

Adapting and piloting the Ubuntu parenting support program with families of children with disabilities in northern Mozambique



Background

As is common in most low- and middle-income settings, parenting programs in Mozambique do not traditionally factor in the special needs of caregivers of children with developmental delays and disabilities (CWDD). At the same time, one of the stated objectives of the current national rehabilitation plan of the Mozambique Ministry of Health is to provide caregivers of CWDD with targeted skills and support the need to care for their children.

The Ubuntu family of programs (Ubuntu, Baby Ubuntu, and Juntos) comprise a set of evidence-based interventions designed to provide parenting support to caregivers of CWDD through support groups. The programs are curated by the International Center for Evidence in Disability at the London School of Hygiene and Tropical Medicine.¹ Ubuntu programs initially focused on children with cerebral palsy but have since become inclusive of other disabilities. The programs have been shown to improve caregiver confidence and parenting knowledge, as well as peer support. This in turn improves caregiver-child interactions. Ubuntu programs have been implemented and evaluated in Bangladesh, Brazil, Colombia, Ghana, Rwanda, and Uganda.

PATH has partnered with the Monapo District chapter of the Associação dos Deficientes Moçambicanos (Association of Disabled People in Mozambique [ADEMO]) in the northern province of Nampula to strengthen their CBR program. Among the areas of technical assistance provided by PATH to ADEMO was the design and implementation of a parenting program based on the Ubuntu program to support caregivers of under-five CWDD. This was based on a 2021 assessment that showed families of CWDD had weak support networks and that less than half of them knew other families of CWDD living close by. Furthermore, nearly 10 percent of families had children with cerebral palsy or other severe conditions who required



A set of parallel bars was constructed by an ADEMO volunteer in the home of a child with a physical disability and is used for daily walking practice. Photo: PATH.

¹ <https://www.ubuntu-hub.org/resources/>

more specialized guidance on how to support positioning and feeding of their children, which ADEMO was unable to provide them with their existing capacity.

Adaptation and piloting of the Ubuntu program for Mozambique

PATH adapted the Juntos Portuguese-language Ubuntu program designed in response to the Zika virus outbreak in Brazil. Additional activities on play and day-to-day care were later added from the Ubuntu and Baby Ubuntu programs. The primary changes to the original Ubuntu content focused on adding risk factors for developmental delays and childhood disabilities specific to Mozambique; referencing locally available protein-rich foods in sections on child feeding; adapting daily self-care, such as toileting, to local realities; and promoting use of local playthings and positioning tools and available government job aids.

Each session maintained the original Ubuntu structure: checking in with the group members about any news or updates on the child or the family, introducing a new topic, demonstrating and practicing specific skills, and agreeing on tasks to try at home. Given low literacy levels among both ADEMO volunteers and caregivers of CWDD, the number of activities were limited to a maximum of three per session and the language was significantly simplified.

The final adapted program consisted of 13 sessions covering the following topics:

- Causes and risk factors for developmental delays and disabilities.
- How to calm an agitated child.
- Helping the child to position and to move him/herself.
- Helping the child to eat and drink.
- Communicating and playing with the child.
- Supporting the child with daily tasks.
- Getting health services the child needs.
- Dealing with stigma in the community.



A child is positioned stomach down on “stuffed pants” during an Ubuntu group session. Photo: PATH.

In addition, each Ubuntu session included playthings made from locally available materials, both to stimulate children and to serve as demonstration aids in activities.

To further accommodate low literacy levels of ADEMO volunteers, a gradual training model was adopted, where volunteers would meet monthly to watch a simulation of each session done by supervisors and to practice activities among themselves. Finally, we adjusted the frequency and duration of sessions. While Ubuntu programs recommend weekly or bi-weekly sessions of 3–4 hours each, this was not feasible in rural Mozambique due to caregivers living in vastly dispersed rural areas with few transport options. Instead, caregivers agreed to meet for 1.5 hours every month in a local health facility, where they could then also access other needed services.

Nearly 200 caregivers (representing 65 percent of ADEMO-supported families) took part in the first round of Ubuntu group parenting support sessions in Monapo District in 2022–2023. **Approximately 60 percent completed half or more sessions.** ADEMO supervisors observed and supported volunteers during the sessions and engaged stronger volunteers to mentor newer volunteers or volunteers with weaker skills.

Results from the pilot of adapted Ubuntu program

At the end of the first round of sessions, an assessment was carried out to check to what extent participation in the group sessions was associated with improved parenting knowledge and practices and increased contact with other caregivers of CWDD. Semi-structured interviews were conducted with 35 caregivers (among them 15 caregivers of children with cerebral palsy) who took part in half or more group sessions. During the interviews, caregivers were asked to demonstrate the practices they had learned, which were documented in writing and through photos.



A boy with cerebral palsy being fed by his sister. Photo: PATH.

Caregivers who took part in Ubuntu sessions said that they had met at least half of the caregivers for the first time when participating in the meetings. Close to 70 percent of caregivers mentioned that they now meet some of their peers outside of sessions. This number was even higher among caregivers of children with cerebral palsy, where 80 percent mentioned meeting other caregivers of children with cerebral palsy outside of the sessions. While no data was collected on caregiver sense of psychosocial support, these **more frequent interactions among caregivers** suggest a positive step toward the establishment of stronger peer networks.

Participation in Ubuntu sessions was also associated with **increased caregiver knowledge.** Over 60 percent of interviewed caregivers were able to mention common risk factors for developmental delays or childhood disabilities. In a 2021 assessment with ADEMO families close to a quarter of caregivers attributed disabilities to supernatural causes. However, only one caregiver did so in this assessment.

*“[Common causes include]: prolonged labor, illnesses of mother during pregnancy, and cerebral malaria.”
— Mother of a 3-year-old child with cerebral palsy*

Furthermore, 86 percent of caregivers were able to mention at least one locally available, protein-rich foodstuff (e.g., eggs, groundnuts, liver, or beans). This is important, considering that 45 percent of children supported by ADEMO are acutely malnourished.

“The most important part of the meetings was to learn to make dishes with greens and groundnuts, give food without too much sugar, give eggs, liver, and grasshoppers.” — Father of a 3-year-old child with a physical disability

Caregivers who took part in Ubuntu sessions started adopting some of the techniques promoted in the program to position children who were unable to sit on their own for feeding, play, or other activities. They did so by using plastic basins, “stuffed pants,”² and their own bodies. Caregivers reported that

² “Stuffed pants” are normal pants filled with cloth or hay and are used to help support a child (usually under the age of two years) who is not able to sit independently or who lacks arm and chest strength to lift her/himself when on the tummy.

these techniques allowed them to do more of their chores and also permitted their children to play and to interact with others.

“I learned how to make the child sit with support of ‘stuffed pants.’ The child is already sitting on his own and is eating by himself; is able to pick something with his hands and to play.” —Grandmother of a 5-year-old child with cerebral palsy

However, demonstrations revealed that **only a portion of the caregivers used positioning strategies correctly**. In many cases, the spine or head were not adequately supported and as a result, the child did not have her/his hands free. As caregivers used materials available at home, in some cases the plastic basins used for positioning were too small for the size of the child, or the “stuffed pants” were not high enough to effectively support a child to sit.

Over 90 percent of caregivers were able to demonstrate playing and talking with their children and were able to show playthings home that had been developed from locally available materials.

However, there was a tendency to simply give playthings to the child and for them to play alone.

When caregivers did engage in play, it was mostly to kick the ball, play with dolls or cars, or pretend to cook something together. Caregiver play with children with cerebral palsy was very limited (e.g., no playthings were given to children who were not yet sitting on their own and games were mostly focused on bouncing the child and drumming on different surfaces).

While interactions between caregivers and their children were generally very warm and joyful, the **conversations were largely limited** to asking the child to do something, bring an object, or point to someone on request (e.g., asking the child: “Where is papa?”). Only 2 of the 35 caregivers observed engaged in more free-flowing conversations with their children. Conversations with children with cerebral



A child with cerebral palsy correctly positioned by her caregiver in a plastic basin. Photo: PATH.



A child playing with homemade car and shaker. Photo: PATH.



A grandmother is calling her grandson by his name and waiting for his response. Photo: PATH.

palsy were even more limited, mostly consisting of calling the child by name, naming some objects in the vicinity, or informing the child what they are about to do (e.g., “It’s time to eat”).

Conclusions

Overall, the initial assessment of the adapted Ubuntu program in northern Mozambique suggested several benefits to caregivers of CWDD (e.g., increased interactions with other caregivers of CWDD, improved knowledge about childhood disabilities and protein-rich foods, and increased use of calming, positioning, and feeding techniques). The interactions between caregivers and children were observed to be warm and positive and CWDD generally had access to a range of playthings in their homes.

At the same time, caregivers living in remote rural areas need to be motivated to attend group sessions more consistently. This may be done by combining Ubuntu sessions with additional services such as savings and loans, cooking demonstrations, and birth registrations.

Furthermore, caregivers of children with cerebral palsy need additional capacity-building to effectively position their children for sufficient head and spine support that also permits hand movement and self-feeding. Caregivers also require support for developing low-cost positioning devices with locally available resources. In addition, play with objects needs to be promoted for children with cerebral palsy and more extensive conversations between caregivers and children should be encouraged in all families with CWDD.

Next steps

The lessons learned from the first round of piloting the Ubuntu program are being incorporated into ongoing work. Namely, during monthly Ubuntu training meetings, ADEMO facilitators review assessment findings relevant to specific sections and make needed adjustments.

Additionally, as a follow-up to the assessment, ADEMO has reached out and partnered with a Mozambican association that has expertise in producing low-cost positioning devices and is being trained on production of such devices using locally-available materials such as bamboo and cardboard.

One of the remaining gaps is a need to identify what content should be added to Ubuntu program around adequately supporting children with cerebral palsy with toileting and other hygiene needs, in the context of the absence of latrines in many families’ homes and current suboptimal toileting practices.

After the second round of piloting, lessons learned will be used to revise the Ubuntu manual and associated job aids further, which will subsequently be shared with governmental and nongovernmental partners working in CBR. Finally, PATH will support ADEMO to seek funding for carrying out a more rigorous evaluation of the adapted and piloted Ubuntu package in order to generate evidence that may lead to its wider adoption within and outside the country.

Learn more

To learn more about ADEMO’s and PATH’s work on children with developmental delays and disabilities, contact us at integratingecd@path.org.