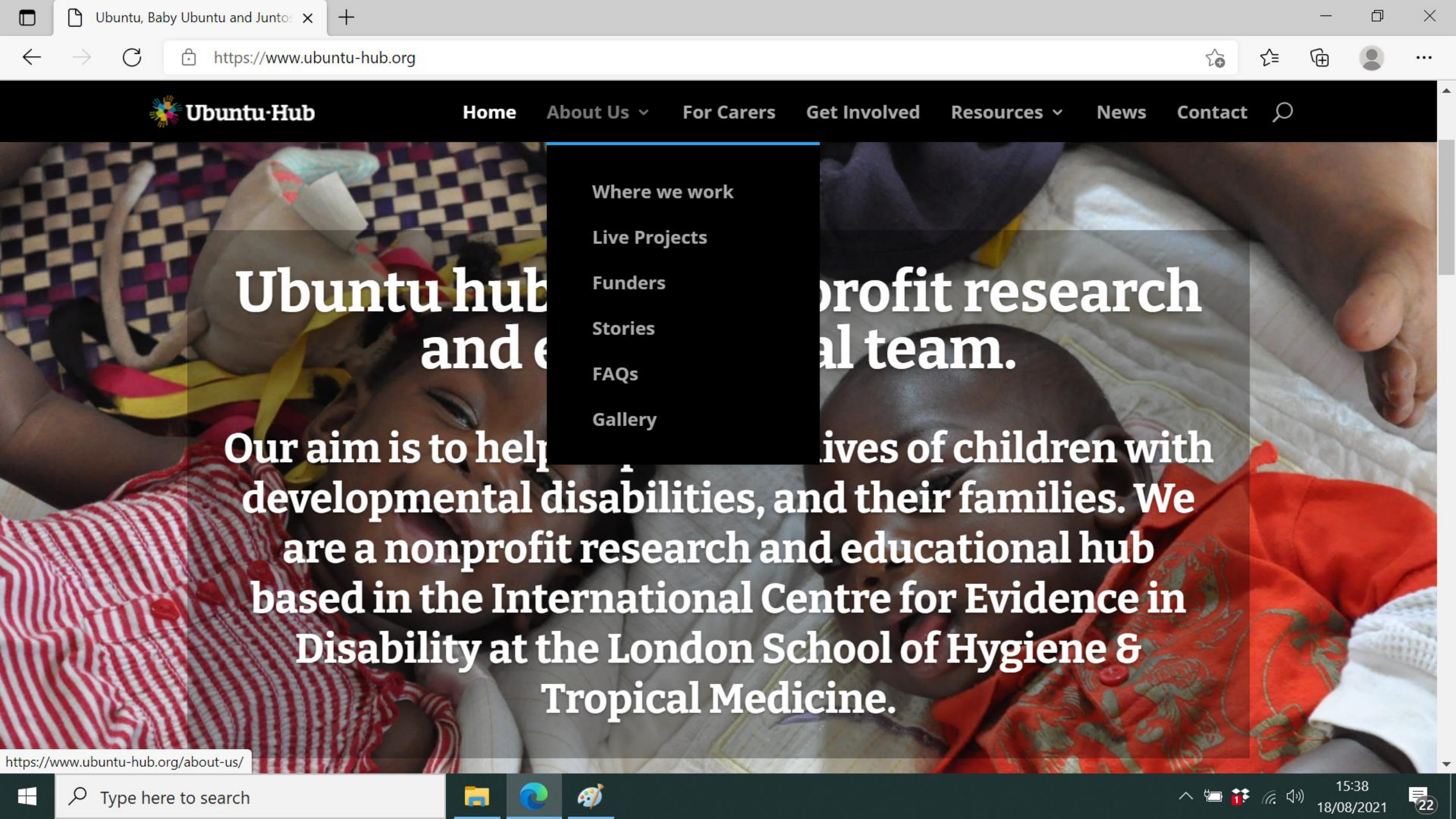
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Ubuntu hub is a non-profit research and educational team.

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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Where we work

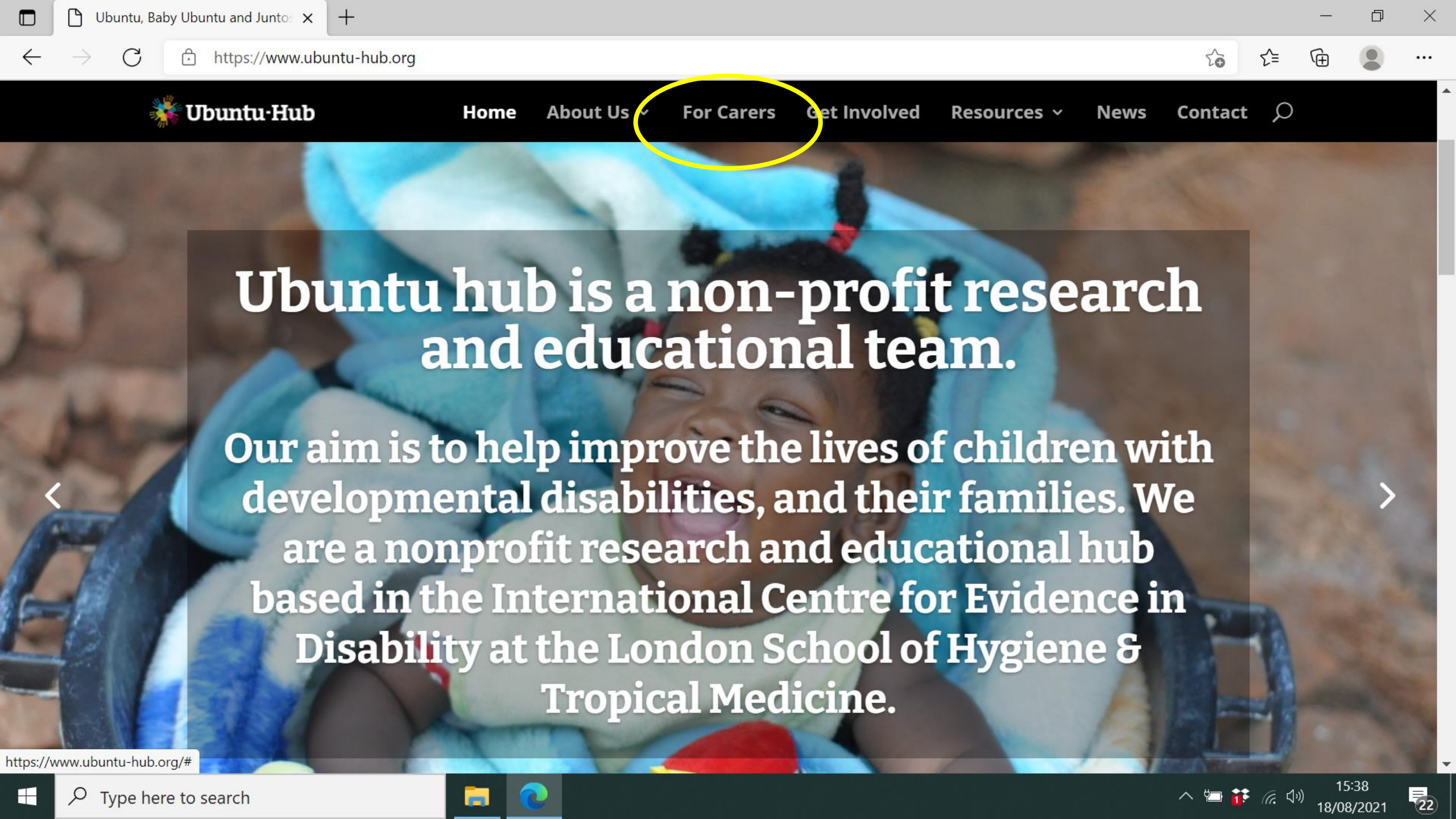
Live Projects

Funders

Stories

FAQs

Gallery



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[For Carers](#)

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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



🔍 Type here to search



16:16

18/08/2021



22

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



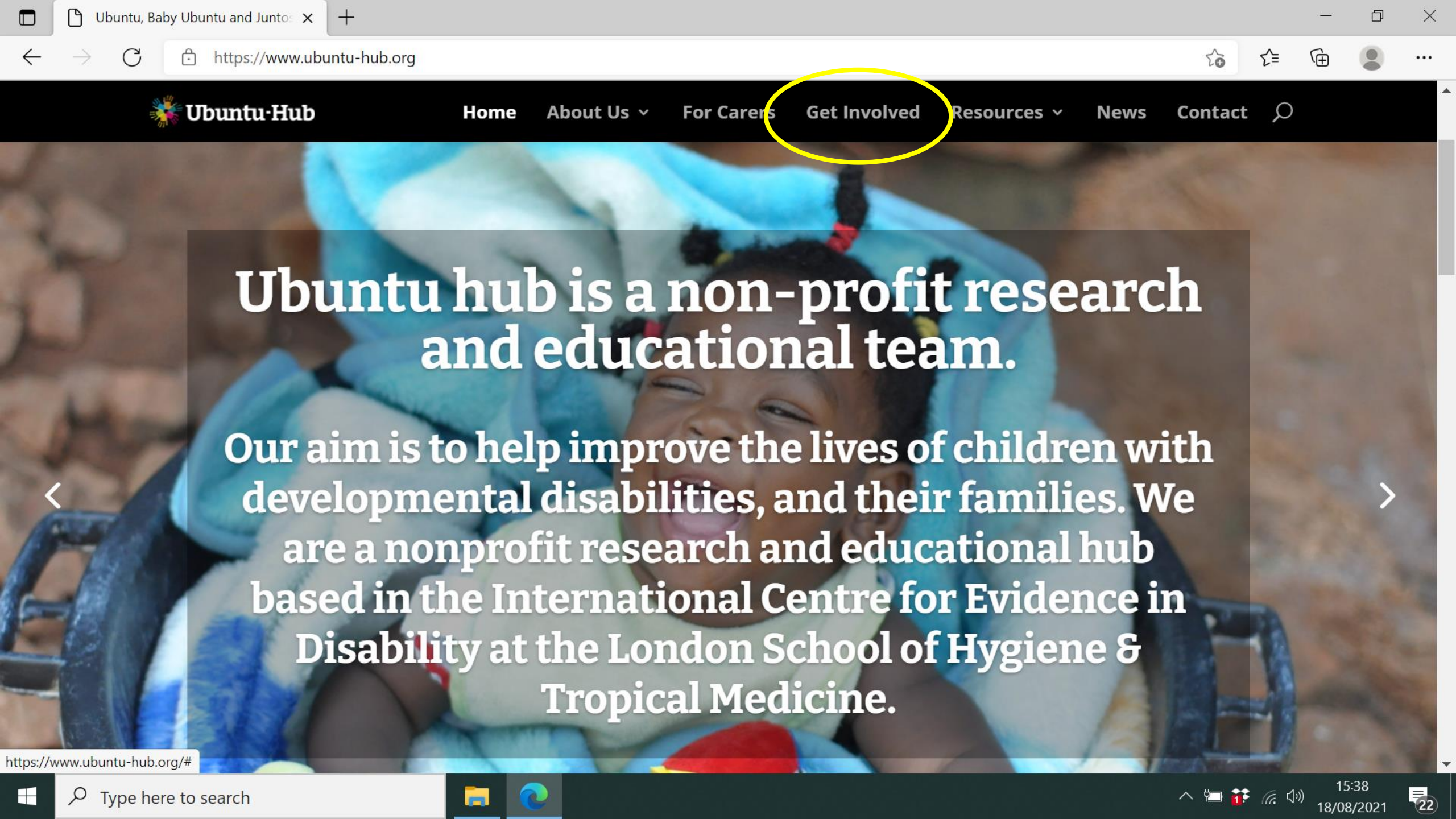
Help your child wash and stay clean



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?

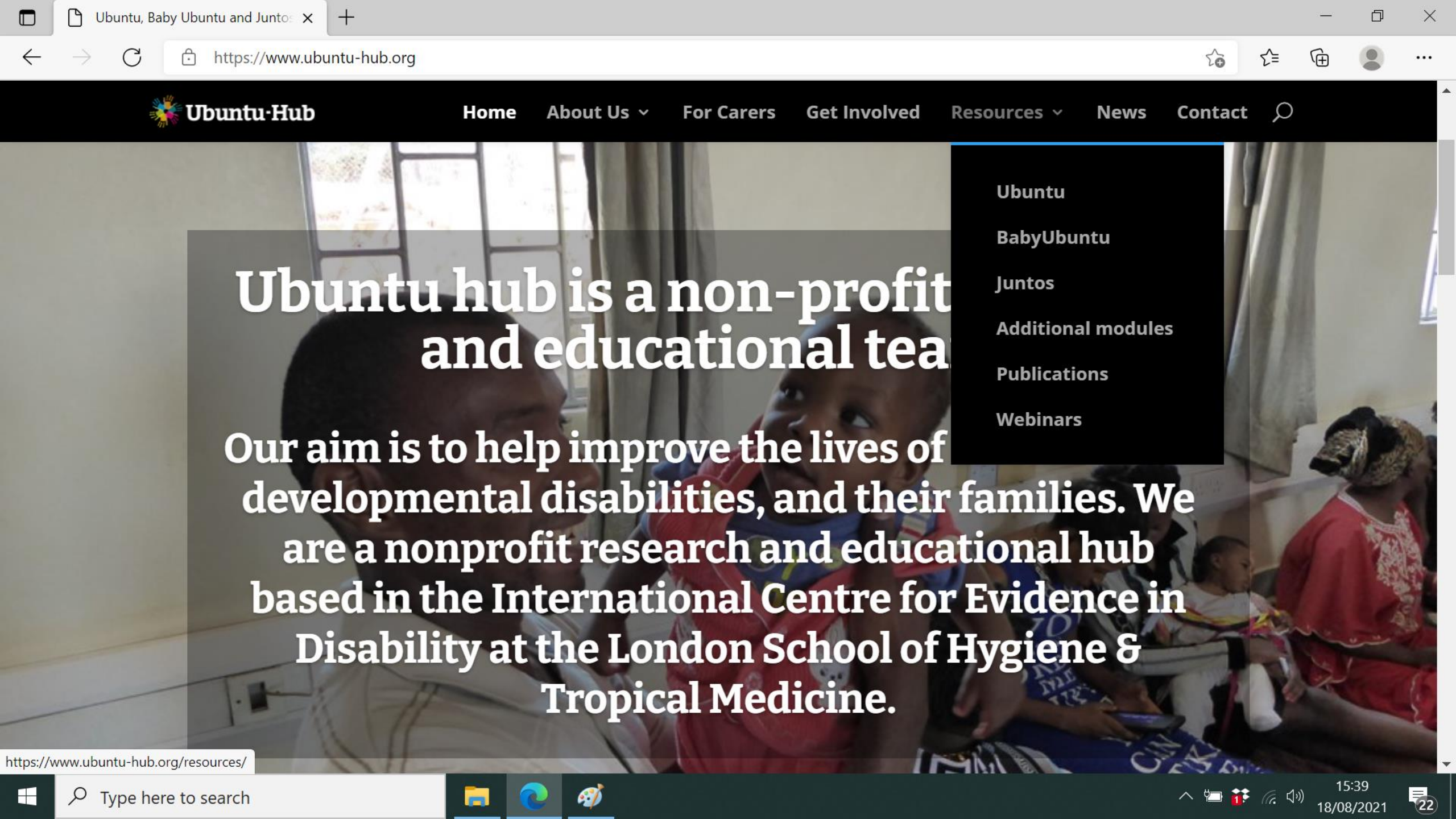
We share ideas and exchange knowledge through:

- 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](#)



Ubuntu

BabyUbuntu

Juntos

Additional modules

Publications

Webinars

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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/updates/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
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Ubuntu

LIST OF MODULES



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LET'S GET STARTED

1

**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

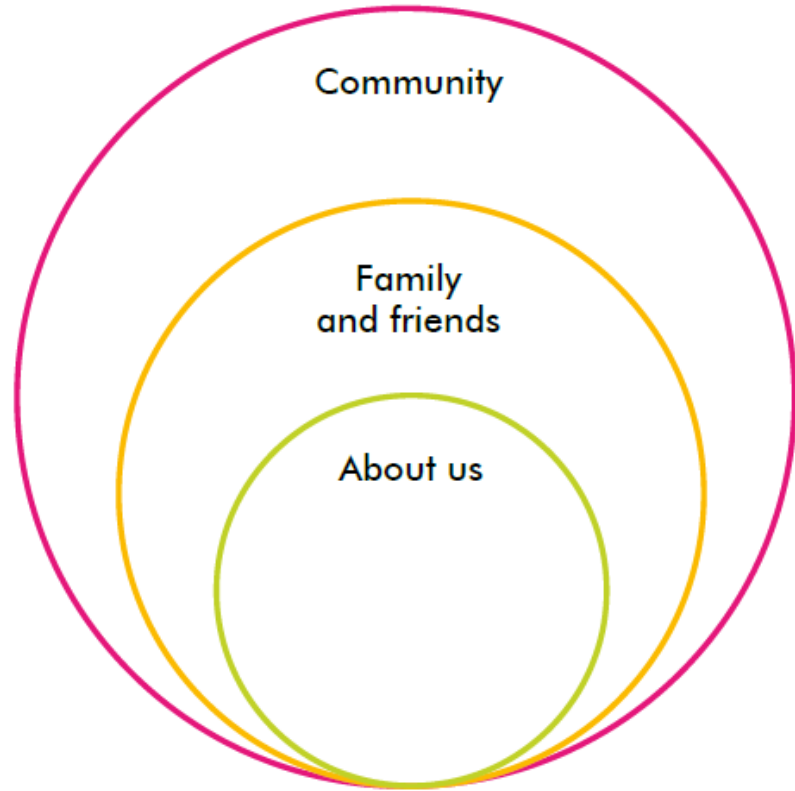
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Our support

Barriers in the community



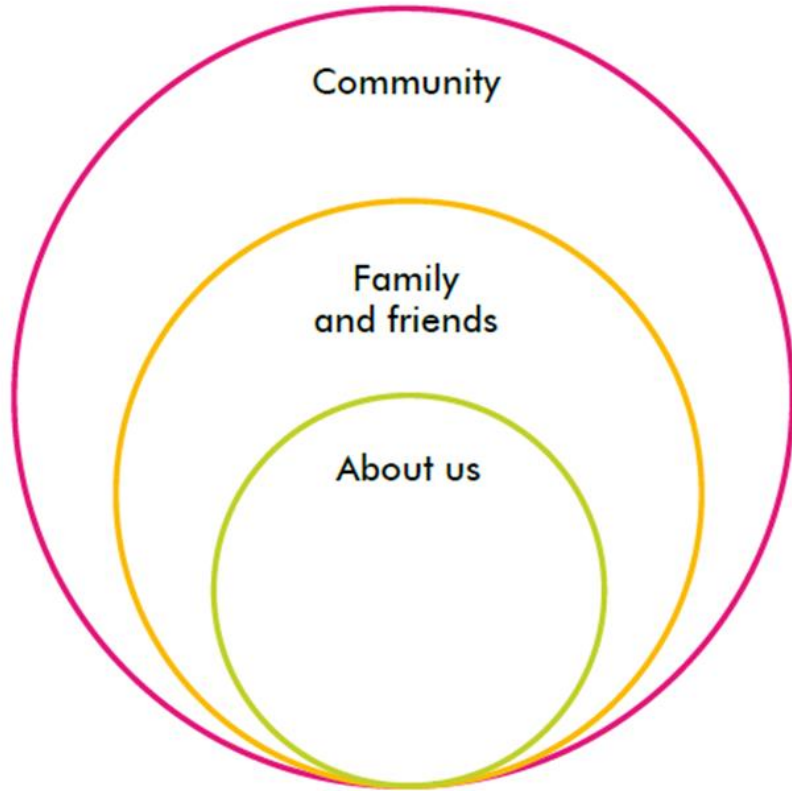
Daily activities

Goals and dreams



Our support

Barriers in the community



Daily activities

Goals and dreams

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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DEVELOPMENT CHART: Movement		
Head and body control	 <p>Lies on stomach and holds head up</p>	 <p>Rolls from stomach to back</p>  <p>Pushes self into sitting</p>
Sitting	 <p>Sits with support</p>	 <p>Sits alone</p>  <p>Twists and reaches</p>

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?*

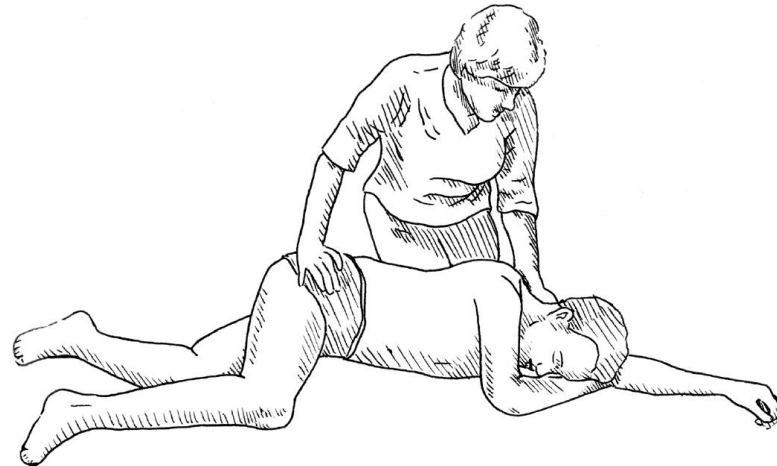
-*What should you do when your child is having a seizure?*

-Practice in pairs placing each other in this position

-Information that could be useful when consulting a health professional

-Additional general advice

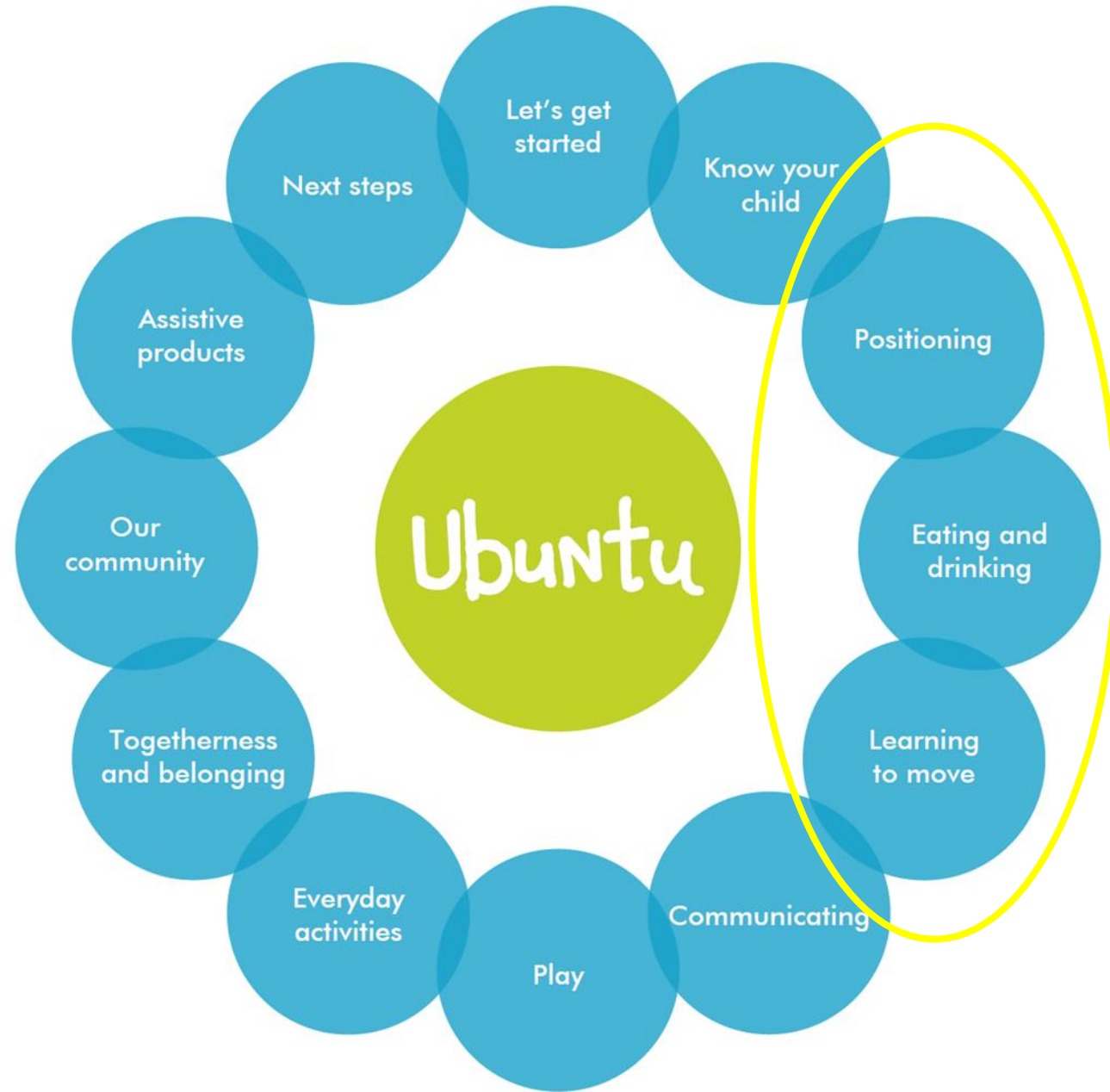
Seizures are caused by evil spirits
My child can get help and early treatment from health workers for her seizures
If my child has a seizure it is because she is cursed
Medical treatment can help my child's seizures
Other children can catch seizures from my child
Uncontrolled seizures can affect my child's 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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LIST OF MODULES





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.

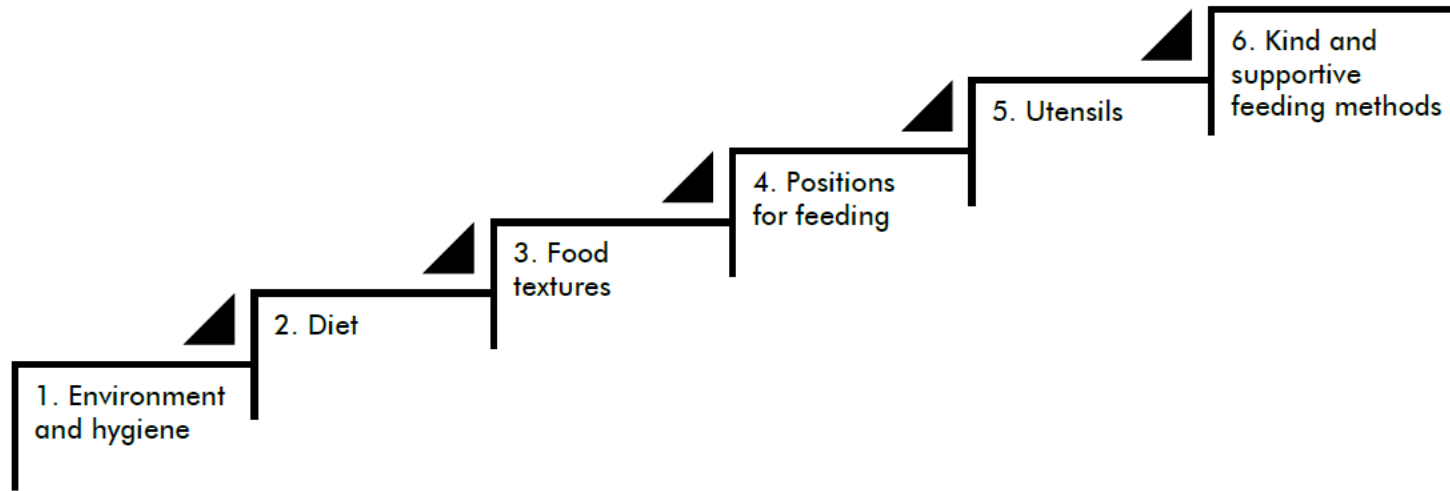


Ask

"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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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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TOGETHERNESS AND BELONGING

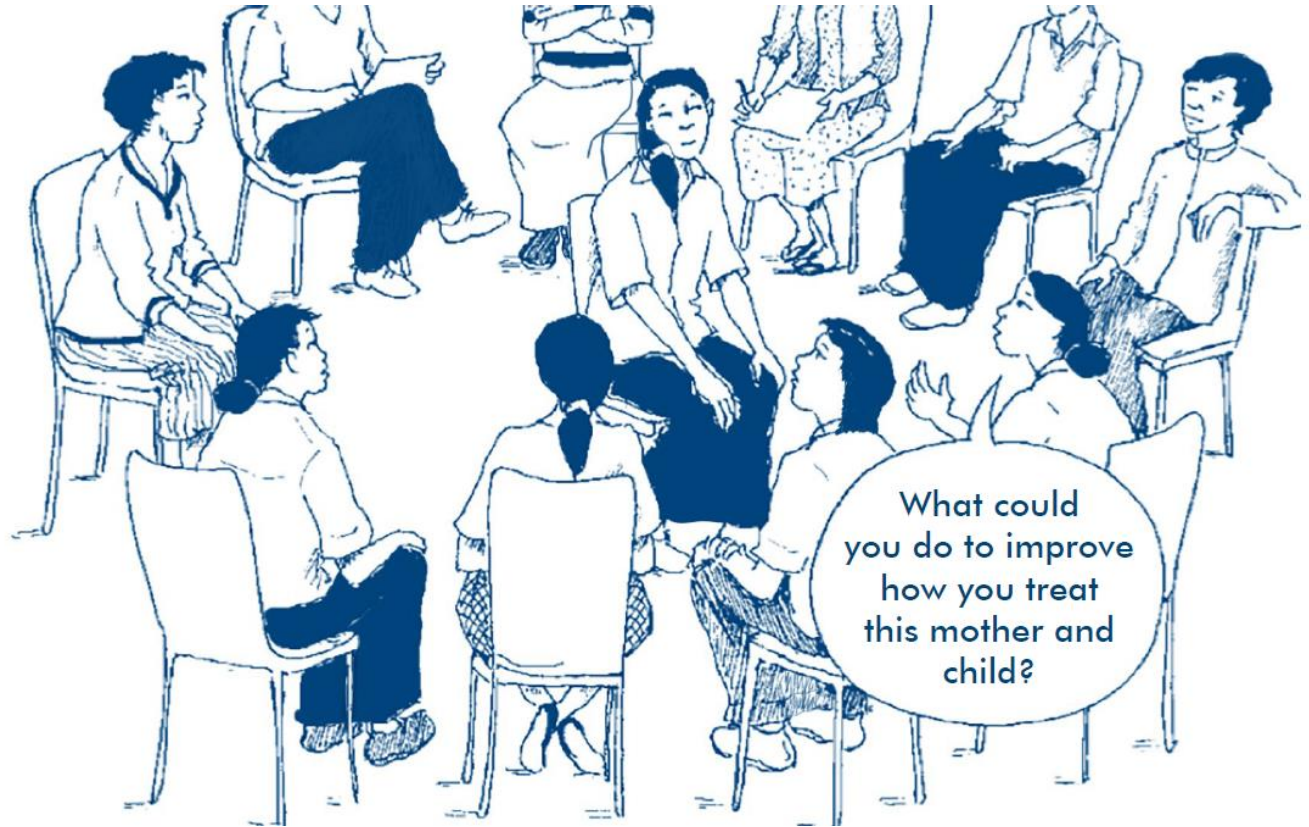
9

**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



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OUR COMMUNITY

10

**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



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- **Module 11 – assistive products**



Photo by: The International Committee of the Red Cross



Photo by: Motivation



Photo by: CECHE Foundation



Photo by: Enablement



MRC/UVRI and LSHTM Uganda Research Unit



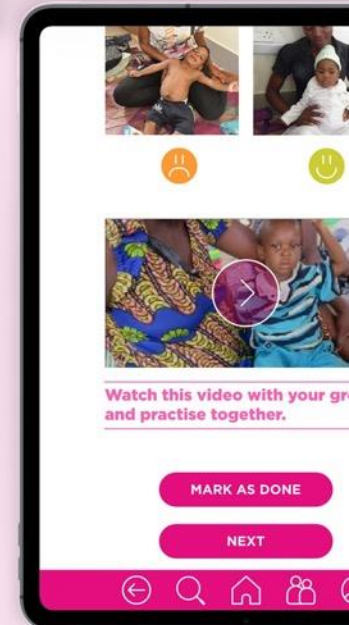
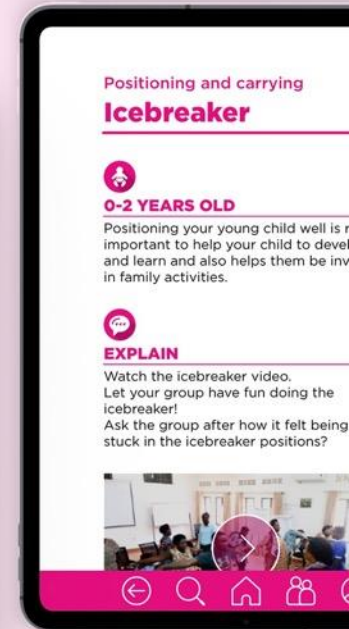
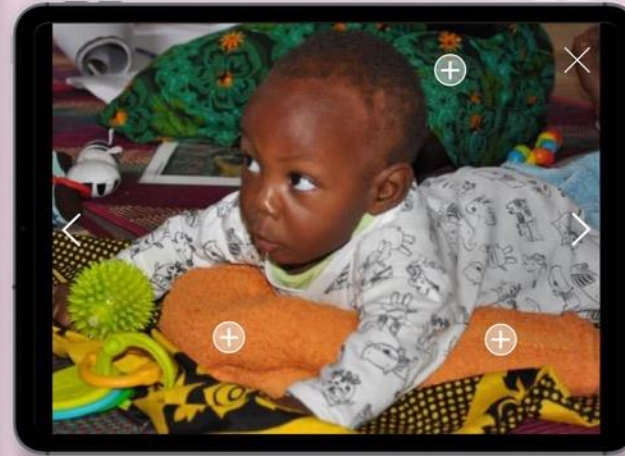


- New Branding for the ABAaNA Early intervention programme
- Early care and support
- New module – Togetherness and Belonging
- Future plans to further harmonise with Ubuntu (more inclusive to a wider range of disabilities)



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





Baby Ubuntu

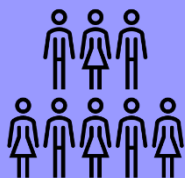
Transition to Scale

Training for fidelity

Literacy,
accessibility & fidelity

Financial impacts

Demand



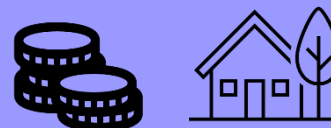
Training package

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



Tablet Application

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



Livelihood Component

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



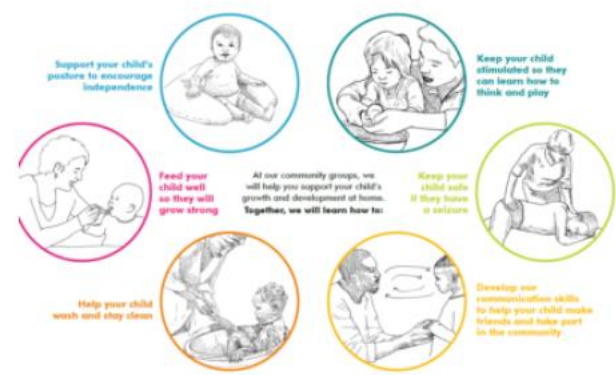
Scale-up strategy, & business model

- 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 a 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!



RESOURCES
for providers

RESEARCH
reports & journals

SUPPORT
for families & carers