Learning, Acting, and Building for Rehabilitation in Health Systems

Integrating rehabilitation into health systems: Lessons learned from the National Clubfoot Programme Uganda
Background

• Clubfoot impacts every 1 in 800 children, with many children in low- and middle-income countries not receiving treatment.

• The World Health Organization (WHO) recommends that rehabilitation services be integrated into national health systems to increase access to services – but how can rehabilitation services be integrated into health systems?

• In Uganda, clubfoot treatment has been integrated into public and private health care facilities through the National Clubfoot Programme Uganda (NCPU), funded by global clubfoot nongovernmental organization MiracleFeet, and the Ministry of Health (MoH) and supported by a local implementing partner.

• The NCPU offers a valuable case study for measuring the integration of rehabilitation services into health systems.
Objectives

1. Document experiences of integrating clubfoot into the health system to inform implementation of ReLAB-HS-supported Networks of Care and broader lessons on the integration of rehabilitative services into health systems.

2. Improve understanding of existing referral processes to support integration of clubfoot screening into maternal, newborn, and child health (MNCH) service packages.

3. Understand how the CAST mobile health application (app) impacts health providers’ behavior and what potential impacts CAST could have on service quality to inform telerehabilitation implementation.

4. Assess the cost of pediatric clubfoot treatment in Ugandan health facilities to inform how rehabilitative care can be co-financed and strengthen sustainability planning.
Methods

- Document review
- Key informant interviews with key stakeholders
- Costing tool administered in seven health facilities
- Thematic analysis, using the Rainbow Model for Integrated Care (RMIC) as a starting point to understand integration

Table 1. Key informant interviews

<table>
<thead>
<tr>
<th>STAKEHOLDER TYPE</th>
<th>NUMBER INTERVIEWED</th>
</tr>
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<tbody>
<tr>
<td>Clubfoot providers</td>
<td>24</td>
</tr>
<tr>
<td>Hospital administrators</td>
<td>7</td>
</tr>
<tr>
<td>Policymakers</td>
<td>1</td>
</tr>
<tr>
<td>Program implementers/MiracleFeet</td>
<td>6</td>
</tr>
<tr>
<td>Caregivers</td>
<td>27</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>65</strong></td>
</tr>
</tbody>
</table>

*Sampled health facilities: Kalisizo, Lira, Gulu, CoRSU Hospital, Mbale, Jinga, Mulago*
Rainbow Model for Integrated Care (RMIC): to analyze how the program is integrated into the health system

Table 2. Dimensions of the RMIC and their definitions

<table>
<thead>
<tr>
<th>DIMENSION</th>
<th>DEFINITION</th>
</tr>
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<tbody>
<tr>
<td>Clinical</td>
<td>Delivering coordinated care to patients</td>
</tr>
<tr>
<td>Professional</td>
<td>Interprofessional partnerships to deliver care</td>
</tr>
<tr>
<td>Organizational</td>
<td>Delivering services in a linked-up fashion across organizations</td>
</tr>
<tr>
<td>Systems</td>
<td>Alignment of rules, policies, and protocols; can be vertical or horizontal</td>
</tr>
<tr>
<td>Functional</td>
<td>Linking non-clinical support functions, such as records and financing</td>
</tr>
<tr>
<td>Normative</td>
<td>Coherent values and norms</td>
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</tbody>
</table>
Analytical frameworks utilized (2/2)

**SWOT Analysis:**

to practically analyze the findings and provide actionable insights

Table 3. SWOT Dimensions and definitions

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Definition</th>
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</thead>
<tbody>
<tr>
<td>Strengths</td>
<td>Things the program does well</td>
</tr>
<tr>
<td>Weaknesses</td>
<td>Challenges for the program or things that can be improved within the program</td>
</tr>
<tr>
<td>Opportunities</td>
<td>Emerging needs or gaps the program could fill</td>
</tr>
<tr>
<td>Threats</td>
<td>Barriers or challenges to the program’s success that exist externally to the program.</td>
</tr>
</tbody>
</table>
Section I: Summary of the Findings
Summary of the program strengths

**Patient-centered:**
- Providers screen patients for other health needs.
- Health facilities ensure services are provided any day the patient comes for treatment, even if it is not a clubfoot clinic day.
- Social workers and parent educators often provide counseling and education when children are identified.
- For patients visiting national referral hospitals, providers describe clear patient pathways; provider collaboration; and continuity of care across surgery, physiotherapy, and orthopedics.

**Fills critical gaps in the public health care delivery system:**
- Services are free of charge via the NCPU.
- Consistent support and in-service training/supervision is provided via CoRSU Hospital.
“We do not treat the feet, we treat children. We tell our orthopedic officers to undress the child and look at the head to toe and turn the baby to see the back….That’s the protocol….We want this child walking, we don’t want only the feet corrected, but you want a child who is going to be productive in the future and that is our emphasis.”

– National-level interview
Summary of the program challenges

Supply Side

• Availability of materials depends on MiracleFeet filling gaps.
• Providers have limited capacity to provide treatment to children over age two who experienced delayed referrals.
• Crowded clinic days increase the demands on the orthopedic officers’ time, which is already very limited.
• Providers in Gulu, Mbale, Jinja, and Mulago indicated limited human resources to manage the volume of patients on clubfoot clinic days.

Demand Side

• Patient adherence is the leading challenge described by providers, especially during the bracing phase.
• Transportation, stigma-related family conflict, geographic access, and low incomes all create barriers for caregivers to adhere to the treatment plan.
• There is limited caregiver knowledge that children can relapse without continued bracing.
“There are times when there is no money and we fail to come….she calls but we still fail to go....but we tell her that what makes us fail to come is the transport problem.”
– Caregiver, Northern Uganda

“‘When the child is affected with this problem, I don’t have any help I get from the community or neighbor concerning the clubfoot disease because they do not want to associate with us.”
– Caregiver, Northern Uganda
### NCPU integration model: roles for each stakeholder

Table 4. Summary of key program dimensions and stakeholders’ roles

<table>
<thead>
<tr>
<th></th>
<th>GOVERNMENT PROVIDES</th>
<th>MIRACLEFEET / LOCAL PARTNER PROVIDES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staffing</td>
<td>Salaried by government</td>
<td></td>
</tr>
<tr>
<td>Physical infrastructure</td>
<td>Facilities, water, electricity, etc. provided</td>
<td></td>
</tr>
<tr>
<td>Supplies</td>
<td>Main supplies (e.g., gloves, plaster of Paris [POP], soft roll/undercast padding) are in the public procurement system and provided by the National Medical Store</td>
<td>Fills gaps when there are stockouts</td>
</tr>
<tr>
<td>Training</td>
<td>Pre-service training and certification; participates in supportive supervision</td>
<td>In-service training, refresher training, supportive supervision</td>
</tr>
<tr>
<td>Information systems</td>
<td>Main register book</td>
<td>CAST app, phones, and allowance for data entry</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>Mobile phone credits for appointment reminders</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Transportation subsidies</td>
</tr>
</tbody>
</table>
“The Ministry of Health is the overall supervisor and the owner of the healthcare provision in the country. Its support is little at the moment because they are supposed to provide care for every Ugandan. When you look at the supplies that are sent to the facilities, they can’t run a clubfoot clinic once a month because they send very little materials and much of these materials are taken up by trauma that has a higher priority.”
– National-level informant
How is the program integrated into the health system? (1/2)

Table 5a. Summary of key findings according to the integration framework

<table>
<thead>
<tr>
<th>DIMENSION</th>
<th>KEY FINDINGS</th>
</tr>
</thead>
</table>
| Clinical    | • There are connections to newborn and child health services for referral and counter-referral, but this is informal and not well integrated; community and self-referral are prevalent.  
  • There are challenges with continuity of care due to demand-side factors; geographical access is a key barrier as the program is not integrated into primary care and community services. |
| Professional| • There are positive working relationships among orthopedic officers and other providers.  
  • There is consistent training and supportive supervision from the local partner, but this remains outside the public system’s supportive supervision process and requires external resources. |
| Organizational| • Providers described clear working relationships between regional referral hospitals and national referral hospitals or private hospitals for complex cases.  
  • Communication to the referring provider requires strengthening. |
How is the program integrated into the health system? (2/2)

Table 5b. Summary of key findings according to the integration framework

<table>
<thead>
<tr>
<th>DIMENSION</th>
<th>KEY FINDINGS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systems</td>
<td>• There is a common understanding of the Ponseti treatment approach among providers; the program has a unified approach to developing treatment processes alongside the MoH.</td>
</tr>
</tbody>
</table>
| Functional| • CAST is very helpful; however, it is added to provider’s existing administrative tasks and is not integrated into government registers for clubfoot patients.  
• Clubfoot supplies are integrated into the public procurement system; however, they are often out of stock, requiring MiracleFeet to fill the gaps. |
What does integration mean to caregivers?

• Making access to health care easy in terms of distance, bringing services closer to the community
• A one-stop center for treatment of clubfoot and other conditions
• Decentralization of clubfoot treatment and other health care services
• Overall reduced family expenditure on health care—leading to savings for other priority needs
• General improvement in the quality of services (leading to improved health and well-being of individuals with clubfoot)
“Immunization and other services we get from Lapem Health Centre III, so here we come for clubfoot treatment only. There is no other health condition that I bring my baby here to the hospital for treatment apart from clubfoot.”
– Caregiver, Northern Uganda
Key takeaway: Integration depends on the strength of different health system components

Components of the health system that support integration:
• Hiring of orthopedic officers into publicly funded and posted health worker positions
• Providing clinical space for clubfoot services in regional referral hospitals
• Designating adequate time for clubfoot clinic days in public health facility facilities
• Existing referral pathways from regional referral hospitals to specialty care

Components of the health system that work against integration:
• Supportive supervision for orthopedic care often requires external resources
• Continuous stock of supplies through the public procurement system remains a challenge
• Early identification and referrals, especially within communities, is very limited
• Awareness building and caregiver education is limited outside the program
Section II: Findings on Clinical Integration

Functioning of the referral system and care continuity
### SWOT analysis: Referral system

<table>
<thead>
<tr>
<th><strong>Strengths</strong></th>
<th><strong>Weaknesses</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Strengthened awareness and referrals of clubfoot overall to improve early detection</td>
<td></td>
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<tr>
<td>• Accepting both formal and informal referrals that maximize the sources of referrals</td>
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<tr>
<td>• Close proximity of referral facilities to some</td>
<td></td>
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<tr>
<td>• Patient-centered care from caregiver’s view</td>
<td></td>
</tr>
<tr>
<td>• Some patients identified during immunization</td>
<td></td>
</tr>
<tr>
<td>• Providers who are greatly invested in the program undertaking their own sensitization efforts</td>
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<tr>
<td>• Informal referrals, largely due to the below</td>
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</tr>
<tr>
<td>• Lack of specific knowledge about clubfoot among non-clubfoot providers (e.g., optimal period to treat, availability of treatment, etc.)</td>
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<tr>
<td>• Limited abilities to identify patients among home deliveries and neglected clubfoot patients</td>
<td></td>
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<tr>
<td>• Inability of providers to track patients who move to higher levels of care or who relocate and change providers</td>
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<table>
<thead>
<tr>
<th><strong>Opportunities</strong></th>
<th><strong>Threats</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Providing support for outreach and training of village health teams (VHTs), community members, and providers in lower-level facilities to further sensitize communities</td>
<td></td>
</tr>
<tr>
<td>• Increasing ability of community members to refer potential patients</td>
<td></td>
</tr>
<tr>
<td>• Learning from and expanding provider-implemented efforts to strengthen referrals and increase awareness</td>
<td></td>
</tr>
<tr>
<td>• Integrating clubfoot into the health management information system (HMIS) form for newborn patients to prompt health care workers to check for congenital birth conditions</td>
<td></td>
</tr>
<tr>
<td>• Clubfoot clinics are located far from patients in many cases</td>
<td></td>
</tr>
<tr>
<td>• Poverty creates geographic barriers to treatment follow-up</td>
<td></td>
</tr>
<tr>
<td>• Limited availability of specialized hospitals/clinics for referring neglected clubfoot patients and/or complicated cases</td>
<td></td>
</tr>
<tr>
<td>• Continued community misperceptions related to stigma (e.g., individuals are “cursed”)</td>
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</tbody>
</table>
How are children initially identified and referred?

In general, participants described depending on existing referral pathways in the national health system to capture new patients; however, referrals from maternal and newborn care services were described as unsystematic and considerably reliant on individual provider knowledge.

The most common referral pathways, according to our participants, were:

- Other newborn and child health services, especially through midwives in the maternity unit, immunization days, and pediatric wards.
- Self-referrals, as a result of community engagement (e.g., radio shows and announcements, immunization days, camps, churches, by relatives or peers) or learning from other mothers or caregivers in the community.

According to participants, patients are less frequently identified at general outpatient clinics or by VHTs or traditional birth attendants.
What are the strengths of the existing referral system?

The existing referral system emphasizes identifying all potential clubfoot patients, regardless of their referral status, age, or possible diagnosis.

Providers observed increasing self-referrals due to provider outreach, community engagement, and increased community awareness. These are “accessible” pathways for caregivers.

“With us, we don’t segregate in age. We receive anybody who comes with a foot [condition] and we health educate them and advise them on what to do.”
– Clubfoot provider

“I gave birth to him and I went back home... It is other people ...when we came back from the hospital that saw the baby. I first lived in denial but they kept on insisting that the baby’s feet have a problem. So, they advised me to come here at the main hospital.”
– Caregiver, Eastern Uganda
Early detection and referral are not systematic

Potential cases are often missed during delivery and are often detected after women are discharged from delivery. Trainings to identify clubfoot are ad-hoc and have not been institutionalized.

“Some of them they do not know when they should refer….They do not know that the kid is supposed to be sent here immediately.”
– Clubfoot provider

Participants agreed that there is limited awareness in lower-level facilities or among VHTs to screen and refer children to appropriate health facilities.

“The VHTs [are] a good idea but most of them are not well equipped with the information.”
– Clubfoot provider
Challenges with referral facilities

From the provider perspective
• Referring providers lose track of patients.
• Referring providers do not know referral adherence rates.
• Referring providers cannot access medical records at the referral facility, even if both facilities are using the CAST system.

From the caregiver perspective
• Referral facilities are often hard-to-access.
• Long distances
• High cost of transport
• Stigma and discrimination
• Language barriers
• Limited knowledge about the condition, undermining adherence and prolonging treatment periods
Provider-led efforts to improve early identification of patients

Providers in referral and specialized hospitals train nurses at the front desk to triage long-term secondary care needs, including clubfoot, to the orthopedic department.

“We have empowered those people, especially midwives, … so we have tried to inform those people in such places, maternity and the pediatric wards.”
– Clubfoot provider

“When a patient comes…, they are registered at the reception and then triaged by the nurse at the nurse’s station.”
– Clubfoot provider

“At the triage, the nurse is able to say this is a clubfoot [patient], this is maybe a cerebral [palsy] patient, this is a patient with a fracture.”
– Clubfoot provider
Provider-implemented initiatives to expand awareness

Some of the providers actively engage doctors and nurses in health centers in their catchment area, as well as nursing students.

Other providers describe advertising free services at lower-level health facilities, the development of booklets and leaflets to be made available at lower-level facilities, the use of radio talk shows, and community awareness meetings.

“We want to spread the message down. We have now done several trainings on clubfoot to nursing students, then we also did trainings for VHTs, [and we] are training on radio talk shows and sensitizing the parents on clinic day.”

– Clubfoot provider
## SWOT analysis: Continuity of care and adherence

### Strengths
- Longitudinal patient records
- Weekly clubfoot clinics
- Follow-up appointments are scheduled after each clubfoot clinic
- Free clubfoot treatment services
- Testimonies and treatment success stories
- Usually regular supply availability

### Weaknesses
- No feedback or access to patient records for referring providers
- Limited support for providers that do home visits or extra clinical visits
- Occasional stockouts
- Lack of a systematic policy for transportation and home visits that support continuity of care

### Opportunities
- Transportation subsidies
- Telemedicine or home visits for brace checks
- Engagement of village leaders
- Non-monetary incentives or recognition for early detection and referral of cases
- Education focused on long-term economic benefits of treatment

### Threats
- Household poverty
- Long distance for patients to travel
- Competing family priorities
- Limited caregiver knowledge during the bracing phase leads to dropouts/relapse
- Stigma and lack of social support
- Domestic violence
Care continuity challenges

Three interrelated challenges were identified from the perspectives of caregivers and clubfoot providers:

1. Financial access, especially transportation costs
2. Stigma and lack of family support
3. Limited caregiver awareness

The length of clubfoot treatment, the need for continual adherence, and the distance to health care facilities all exacerbate these challenges.
“I must treat my child for five years. When you walk in with your fracture, you will walk in once, I treat you, you get okay, and you will stop coming to the hospital. But for [the parents of the child], every week or month [they visit], after 3 months or 6 months, [they] must take this child to hospital. Financial implications in terms of transport lies on the head of the parent or guardian of the child.”

– Clubfoot provider
“The experience is that the disease takes long to get cured, it takes quite some time and another thing is that transport costs are high being that I come from far the distance is very long where we come from.”

— Caregiver, Kampala
Care continuity: Financial barriers

Poverty creates considerable financial access barriers and hinders families from meeting their basic needs.

“There is generally nothing that we do at home because we are poor. My husband has no source of income that can help support the child. So, you just go and ask for help from other people while you have left him at home.”
– Caregiver, Eastern Uganda

“Very poor families who are in remote areas, they have to move long distances to access a clubfoot service. Because the service takes a little longer, they tend to fall out in the course of treatment because of distances. The weather, when it is bad, you will find a challenge that you [the provider] have reached the unit at eight, a client is coming at five.”
– Clubfoot provider
Care continuity: Stigma and lack of family support

Stigma and discrimination hinder continuity of care.

“[Community members] have a lot of stigma and also criticisms…‘You are wasting your time, this child is ojok (a demon), and cannot be corrected.’…not only one, they are many. There were some who started [to] bring the children, and the community started talking, …‘This child is ojok (a demon), you are wasting your time.’”
– Clubfoot provider

“My father in-law, people from the side of the father of the baby, they are the ones who said that you have delivered a witch.”
– Caregiver, Northern Uganda
Patients drop out during the maintenance phase because the feet “look normal,” leading to failure in clubfoot management.

“There is a mother I asked, and she said that after she saw her son walking well, she thought that he was fine and she stopped taking him for treatment.”
– Caregiver, Eastern Uganda

Some facilities have implemented caregiver education as a strategy to reduce dropouts.

“For some parents when they realize the foot is actually okay, they stop coming. You look for this parent and you do not see them anymore. We tell them this clubfoot can come back you know please come, and we take care of the child until when they are five years and then we tell you what to do thereafter.”
– Clubfoot provider
Parent educators play a crucial role

The new role of parent educators is well aligned to combat care continuity challenges. They:

• Ensure caregivers are aware that clubfoot is a treatable condition and combat social stigma.
• Prepare parents for the prolonged treatment process across stages of treatment.
• Ensure caregivers understand the consequences of stopping treatment.
• Obtain informed consent from caregivers to enroll in CAST.
• Help parents overcome challenges with transportation support and psychosocial support.
• Educate caregivers about the consequences of non-adherence to or discontinuity of treatment.
• Support caregivers in enhancing proper home-based care for clubfoot children.
• Encourage caregivers to adhere to appointment schedules and follow up if appointments are missed.
• Counsel and comfort discouraged caregivers.
• Support timely identification and treatment of cases.
Providers’ efforts to increase patient adherence

In addition to parent educators, providers described other strategies to increase adherence:

- Group patient/parent education sessions during the clinic day enhance parent confidence in treatment for positive outcomes.
- Providing transportation assistance reduces out-of-pocket expenses.
- Support for income-generation activities enables parents and caregivers to attend follow-up appointments.

“When someone says, ‘Have you seen my child? She used to be badly off but now she is like this.’ And then I also saw those being discharged after they recovered. So I became strong and made sure that I always took my own for treatment.”

– Caregiver, Eastern Uganda
Section III: Findings on Professional Integration

Human resources, collaboration, and training
Training programs

• Most clubfoot providers indicated they have been trained on the Ponseti method in school with occasional in-service training.

• Several providers indicated the positive effect of using the CAST app on following treatment standards (e.g., performing Ponseti scoring every visit) and improving follow-up care.
  • However, CAST and in-service training are reliant on MiracleFeet/CoRSU Hospital and are not integrated into government processes.

• Most providers requested more trainings for the sources of referrals and clubfoot providers, because:
  • There is a high turnover rate among nursing professionals.
  • Refresher meetings boost morale and strengthen skills.
Collaboration and coordination among health workers

• Within clubfoot clinics, orthopedic officers described strong collaboration with one another, orthopedic surgeons, nurses, social workers, and caregivers.

• Higher-level hospitals have more formal and comprehensive referral systems and coordination between different providers and departments compared to regional referral hospitals.

“We were educated first on how to tie these braces. So, that’s the first treatment….Dr. Alex also checks the child and writes in the book. When we don’t find Dr. Alex, or when he is attending to another patient, he gives us another health worker who also treats and handles us well and after, we go back home.”

– Caregiver, Eastern Uganda
Meeting increased demand is a growing challenge

In Gulu, Mbale, Jinja, and Mulago, providers indicated that demands for clubfoot services are increasing due to continuing community sensitization and increasing midwife training; however, the orthopedic workforce has not increased.

As clubfoot management is a prolonged process, clinics are likely to become crowded with both new and follow-up patients.

Several clubfoot providers expressed their need for more financial and non-financial recognition for the long work hours.
“Orthopedic officers are not meant to treat clubfoot alone, they have other patients....In the beginning, when they are starting, they can see 3-5 patients and when you do it overtime, the number accumulates, and you can be having over 30-40 patients. There are only two orthopedic officers, they have trauma cases that are waiting for them.... Orthopedic officers are kind of overwhelmed and burnt out and they think that the program maybe is putting too much pressure on them.”

– National stakeholder
Gaps in the skill mix: Tenotomy

Only orthopedic surgeons and a few trained senior orthopedic officers are qualified to do tenotomy.

“Tenotomy is done by me because I went to Mulago and trained in that because we used to get some hardship with our surgeons, they were so busy, their schedule was busy, so the only alternative was for me to go and train and I am doing it this side.”
– Clubfoot provider

Training providers at a small number of clubfoot clinics can have unintended consequences.

“A senior [orthopedic provider] was trained and qualified to do tenotomy, leading to improving waiting time and coordination within the facility and reducing needs to refer out. And consequently, there was increasing number of referrals from other facilities for performing tenotomy, so different challenges of equipment and coordination exist.”
– Clubfoot provider
Section IV.A: Findings on Functional Integration

Medical Records and CAST
## SWOT analysis: CAST

### Strengths
- CAST streamlines patient tracking, improving the ability to manage and organize patient data.
- The app's reminder system contributes to higher clinic attendance rates, positively impacting patient care.
- CAST emphasizes improved data quality through a design that validates inputs, minimizing the chance of erroneous data entry.
- The app facilitates better communication between providers and patients, especially in remote areas.
- Providers can access real-time information about patient progress and appointments, aiding informed decision-making.

### Weaknesses
- Network issues occasionally hinder the seamless use of the app, impacting data access and entry.
- Some providers require additional training to fully utilize the app features and functionalities.
- Longer patient absences can lead to memory loss within the app, affecting data retrieval.
- Use of the app increases provider workload due to lack of integration with the national HMIS.

### Opportunities
- The CAST app gives providers access to other clinic locations, improving referral tracking and clarifying patient relocation.
- The success of the app suggests its potential applicability beyond clubfoot treatment, such as fracture management and orthopedic conditions.
- The app's efficient recordkeeping features could be extended to other medical departments, enhancing overall patient care.
- Providers' feedback can lead to app enhancements, addressing challenges like memory loss and network connectivity.
- The app's benefits can extend to remote clinics, facilitating access to care and tracking patient progress.

### Threats
- Reliance on the app can be threatened by technical glitches, affecting the continuity of patient care.
- Limited resources, such as the availability of phones for every provider or running out of data, could hinder the full realization of the app's potential.
- Some providers might resist transitioning to a digital solution, preferring traditional methods to which they are accustomed.
How does CAST support quality assurance and improvement?

• Data accuracy improves the quality of patient information, reducing errors in treatment planning and follow-up.
• Standard recordkeeping and tracking patient progress through the app facilitates outcome monitoring, aiding clinical decision-making and allowing providers to adjust treatment plans as needed.
• The reminder system enables timely follow-up, contributing to improved patient outcomes and treatment adherence.
• Providers' ability to easily communicate with patients through the app enhances the quality of care and patient engagement.
• The app's integration into providers' workflow minimizes manual processes, reducing the risk of data entry errors. To ensure this, however, all providers need to have a dedicated phone during patient consultations.
“CAST has changed my day-to-day routine as a provider. It has helped me know whether this patient has defaulted. It has also helped me to dig deeper and finding out why we are not improving, why a patient has defaulted. It has helped me because it follows the patient, and it even gives those reminders that you’re supposed to come, it gives them a reminder that if you have a problem, you contact the health care provider, so it has helped to follow up my patients to the grassroot.”

– Clubfoot provider
More details

Quality assurance, quality control, and improvement from the provider perspective

“We collected detailed personal information, we edit due dates during follow-up visits, [send short message service (SMS)] reminders for patients, synchronize data after every clinic day. We are able to see which patient showed up and which dropped out and able to identify relapses. We conduct good follow-up care of 3-5 minutes for each patient.”

– Clubfoot provider

“We encourage scoring during every visit to see we followed treatment standards and this provides real-time feedback for progress in scores and we improve something wrong, capture what materials were used. The inbuilt consent process in the CAST tool also enhances patient education.”

– Clubfoot provider
Perspectives from participants: What does sustainability for CAST mean? (1/2)

• **Long-Term Usability**: The participants emphasize that the app has brought a sense of sustainability to their practices by allowing them to have a systematic and organized way of handling patient data. This systematic approach ensures that records are accurate, accessible, and easily retrievable for the long term.

• **Improving Clinic Performance**: The app’s ability to track patient data and clinic attendance over time has given the providers a tool to assess the clinic's performance and popularity. This insight into patient numbers and appointment adherence contributes to sustaining the clinic's functionality and effectiveness.

• **Enhanced Communication and Follow-Up**: The reminder system within the app aids in sustaining patient engagement and adherence to treatment plans. By facilitating communication and follow-up, the app helps ensure that patients continue to receive care as needed, leading to better treatment outcomes.
Perspectives from participants: What does sustainability for CAST mean? (2/2)

• **Efficient Planning:** The respondents highlight that the app’s features enable them to plan and allocate resources more efficiently. Knowing patient numbers, appointment dates, and locations helps them anticipate needs, which contributes to the sustainable provision of quality care.

• **Backup and Redundancy:** The app’s role as a backup for patient data addresses the concern of data loss, contributing to the sustainability of accurate recordkeeping. In case of data loss in one system, the app’s redundancy helps maintain the continuity of patient information.

• **Adaptability and Growth:** The participants mention that the app’s benefits extend beyond clubfoot treatment, suggesting its potential applicability to other medical conditions. This adaptability contributes to the app’s sustainability as it can be integrated into different areas of health care.
Section IV.B: Functional Integration

Procurement, equipment, etc.
Integration of supplies

The MoH provides supplies and equipment through its procurement system, indicating functional integration. However, providers described regular stockouts and their continued reliance on MiracleFeet to fill supply gaps, challenging integration.
Competing priorities and limited resources influence the availability of supplies

Prioritization: Other orthopedic conditions capture a large share of supplies.

“We have been having many road traffic accidents in this country, so sometimes the preferential treatment that you get is that most plaster materials are diverted for the management of fractures of adults. And because children are not in pain, they are not complaining, so you find that plaster used to treat one adult could have probably been enough to manage 10 children with clubfoot.”
– Clubfoot Provider

Limited resources for all patient profiles: MiracleFeet prioritizes treatment for children under two due to available evidence and cost-effectiveness; however, several providers mentioned frustration with not having supplies for older children.

“The children come in different age groups. I appreciate that we get materials, but if you get plaster or pads, the size we get [are] a very small size, which is okay, but if you get an older kid of around three years, this size is not a very good size to be used. The different types or categories of materials could be looked at, which is very important for us.”
– Clubfoot Provider
Section V. Systems Integration

Clinical standards and sustainability of the program
Clinical standards are well integrated

Providers described clear treatment protocols for children under two and aligned training across pre-service training and the in-service refresher training supported by MiracleFeet and CoRSU Hospital.

“It was integrated into the Ministry of Health guidelines, and we were trained…at school on how to use the Ponseti methods of treating clubfoot. After school, the NCPU, [MiracleFeet] and then CoRSU, help in the refresher training, reminding you of what needs to be done.”

– Clubfoot provider

Some providers highlighted a lack of clarity on how older children should be treated.

“For clubfoot management for the little children we have a protocol that we follow….But clubfoot is not only in children below two years, it also exists in older children….We try to modify but basically it remains Ponseti treatment.”

– Clubfoot provider
## SWOT analysis: Sustainability

### Strengths
- Clubfoot services and supplies are included in orthopedic workshops; the government provides staff and the ability to procure through the National Medical Store.
- The MoH is increasing number of trained health care providers.

### Weaknesses
- Orthopedic workshops overall, including clubfoot, are "unfunded priorities" in the government's budget.
- No participants articulated a medium- or long-term sustainability plan.

### Opportunities
- Integrating clubfoot screening and treatment into pre-service training programs
- Including clubfoot indicators in the HMIS to quantify patient needs and treatment volumes
- Strengthening funding for components of the program that are well integrated (staff, supplies)

### Threats
- Possibility of donor priorities shifting
- Increasing program costs due to increased awareness leading to more patients
- Provider turnover
- De-prioritization of clubfoot services due to increasing patient load for other orthopedic conditions
Cost findings (summary)

- Financing for the NCPU is shared between the MoH and MiracleFeet.
- Clubfoot providers and clinic staff have limited knowledge of service costs, as oversight of the budget is fully managed by MiracleFeet or the MoH.
- There is a lack of clarity on the public sector supply management process, as stockouts are frequent and require outside resources to fill gaps.
- Cost for each service appears to vary considerably, suggested by the large variance in time spent and number of procedures per patient.
- Labor costs are an important component of cost, making it difficult to increase productivity. Yet, there are cost-efficient opportunities to improve labor productivity:
  - High variability in clubfoot treatment cost across similar health facilities may indicate inefficiency or selection problem due to the case-mix, or it could be indicative of variation in labor productivity (which would point to policies aimed at improving motivation).
“Sustainability, that is my worry because if MiracleFeet pulls out, what is the way forward? Orthopedic workshops are unfunded priorities….When the budget is being presented, there is the section of funded priorities and the unfunded ones like orthopedic workshops. When government gets money, it will pull that aspect from unfunded section and bring it forward. But from time immemorial, orthopedic workshops have been unfunded priorities….Now if [donors] pull out, what will happen to these children? That is the question which has no answer and yet, they are aware of it.”

– Clubfoot provider
Challenge: Demand-side efforts are not integrated into the system in a sustainable way

Participants emphasized the importance of demand-side efforts – such as home visits or transportation subsidies – to increase treatment adherence.

“Last year, we received transport for two people but remember that is like two to three visits only and after those visits, they stopped coming.”
– Clubfoot provider

However, these demand-side interventions have been supported by MiracleFeet and are considered unsustainable.

“MiracleFeet brought in another component of instead of giving transport, they facilitate an orthopedic officer from the clinic to go out and meet those clients. But it is also not sustainable. You go there, they tell you the person has gone to the garden. They are many and scattered in different villages.”
– Clubfoot provider
Section VI.A: Implications of the Findings for the NCPU
In summary: Implications for strengthening integration (1/2)

Table 6a. Summary of implications according to the integration framework

<table>
<thead>
<tr>
<th>DIMENSION</th>
<th>IMPLICATIONS</th>
</tr>
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</table>
| Clinical    | • There is a need to formalize early detection, screening, and referral for clubfoot cases.  
|             | • Integration of screening into newborn health programs is a key opportunity.  
|             | • Targeting demand-side barriers is key to improving patient adherence.                                                                   |
| Professional| • Strengthen the inclusion of clubfoot awareness training in non-orthopedic pre-service and in-service training programs.  
|             | • Consider how supportive supervision can be integrated into MoH-led supportive supervision and quality assurance processes.             |
| Organizational | • Consider opportunities to use CAST to document and track referrals.                                                                      |
In summary: Implications for strengthening integration (2/2)

Table 6b. Summary of implications according to the integration framework

<table>
<thead>
<tr>
<th>DIMENSION</th>
<th>KEY FINDINGS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systems</td>
<td>• Consider opportunities to build the evidence base on treating children over two and provide further training and guidance to providers on how to support the treatment of older children.</td>
</tr>
<tr>
<td>Functional</td>
<td>• Explore how the CAST app can be linked with the HMIS to improve national-level data and reduce provider workload.</td>
</tr>
<tr>
<td></td>
<td>• Better document the relative contribution of MiracleFeet to the procurement of supplies and commodities and initiate sustainability planning.</td>
</tr>
</tbody>
</table>
How can the referral system be strengthened?

• Incorporate clubfoot training into pre-service and in-service training for non-clubfoot providers, especially midwives.
• Systematize the integration of clubfoot screening into delivery, postnatal care, and routine immunization services.
• Train and continually sensitize VHTs to identify clubfoot patients at a very young age, especially newborns of non-institutional deliveries.
• Explore the potential role of CAST in improving patient record management across facilities and providing referring providers feedback on their patients.
How can patient adherence be improved?

Providing transport subsidies improves access to clubfoot clinics; however, this may not be sustainable and therefore could undermine integration.

“But time came when money for transport became hard and I cried out to the health provider because there was a time we missed and she called me and told me that you borrow some money and come next Thursday and you bring him, I will get for you transport so god helped us like that, we took him and she gave us back 10,000 shillings transport for going and then coming back.”

– Caregiver, Eastern Uganda

Some providers saw the potential for VHTs to have a role in identifying patients and supporting adherence to follow-up care, leveraging available patient records.

“We have to do a follow up in the community…because in that recordkeeping register we have all the contact details of the parent like the phone contact and the village… the bordering facility, all those.”

– Clubfoot provider
Opportunities to further leverage CAST

• Leverage patient profiles to proactively identify those at high risk of dropping out and who are likely to need transportation and other family support.
• Give providers access to data from other clinic locations, improving referral tracking and giving additional insights into relocated patients.
• Explore new opportunities: could CAST be a mechanism to pilot remote bracing reviews or other telemedicine innovations?
• Incorporate a patient feedback mechanism into CAST, aiding in identifying areas for improvement.
Section VI.B: Implications of the Findings for the Integration of Rehabilitation into Health Systems
Key takeaways for rehabilitation services

• NCPU’s successes rely on a long history of clubfoot treatment in Uganda – development of “new” services in the system takes considerable time.

• Rehabilitative care relies on the referral system—which is often weak.
  • For example, you can only identify children through MNCH services if the services are available and the patient attends them.
  • Other health care providers must be aware of rehabilitative services and know when, how, and where to refer patients.

• Success of rehabilitative services relies equally on demand-side interventions and community factors—stigma, low awareness, and patient/family vulnerabilities make this especially critical.

• VHTs, nurses, and midwives are potentially underutilized in rehabilitation referral pathways.

• Sustainability plans should be developed from day one.
Relatively low patient volumes for certain conditions create challenges to integrating services into primary care

This study identified a key tension in integrating rehabilitation services into health systems:

• From the patient’s perspective, integration usually refers to vertical integration, with most services available at primary care facilities and connections to higher-level care for complex cases.

• However, for clubfoot treatment, there is a need to maintain regular, adequate service volumes for providers to maintain high-quality services. This requires pooling enough patients in a single health care facility, generally a regional referral hospital.

The question becomes – how to support patients/caregivers to overcome barriers to accessing higher-level facilities?
Lessons for the development of telerehabilitation applications

Three Main Pillars for Implementation:
• Provider Capability
  • Training modules for competence
  • Strengthening referral systems
• Resource Management
  • Efficient patient tracking
  • Time and resource management tools
• Community and Demand
  • Extending services to rural clinics
  • Financial aid and reminders for adherence

Enabling Factors:
• Real-time data for health care surge planning
• Plan for complex cases
• Systemic improvements
ReLAB-HS is made possible by the generous support of the American people through the United States Agency for International Development (USAID) and is implemented under cooperative agreement number 7200AA20CA00033. The consortium is managed by prime recipient, Johns Hopkins Bloomberg School of Public Health.