

# Integrating rehabilitation into health systems: lessons learned from the National Clubfoot Programme Uganda

## Policy Brief – January 2024

Affecting one in every 800 children, clubfoot is one of the world’s most prevalent birth conditions.<sup>i</sup> Although curable, it is estimated that up to 85% of children in low- and middle-income countries LMICs remain unreached,<sup>ii</sup> leading to lifelong disability. Common challenges in LMIC clubfoot treatment programs include a lack of supplies, a shortage of health care professionals, a lack of space in clinics, limited time to provide treatment due to competing demands, a lack of training, and missed opportunities to diagnose at birth.

The prevalence of clubfoot in Uganda is estimated to be between 1.2<sup>iii</sup> and 1.4<sup>iv</sup> per 1,000 live births. Uganda has a long legacy of supporting clubfoot treatment. The first national clubfoot treatment program began in 1999, with several iterations of the program supported by different donors at different levels of scale over time. In 2011, the previous Uganda Sustainable Clubfoot Program was transitioned fully from external donor support to the Government of Uganda, initiating a gradual decline in service availability due to the lack of service integration into the health system and limited financial sustainability. The current clubfoot treatment program is the National Clubfoot Programme of Uganda (NCPU), which began in 2017 and aimed to revitalize clubfoot treatment through strong integration into the health system.

Learning, Acting, and Building for Rehabilitation in Health Systems (ReLAB-HS), funded by the United States Agency for International Development (USAID), supports the strengthening of health systems that are responsive to the growing needs for rehabilitation within populations. ReLAB-HS focuses on integrating rehabilitation and AT services across all levels of care within health systems. To learn from the NCPU and how it is integrated into Uganda’s health system, ReLAB-HS conducted a qualitative analysis. The study conducted 59 key informant interviews with health care providers, hospital administrators, caregivers, and other stakeholders. ReLAB-HS used the World Health Organization’s (WHO) health systems building blocks framework<sup>v</sup> to organize the findings, including community engagement as a critical component of service delivery.

**This brief provides an overview of the study findings, identifies opportunities for strengthening clubfoot care in Uganda, and outlines broader strategic considerations for strengthening the integration of rehabilitative services into health systems.**

## About the National Clubfoot Programme of Uganda

The NCPU provides clubfoot treatment via a tripartite memorandum of understanding between the Ugandan Ministry of Health (MoH), MiracleFeet (an international nongovernmental organization), and the local implementing partner (at the time of this study, CoRSU Rehabilitation Hospital, and now World Alliance for Lung and Intensive Care Medicine in Uganda [WALIMU], a Ugandan nongovernmental organization). By the end of 2023, the NCPU had supported clubfoot

treatment in 26 public and five private secondary- and tertiary-level hospitals, reaching 4,390 children since 2017.

The NCPU represents an innovative approach to integrating rehabilitation services into the health system in a low-income country. In public hospitals, clubfoot treatment is provided by public sector health care providers (primarily orthopedic officers) using existing clinic space and infrastructure. At least one provider in each facility is also trained as a parent educator to ensure that parents are informed about clubfoot and the treatment process. The National Medical Store provides required supplies (e.g., gloves, plaster, soft roll/undercast padding) and has integrated these into the hospital's procurement system. MiracleFeet funds the procurement of foot abduction braces. In partnership with the MoH, MiracleFeet and the local implementing partner also provide in-service training and supervision visits.

Clubfoot service data is entered in several formats. Facilities maintain a dedicated register for clubfoot patients and also record visits in their standard outpatient registers. This ensures that clubfoot data is included in health facility monthly reports. In addition, MiracleFeet provides mobile phones with the CAST mobile health application to providers who treat clubfoot. CAST offers appointment tracking, decision-making support for treatment, and comprehensive longitudinal medical records for patients.

## Strengths and challenges of the program

The NCPU fills critical gaps in the public health care system to expand access to clubfoot treatment services while fostering country ownership by providing services in public hospitals. These strengths demonstrate important aspects of designing a rehabilitation intervention in the Ugandan context. However, program stakeholders also identified several challenges, many of which reflect broader health systems challenges and/or the socioeconomic vulnerability of many clubfoot patients and their caregivers.

## Governance and Leadership

A key strength of the NCPU is **leadership from the MoH** and its commitment to maintaining the program. However, this commitment does not automatically translate to increased resource allocation or policy prioritization. In general, participants indicated that orthopedic workshops (where clubfoot services are provided at the health facility) are **unfunded priorities in the government budget** and thereby require external financing to provide services.

## Financing

Caregivers universally appreciate that the program offers free services and foot abduction braces. MiracleFeet and the MoH cover most of the costs of the NCPU, **reducing out-of-pocket payments required by patients and their caregivers**. However, lack of clarity on the unit costs for treatment is a barrier to sustainability planning and budgeting for increased scale-up. This study **estimated that for every \$1 the MoH spends on clubfoot care, MiracleFeet spends \$1.61**; however, these costs were largely based on expert opinion and reference cases from other countries. Efforts to estimate the unit cost of delivering clubfoot treatment proved challenging due to the unclear nature of costs at the hospital level and a considerable degree of variation in per-patient costs. This was due to a large variance in the time spent by health care providers and in the number of procedures each patient requires.

## Service Delivery and Community Engagement

Clubfoot providers and caregivers overwhelmingly described **respectful, patient-centered care**. Examples included accepting walk-in referrals during non-clubfoot clinic days; screening children for other conditions while receiving clubfoot care (including other disabling conditions, nutrition, and general health and wellness); connecting caregivers to social workers; and providing caregiver education on clubfoot and its treatment processes. In addition, caregivers and health care providers alike recognized **the important role of parent educators** in preparing parents for prolonged treatment processes, offering comfort and encouragement throughout the treatment process, and encouraging continuity of care and regular clinic attendance.

However, the **early identification of clubfoot patients continues to be a challenge**. Participants attributed the high number of missed cases to low awareness of clubfoot among maternal and child health providers and village health teams. Some children are identified via immunization days and within maternal and newborn care; however, all participants indicated that this needed to be systematized and strengthened.

Once patients are identified and enrolled in treatment, clubfoot treatment is provided at secondary- and tertiary-level facilities. Services are consolidated at these levels of care because each hospital needs to maintain adequate clinical volumes for providers to maintain their skills. However, providing services in hospitals results in **long travel times and high transportation costs to access clubfoot clinics for many patients and their caregivers—a major barrier to treatment continuity**. Caregivers described considerable challenges to sustaining the cost of regular transport to conduct brace reviews at the hospital. Providers described patients who regularly reach the clubfoot clinic after hours due to lengthy travel times on public transportation.

Caregivers and providers both described high rates of **household poverty, stigma, and domestic violence** as barriers to treatment. Both groups relayed that mothers who give birth to children with clubfoot are particularly vulnerable to **societal and family stigma**. This stigma can limit a caregiver's ability to access the financial resources needed to travel to clubfoot clinics, exacerbating barriers to treatment adherence.

Despite these challenges, participants indicated that there was **increasing awareness of clubfoot** within communities, leading to an increase in self-referrals and a growing number of children starting treatment.

## Human Resources

The study identified several **provider-implemented efforts** to increase referrals and enroll more children. These included sensitizing non-orthopedic providers (e.g., midwives, nurses) in the catchment area to identify children with clubfoot, developing informational leaflets to improve caregiver education, hosting educational sessions at nursing schools, advertising free services at lower-level health facilities, and running parent support groups during clinic days. This finding demonstrates health care providers' commitment to increasing treatment of clubfoot in their communities.

Despite this commitment, several providers indicated that **staffing clubfoot clinics, in addition to addressing other patient orthopedic needs, can be challenging** because clubfoot treatment requires two trained providers for each patient at a time. They conveyed that the ability

to provide high-quality treatment to patients is limited when one of the two providers has to support other orthopedic services on a clubfoot clinic day.

## Supplies and Equipment

Though clubfoot supplies are integrated into the public procurement system, nearly all providers experience **frequent stockouts**. Several participants described that the limited orthopedic supplies available in regional referral hospitals are commonly diverted to trauma patients (especially road traffic injuries), reducing supplies for clubfoot. Most supply gaps are filled by MiracleFeet. This limits the impact of stockouts on service provision but hinders the integration of the NCPU into the health system and undermines sustainability.

## Health Information Systems

Providers universally appreciated the CAST mobile health application as a means to improve service quality and continuity of care. However, CAST data is not integrated with the national health management information system, and providers still maintain duplicate registries for national reporting.

## Call to Action: how can these findings be used to strengthen rehabilitation services?

### Opportunities to strengthen clubfoot treatment

**Financing:** Explore a combination of innovative financing models, mechanisms to improve efficiency, and more transparent financial information systems. Clearly defining and systematically tracking the unit costs of clubfoot treatment are important first steps to improving efficiency and are essential inputs for sustainability planning. There may be opportunities to leverage the CAST application for cost management, budgeting, and supply management, and the digitization of paper registers via CAST could improve efficiency.

### **Service Delivery and Community Engagement: Strengthen and formalize the screening and referral system to improve early detection and initiation of treatment while reducing geographic barriers to access.**

- **Ensure clubfoot is included in pre-service and in-service training programs.** A critical first step is expanding awareness of clubfoot among other health care providers working with newborns and children under two. Opportunities include formalizing the inclusion of clubfoot in pre-service training programs, particularly for midwives, including clubfoot in health care providers' continuing medical education and integrating training on clubfoot into village health team training programs. Integrating clubfoot identification into training programs has already been identified as a key opportunity by the NCPU, and this study's findings further emphasize its potential.
- **Integrate clubfoot screening into protocols for services with the same patient population.** Institutional delivery and routine immunization are two high-potential services where screening for clubfoot could be integrated into existing service protocols. Some caregivers and providers indicated that children were referred from immunization programs, suggesting that this could be a feasible pathway to increase early detection.
- **Explore telemedicine solutions to bring services closer to patients.** Remote monitoring of children in the bracing stage of treatment could reduce the burden of follow-up visits to hospitals, improving patient adherence.

## Strategic considerations for integrating rehabilitation into health systems

This study demonstrated the trade-offs facing rehabilitation programs: increasing integration of rehabilitation services into health systems can expand access to care; however, these services are also subject to the existing weaknesses of the health system.

Study findings highlight the importance of taking a “diagonal” approach to the integration of rehabilitation services into health systems. This approach ensures that funding and technical support for specific health care interventions or conditions are leveraged to strengthen the overall health system. This is particularly important in low-resource settings where weaknesses in the health system limit the integration of new services.

**Governance and Leadership:** A key component of the NCPU’s success has been a continual, long-term commitment to integration within the health system and the careful building of stakeholder trust in and commitment to the program. Service integration relies on strong stakeholder engagement in all phases of the process to foster ownership.

### **Service Delivery and Community Engagement:**

- **Engage non-rehabilitation health care providers.** Integrating rehabilitation into the health systems requires a continual focus on non-rehabilitation health care provider awareness and an explicit strengthening of the referral system to ensure patients are identified.
- **Program planners and managers should introduce demand and supply interventions simultaneously when integrating new rehabilitation services into service delivery packages.** On the demand-side, both initial access to and continued participation in rehabilitation services are likely to be heavily influenced by socioeconomic and community-level factors. Improving geographic access and reducing societal costs (e.g., transportation, travel time), are key to enabling adherence and improving patient outcomes. As community awareness increases and demand is generated, the supply side must be ready to accommodate increasing referrals. This is particularly challenging for longer-term treatments such as clubfoot, in which the number of patients receiving care grows considerably before patients “exit” treatment, requiring an increase in human resources, clinic space, and supplies.
- **Plan for a higher-than-expected number of “complex” cases.** Limited service availability, low awareness, and high access barriers often prevent early detection and treatment for many conditions that could benefit from rehabilitation. This may result in a higher-than-expected number of complex cases when compared to higher-income settings.

**Human Resources:** Especially in low-resource settings where human resources are limited, careful planning is required **to measure the increase in per-provider time required to provide a new service.** This is particularly important to avoid reducing the available human resources for existing services.

**Health Information:** Mobile health applications are appreciated by health care providers. However, it is critical that new applications are designed for interoperability, both across services provided in the health facility and with other health management information systems, and that implementation of these tools strengthen the overall health information system.

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- <sup>i</sup> MiracleFeet. "About clubfoot." Accessed February 17, 2021. <https://www.miraclefeet.org/about-clubfoot>
- <sup>ii</sup> Owen, R.M., B. Capper, and C. Lavy. "Clubfoot Treatment in 2015: A Global Perspective." *BMJ Global Health* 3, no. 4 (September 3, 2018): e000852. doi:10.1136/bmjgh-2018-000852. PMID: 30233830; PMCID: PMC6135438
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- <sup>iv</sup> Mumpe-Mwanja, D., Barlow-Mosha, L., Williamson, D. et al. "A hospital-based birth defects surveillance system in Kampala, Uganda." *BMC Pregnancy Childbirth* 19 (2019): 372. doi:10.1186/s12884-019-2542-x.
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## Our partners

