

Improving identification, referrals, and treatment of children with disabilities in Mozambique through a community-based model linked to primary health care



Background

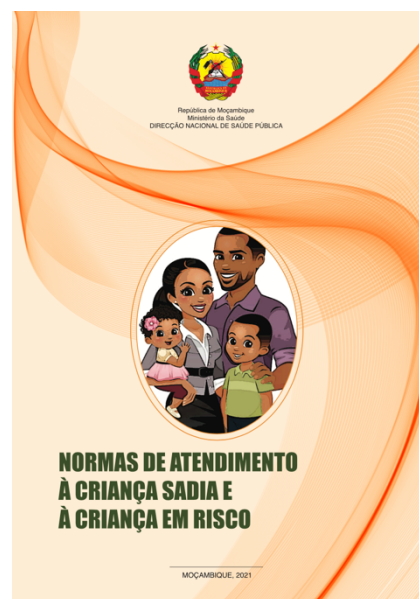
It is estimated that 10 percent of under-five children in sub-Saharan Africa have a developmental delay or disability.¹ The recent Demographic & Health Survey (DHS) in Mozambique has identified that 5 percent of children 2–4 years have functional difficulty in at least one area such as vision, hearing, walking, using fingers for manual tasks, communication, learning, playing, or exercising self-control.² Major risk factors known to be associated with such functional difficulties—and more generally with developmental delays and disabilities—in Mozambique include birth-related complications (postpartum asphyxia, premature birth, low birth weight, jaundice, neonatal sepsis, and birth trauma), congenital birth defects, severe malaria, and acute malnutrition.³

With financial support from the Conrad N. Hilton Foundation, PATH has provided technical assistance to Mozambique's Ministry of Health since 2014 to improve monitoring, detection, and referral of children with developmental delays and disabilities (CWDD). It supported development of milestone charts, revision of child health registers and consultation guidelines, and training of health providers to conduct developmental monitoring and refer cases of suspected developmental delays and disabilities. In 2019, PATH went a step further and partnered with the Monapo District (Nampula Province) chapter of a national organization of people with disabilities (ADEMO). PATH provided technical assistance to ADEMO to improve identification, referral, and treatment of CWDD beyond what can be achieved through the health sector alone.

Supporting identification of developmental delays and disabilities in under-five children

Monapo is the second largest district in Nampula, the most populous province of Mozambique. It has an estimated 67,000 under-five children. According to DHS, in Monapo, one could expect to find over 2,000 children 2–4 years with some functional difficulties. Prior to 2019, ADEMO had identified and was supporting 53 under-five CWDD in the district. Through PATH's technical and financial support to ADEMO, over the next five years, the number of under-five children identified with developmental delays and disabilities increased by more than fifteen times to 832. This was made possible through:

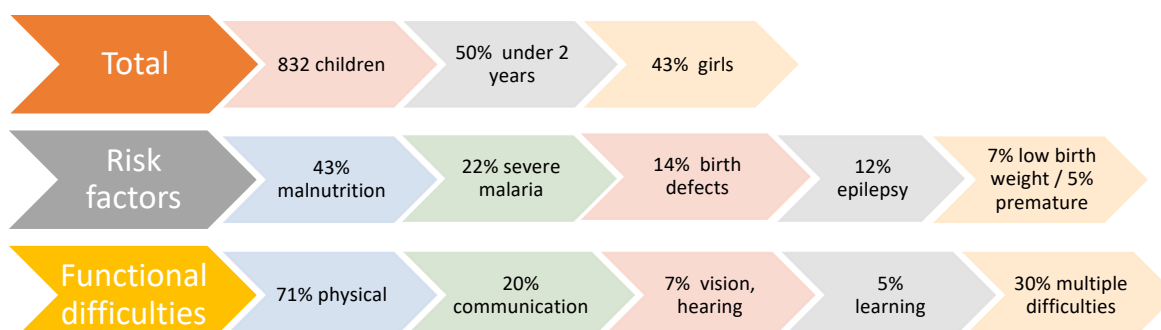
- Expanding the network of ADEMO volunteers from 7 to all 17 health subdivisions of Monapo District.



Mozambique national well-child and at-risk-child service guidelines (2021) with updated developmental monitoring protocol.

- Training and mentoring ADEMO volunteers to identify developmental delays, birth defects, and disabilities.
- Strengthening collaboration between ADEMO volunteers and local health services.
- Engaging community leaders to help identify CWDD in their communities.
- Families of CWDD seeking out ADEMO volunteers as their work became more known.

Among under-five children with functional difficulties identified by ADEMO volunteers between May 2019 and June 2024, acute malnutrition and severe malaria appear to be the most prevalent risk factors, followed by birth defects and epilepsy, as confirmed by medical outreach brigades. Additionally, the most common functional difficulties are physical difficulties followed by difficulties in communication and vision and hearing. Importantly, 30 percent of children with functional difficulties present more than one difficulty.



Characteristics of risk factors and functional difficulties in under-five children identified by ADEMO in Monapo District.

Supporting referrals of children with suspected delays and disabilities

Physiotherapy data collected in October 2017–September 2018, prior to PATH supporting ADEMO, was retrospectively analyzed as the baseline along with endline data collected by ADEMO and PATH in May 2023–April 2024. This data showed that **the number of children entering physiotherapy annually had almost tripled** during this period and that the average number of children entering physiotherapy each month had increased from 4 to 10. This is not surprising, as close to 60 percent of children identified by ADEMO volunteers with developmental delays or disabilities had never been referred to a health facility.

Additionally, while only three of the health facilities in the district (19%) at baseline were referring children with suspected delays and disabilities, **at endline, nine health facilities (53%) were referring children to physiotherapy**. This can partly be attributed to ADEMO’s strategy of allocating a volunteer in each health area and strengthening direct linkages between ADEMO volunteers and their local health facilities.

In addition, there were changes in the most common risk factors associated with developmental delays and disabilities recorded in physiotherapy registers at baseline versus endline. At baseline, birth defects (40%) and birth trauma (24%) represented the bulk of cases. **At endline, three additional risk factors were frequently reported**—namely, birth asphyxia (24%), severe malaria (11%), and acute malnutrition (6%)—which suggests improvements in both identification and record-keeping on CWDD.

Timeliness of referrals did not change for birth trauma cases at baseline versus endline, with about half of all cases being referred in the first month after birth in both instances. However, **certain birth defects, such as club foot, were now detected and referred earlier**. For example, at baseline, 25 percent of club foot cases were referred within the first month after birth; this number increased to 40 percent at endline.

Supporting treatment of children with confirmed delays and disabilities

A data analysis exercise conducted by PATH in 2020 demonstrated that among CWDD identified at primary health care level and referred to specialists, only 19 percent had completed the referral or followed the course of treatment prescribed by the specialist. The primary challenges included the large distances between communities and referral facilities and associated transport costs, as well as the high frequency of required visits to see a specialist.



A physiotherapist examines the physical development of a child during a mobile outreach brigade. Photo: PATH.

ADEMO and PATH put in place several strategies to improve treatment of children identified with developmental delays and disabilities. The first strategy was to **provide a transport subsidy to families of CWDD living in remote areas to access needed services and treatments** at a referral facility. Over 30 percent of families used this subsidy to access referral services.

Additionally, **mobile outreach brigades**, consisting of a medical doctor, nutritionist, and physiotherapist (and occasionally, a psychologist), were organized to reach families of CWDD living in remote areas by providing the necessary services at their nearest health center. ADEMO volunteers usually shadowed these outreach visits to understand how to continue supporting the families at home.

ADEMO also advocated with district health and social action services to **make anti-epileptic medicine available for children in remote health facilities**. As a result, the number of health facilities stocking the medicine has increased from three to eight.

“[The child is improving] because he is getting epilepsy treatment at the hospital and receives visits from the volunteer.” (Mother of a two-year-old child with epilepsy and speech difficulties)

For more difficult cases, where treatment was not available within the district, ADEMO **collaborated with the district hospital to secure inter-hospital referrals** to the next level of care (e.g., in case of macrocephaly and other cases requiring surgeries); or liaised with a partner supporting specific services at the referral hospital (e.g., in case of club foot treatment). As an example of the latter, a partnership with Hope Walks has resulted in all children identified with club foot being supported to receive regular treatments at the Nampula Provincial Hospital’s dedicated club foot clinic.

ADEMO has also scaled up **support for families in their communities**. ADEMO volunteers conduct home visits where they help families practice the exercises demonstrated by specialists in referral facilities, model play and communication activities, support caregivers to produce assistive devices using locally-available materials, and provide counseling on nutrition and hygiene. In 2024, ADEMO partnered with Orebacom, a local organization in central Mozambique, to learn how to produce positioning devices for children with cerebral palsy. The aim of this collaboration is to ensure that all children in Monapo with cerebral palsy can have access to such devices in their homes, produced in ADEMO’s workshop.

Additionally, recognizing the importance of caregiver mental health and peer support, and the absence of a network of caregivers of children with disabilities in Monapo, since 2023, ADEMO volunteers convene caregivers every month to share news, support each other, and learn new ways of addressing their children’s special needs. The sessions, based on the global Ubuntu program,⁴ have been attended by 60 percent of all caregivers of CWDD served by ADEMO.

“[My child improved] because I was going to physiotherapy, did massage at home, and took part in group meetings.” (Mother of a two-year-old child with cerebral palsy and demonstrating insufficient growth)

Remaining gaps and future directions

Over 90 percent of caregivers interviewed as part of an assessment in 2023 perceived improvements in their children’s conditions. When asked what they thought had made the biggest difference for their children, most caregivers attributed the improvements to both ADEMO’s efforts and to the health services.

“It was because of the support of the volunteer and tireless trips to physiotherapy.” (Grandmother of a five-year-old child with cerebral palsy)

However, a few gaps remain, which can form the basis of future work. One challenge is to **increase the use of preventive services**, especially in remote areas. Most families go to a health facility only when the child is sick or undergoing treatment. Uptake of preventive services is low, and the situation is aggravated by the fact that many families (40 percent among ADEMO-supported families) do not have national health cards. As a result, it is not possible to track uptake of preventive services and remind families to access them in a timely manner. ADEMO is already working with a district nutritionist to obtain health cards for the families that they support. Subsequently, training of volunteers on the health card and on how to use it to motivate families to access preventive services is being planned.

For referrals, while birth asphyxia cases are now being tracked in physiotherapy registers, most children with this condition are referred starting only from the age of six months (i.e., the age by which they are expected to be sitting). Although over 10 cases of birth asphyxia were recorded in the main district health center in the past six months, none of these cases were referred to physiotherapist. Similarly, while premature children are advised to start physiotherapy as soon as possible, only one case of prematurity was recorded in the physiotherapy register in the past year, despite six premature births recorded in the main district health center, alone, in the past six months. Therefore, it is critical that **early referrals of children with risk factors for delays and disabilities be promoted at maternity and as part of newborn care**.

Finally, certain treatment approaches such as those requiring inter-hospital referrals—especially for difficult conditions such as macrocephaly—are yet to yield expected results. Lack of communication on part of hospital staff to the families and long waiting times to receive services lead many families to abandon the referral hospital and return to their community. There is a need to **train and position volunteers to receive and support families who arrive at referral hospitals**, help them navigate registration and treatment process, sensitize hospital staff to provide timely updates to families, and ensure that families obtain the necessary social and practical support while they are away from home.



An ADEMO volunteer demonstrating a stimulating activity during a home visit. Photo: PATH.

¹ Global Research on Developmental Disabilities Collaborators. Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet*. 2018;6(10):E1100-E1121.

² Mozambique Demographic Health Survey 2022-2023.

³ Normas de atendimento à criança sadia e à criança em risco, MISAU, 2021.

⁴ <https://www.ubuntu-hub.org/resources/>