Handicap International’s interventions related to clubfoot

Rehabilitation services Unit
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The treatment of clubfoot requires the work at different levels and from different actors, this work is exposed in this paper; Handicap International does not aim at working in all the activities exposed in the paper in one program, the aim is to present the scope of work that need to be implemented in order to set up accessible, sustainable and quality clubfoot services that need to be implemented by a range of coordinated actors.

The existence of specialized international actors of clubfoot in conjunction with our already ongoing rehabilitations projects working within and with local health structures generates an excellent opportunity for establishing partnership dynamics that should and most likely catalyze the existence of much more clubfoot attention and therefore much more children escaping from a life-long disability.

Treatment of clubfoot is relatively inexpensive, has a very clear and reasonably easy protocol and it is not difficult to learn. The braces needed in the last phase are also not difficult to produce locally and can be reused for several children. It is the human dimension that most of the time needs to be engaged in, from coordinating actors, facilitating processes, advocating and training.

The set of reference tools available on http://globalclubfoot.com/resources/ should be used in tandem with this Handicap International’s interventions related to clubfoot Policy Paper, as well as a set of internal tools available on Hinside.
1. Definition, importance and context

**Clubfoot** (medically known as congenital talipes equino-varus) is one of the most common congenital anatomical structure deformities that occur worldwide with birth prevalence that ranges between 0.51 and 2.03/1000 live births in low and middle income countries (LMICs)\(^1\). 80% of the children born each year with clubfoot around the world are born in low and middle income countries where birth rate is very high\(^2\).

The cause of clubfoot is unknown but likely represents a multi-factorial genetic origin. Between the 14th and 17th weeks of pregnancy, contracture of connective tissues (tight ligaments) occur on the back and the inner side of the foot causing deformities downward and inwards while growing. Clubfoot deformity may occur associated with other congenital abnormalities such as arthrogryposis but most of the cases are idiopathic (isolated deformity).

In low and middle income countries where early detection and access to appropriate treatment is poor or inexistent, clubfoot is one of the main causes of mobility impairment. **Children and adults with not treated** ("neglected") clubfoot will only be able to walk short distance because of pain and skin breakdown, they develop large calluses on the external side of the foot and will not be able to wear normal shoes. Often this walking impairment restricts children to go to school and the poor appearance makes them suffering of stigma, bullying and exclusion from society. If not treated in the first weeks of life, clubfoot causes severe fixed deformity and will need complex, extensive and expensive surgery to be corrected.

The Ponseti method has become the standard of care for clubfoot treatment throughout the world. In 1950, Ignacio Ponseti developed a method with a specific technique of manipulation and casting with limited surgical intervention. Dr. Ponseti developed this technique in response to poor results of surgical treatment he witnessed. It is only during the last two decades that this technique has become popular and considered as the most efficient standard of treatment for clubfoot worldwide. Numbers of publications in scientific


\(^2\) Incidence in Caucasians: 1/1000 live births; Africans: 2-3/1000; Polynesians: 6/1000

Journals have demonstrated the unanimous recognition of this method as the “gold standard”. This method is inexpensive and effective. Long-term follow-up studies show that feet treated by Ponseti management are strong, flexible, and pain free. It is recognized worldwide that the Ponseti management of clubfoot is best for all countries and cultures. The main advantage of Ponseti method particularly for underserved context is that this is a nonsurgical technique. The core clinical activity consists of:

- Serial casting and manipulation
- Minor intervention (Achilles tenotomy), needed in 90% of the cases, and last cast
- Bracing protocol.

Clubfoot can be **successfully and cost effectively corrected**, if treated in the early days of life. If the noninvasive technique shows more than 93% successful correction when treatment starts in the first year after birth, older children with neglected clubfoot can also be treated with Ponseti method but with less expectation of success and sometime require added surgical procedure. Fixed deformities in neglected clubfoot require complex and extensive surgery; however, some Ponseti casting done before surgery can ease the procedure.

## 2. Why intervene

- Birth prevalence of clubfoot ranges between 0.51 and 2.03/1000 live births in LMICs
- Millions of children in the world live with a big preventable physical impairment due to lack of treatment
- Early treatment of clubfoot is relatively inexpensive, effective, not complicated and has very good long term results
- 95% of the children early detected and treated will live a life without pain, deformity, restricted mobility or stigma (due to foot deformity).

Handicap International is present with rehabilitation in 63 projects in 40 countries and has presence in 59 countries in 2015. The inclusion of the clubfoot thematic within the ongoing rehabilitation activities at all levels is compulsory to address issues such as: integrating early intervention of clubfoot into national plans, health policies development, availability of braces, training of professionals and mentoring of the clinical work...

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3 [http://globalclubfoot.org/reference-list/](http://globalclubfoot.org/reference-list/)
3. Principles of intervention and linkages to other sectors

A comprehensive explanation about the principles of intervention and approaches to rehabilitation services can be found in the 2013 Physical and functional rehabilitation policy paper. This document is only a supplement of it that presents the frame of work to be implemented with a specific group of beneficiaries: clubfoot children and their families. The following principles of intervention apply.

A public health issue

HI takes clubfoot care as a public health issue and strategizes utilizing principles such as contributing to prevention of disability initiative, capacity building of national health care staff, meeting the needs of treatment, surveillance and data collection on birth defect, integrate clubfoot management into the national health programs, structures and policies and access a large scale of the population.

Universal Health Coverage (UHC)

The goal of universal health coverage is to ensure that all children with clubfoot get the health services they need without directing their families to suffer from financial hardship when paying for services\(^5\). Clubfoot treatment is also ideally applied to newborns which in many countries is already free of charge. Clubfoot orthosis are already inserted in the 50 priority assistive devices from WHO\(^6\). The comprehensive treatment of clubfoot needs to be included in Rehabilitation national plans and its financial plans in order to guaranty equitable, quality access without falling in catastrophic expenditures and impoverishment for families. A club foot treatment in Burkina Faso is estimated to cost US$400 per child\(^7\). In 2015, a study\(^8\) assessed that the level of catastrophic health expenditures\(^9\) in the country is equals to $45.1. Consequently, a club foot treatment has a risk to incur in catastrophic spending for a household.


\(^7\) CURE’s global average costs for club foot treatment.

\(^8\) Handicap International 2015, IFAR diagnostic in Burkina Faso

\(^9\) According to WHO methodology, health expenditures are considered to be catastrophic when a household spends greater than or equal to 40% of its annual capacity to pay (or household non-subsistence income, i.e. income available after basic needs have been met) in out-of-pocket payments.
Advocacy work and networking

Handicap International is a member of the Global Clubfoot Initiative\textsuperscript{10}, a worldwide collaboration to improve access to clubfoot management. As part of this organization, we have a chance to contribute to global advocacy on this.

Handicap International should also promote the issue of identification and management of birth impairments, including clubfoot, within broader health networks, particularly maternal and child health networks (see below). This can include presenting at global and local maternal and child health conferences, engaging in regional and global initiatives (meetings, consultations etc.) and creating communication materials on clubfoot to disseminate through the HI Federation network.

Good outcome makes good advocacy

HI considers actions on clubfoot as an “early win” for the national strategy on prevention of disability as several favorable factors for success are present in clubfoot management:

- High birth prevalence: between 0.51 and 2.03/1000 live births in LMICs
- Easily detectable (with simple additional training of Primary Health Care and community staff)
- Cost-effective treatments (work has to be done to make them available in the countries)
- High functional outcomes.

Evidence-based and surveillance

HI encourages evidence-based policy development and surveillance of clubfoot through constant collection of data on newborn baby with clubfoot and on treatment outcomes. Handicap International intends to contribute to the national and global data gathering and is committed to sharing them systematically with Global Clubfoot Initiative and other organizations involved in birth defect surveillance. We will see later a full chapter on the information system and research (see information system and research part), only with the production, analysis, dissemination and use of data, advocacy can be substantiated and decision makers can take opportune decisions.

Services continuum—Integrated services

Handicap International promotes a model of rehabilitation service for clubfoot that includes a continuum of integrated services; this includes health promotion, identification, diagnosis, treatment, rehabilitation and follows up, through the different levels and sites of care within

\textsuperscript{10} http://globalclubfoot.com/
the health system, and according to the user needs throughout the life course. There is further development on the integrated services part.

**Mother, newborn and child health**

Handicap International interventions in Mother, Newborn and Child Health (MNCH) have two mains objectives. The first one is to improve the access to MNCH health services for pregnant woman with disabilities, working mainly on physical accessibility, stigma reduction and elaboration of adapted information, education and communication (IEC) materials.

The second one aims to the integration of prevention, detection and management of MNCH related impairments for the mother and the 0-5 children into existing services. Concerning the Mother Handicap International works for the prevention, detection and management of obstetrical fistula, providing psychosocial support and perineal rehabilitation.

For the 0-5 children Handicap International works with newborn on early detection-early intervention on congenital conditions, such as clubfoot, cleft lips, brachial plexus paralysis and sensorial impairments and later on psychomotor milestones assessment to detect and manage children living with cerebral palsy.

**Inter-sectorial and community approach**

Collaborative work across professionals and the services continuum to raise standards of health is essential to tackle the clubfoot approach. Early and appropriate detection of the children as well as adhesion to rehabilitation treatment can only be reached by working in interdisciplinary teams and involving local communities and users as partners in the service delivery, planning, operating and monitoring.

In countries where no early detection mechanisms exist, collaborations with the education sector, especially nursery schools, can be promoted to detect and treat neglected clubfoot.

**Continuum emergency development**

It is important to examine the nature of the relationships that can exist between emergency relief, rehabilitation and development from the perspective that, at times, all three can be brought into play simultaneously, in a manner that is mutually supportive and complementary.

For simplicity the analysis will be broken down into three parts:

- Better development can help emergency assistance: for instance if there is a clubfoot focal point in each program; he/she could potentially be involved in the emergency relief of the same country or a neighboring country in case they identify children in need of clubfoot treatment;
• Better relief can be consistent with and reinforce development, for instance if children are identified during the emergency and there is no services for clubfoot available, a specialist can be brought over to do direct treatment and also coach local rehabilitation professionals on the treatment, in one week, local professionals will be able to include this specialization in their current practices11;
• Better rehabilitation can offer more than a simple return to the status quo: children with clubfoot identified and treated during emergency response would have in this case prevented a permanent disability and would need follow up that needs to be organized.

Inclusion of emerging technologies: Crossing the rural-urban health divide through mHealth

The inclusion of new technologies in the development of rehabilitation services can, and most probably will, influence the new generations’ strategies to improve access and quality of rehabilitation service and reducing costs. Handicap International has strong expertise in the field of rehabilitation and also a strong determination to explore how to integrate new technologies to improve our strategies and approaches to address barriers to rehabilitation. This approach is congruent with the recommendations of World Health Organization to remove obstacles to rehabilitation service provision.

Today, we are developing pilot activities were new technologies are (or will be) a clear added value, on clubfoot programs the most relevant ideas could be:
• Improving access to service (telemedicine for consultation with specialists...)
• Improving information, follow up of users and monitoring activities (e.g. SMS for user follow up, collection of data, users groups)
• Improving training and connectivity of professionals (distance learning, collaborative communities, platforms...).

11 See list of accredited specialists if needed: http://www.ponseti.info/ponseti-doctors-by-location.html
The six building blocks, that the World Health Organization (WHO) uses to analyse the health systems, will be used in this section to organize the different components that need to be developed in a comprehensive clubfoot intervention.

1. Services delivery

“Good health services are those which deliver effective, safe, quality personal and non-personal health interventions to those who need them, when and where needed, with minimum waste of resources.”

Specific objective

Improve availability and access of qualitative clubfoot treatment (within the local health service provision) that meet a minimum quality standard.

12 http://www.wpro.who.int/health_services/health_systems_framework/en/
13 http://www.wpro.who.int/health_services/health_systems_framework/en/
**Description**

Early detection and treatment of clubfoot prevents disability. Handicap International Rehabilitation projects are in its majority working within or with the local health system in place. Embedding club foot detection and treatment into the service delivery already in place is cost effective (human resources already in place), supports a more comprehensive approach and facilitates a possible scaling up when appropriate.

**Activities to promote rehabilitation within the health system**

The system to put in place in order to properly address clubfoot treatment and prevent disability consists of 8 basic steps described in the two figures below.

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>LEVEL</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Incorporated screening in normal screening of all children - Identification</td>
<td>Primary health care facilities</td>
</tr>
<tr>
<td>2. Referral and follow up</td>
<td></td>
</tr>
<tr>
<td>3. Diagnosis and registration</td>
<td>Clubfoot clinic integrated in a first or second level health facility</td>
</tr>
<tr>
<td>4. Parent counseling</td>
<td></td>
</tr>
<tr>
<td>5. Serial manipulation and casting</td>
<td></td>
</tr>
<tr>
<td>6. Achilles tenotomy (90-95%) and last cast</td>
<td></td>
</tr>
<tr>
<td>7. Bracing protocol</td>
<td></td>
</tr>
<tr>
<td>8. Monitor to maturity</td>
<td></td>
</tr>
</tbody>
</table>

*Only when very complicated cases or problems arising*

| Diagnostic and further intervention | 3rd level facility |
Club foot pathway
a) The work done at the primary health care/community level: The entrance door

Ideally a clubfoot project will start with all the work related to early detection & referral of new-born with clubfoot. This should be organized in collaboration with ministry of health through the nurses, midwifes, the birthing centers, early childhood follow up and the immunization network system. The aim is to include the screening of clubfoot in their everyday practice with all the children and to incorporate it in their daily duties.

Key messages are:

- What is clubfoot and how to recognize it? (Identification of clubfoot signs)
- Clubfoot can be completely corrected if early referral after birth for treatment (Information)
- Where and how to get treatment? (Referral).

It is not necessary to develop too deeply the technical capacities of the health workers at such level; the detailed information for parents will be delivered during treatment after referral at the clubfoot clinic. On the other hand the personnel of this level of care are the entrance door of children to the treatment so it is very important to emphasize their role and to make sure they incorporate the new basic skills in their daily practice.

Posters, flyers and awareness sessions organized in community health, birthing and immunization centers can also support clubfoot early recognition and mobilize health care and community staff and parents to act for getting treatment as soon as possible. Visits of supervision and support to the primary health care centers will also provide relevance to the thematic and improve their practical skills. In Appendix 1, find a fact sheet that was designed to target health staff to improve early identification of cases and referral for treatment in Nepal.

It is frequently forgotten in projects, but taking time with health and community authorities to properly and formally organize the referral has a big impact in the number of children that arrives at the clubfoot clinic. In many countries there is a big gap between the children identified by the primary health care services and the ones that actually arrive at the clubfoot clinic; proper monitoring of these processes needs to be put in place in order to learn from the gaps in the project and reinforce the weaknesses it might have.

b) The work done at the clubfoot clinic (frequently within a Primary or secondary health facility)

A weekly “clubfoot clinic” system is the most frequent set up instead of random distribution of clubfoot treatment sessions all over the week. When possible the clubfoot clinic will be organized on a weekly basis (or more) in hospital and primary health care setups. Decentralization of clubfoot clinics in district hospital and community is encouraged as cost
of transport and distance are two of the major barriers to access treatment. Advantages to have a weekly clubfoot clinic:

- Facilitate management mentorship and mobilization of resources at the same time and location
- Ease the communication on when and where to get treatment
- Having parents together in the clubfoot clinic can be very helpful for peer to peer parents' exchanges of experiences, discussions and self-encouragement
- A nurse or the receptionist or special counselor of the clinic can animate the group of parents in the waiting area by showing communication material, broadcasting video, answer questions and facilitate “parents' club”.

c) Working with parents: Parent/caregiver involvement and counseling

Treatment of clubfeet is hard on parents, parents report that the most difficult components of treatment include maintaining the child hygiene during the casting period, skin problems during bracing or casting, adjusting to the first week of brace use, and high levels of anxiety in terms of the diagnosis and anticipation of the Achilles tenotomy (Nogueira et al, 2013).

Commitment to follow up the treatment strictly and constancy to do so is the main key to treatment adherence and success. Preparing training sessions with parents is therefore compulsory. After the training the parents should be able to:

- Understand the type of their child’s clubfoot and that it is treatable
- Understand all aspects of the upcoming treatment including the reasons for relapses
- Communicate regularly and openly with clinical staff throughout all phases of treatment
- Openly discuss social, cultural, and financial constraints to treatment
- Comply strictly with the bracing protocol and follow-up appointments
- Seek support from family, community, health workers, and others, as needed.

d) The clinical work (correction and maintenance of the correction)

Ideally treatment of clubfoot is started in a baby’s first two weeks of life, though best if started before the child starts to walk, clubfoot clinics are achieving good results with the Ponseti method in patients up to 20 years old.

The treatment consists in the following phases:

- **Diagnostic and registration**: the importance of data collection is discussed further down in the information system and research part, nevertheless it is important to

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14 Adapted from guidelines of Ponseti association: [http://nebula.wsimg.com/5c1f073fe017cd384d028c981c352ebef17C75687F76E8655&disposition=0&alloworigin=1](http://nebula.wsimg.com/5c1f073fe017cd384d028c981c352ebef17C75687F76E8655&disposition=0&alloworigin=1)
state here that the clinic treatment has to start, continue and finish with a well-organized data collection strategy.

In order to achieve the correction:

» **Manipulation and cast**: the affected feet are gently stretched and manipulated towards a more correct position using the Ponseti method (the manipulation needs to be well instructed to the professional as it has to be applied meticulously). The position is held in place **by a long leg plaster** cast that is applied from the toes to the groin. The cast stays on for 4 to 7 days. The cast is then removed. The affected feet are stretched and manipulated again and another cast is applied. This process of manipulation and castings is usually repeated 5 to 8 times.

» **A minor operation**: In most cases (around 90%), once the tendons and ligaments are stretched enough to allow the bones of the foot to move into the correct position; a minor procedure and a final casting is needed. Usually under local anesthesia, the heel cord is snipped. When the final cast is removed, the heel cord has healed and the regenerated to the correct length. The last cast usually is left on for 2-3 weeks.

In order to maintain the correction:

» **Bracing protocol**: Wearing foot abduction braces is critical in the Ponseti management; it is essential in preventing relapse, failure to wear them is the most common cause of recurrence. Each child treated in the clubfoot clinic needs to wear foot abduction braces directly after removing the last cast (three weeks after tenotomy). Each child will wear the brace 23 hours per day for the 3 first months and during night and naps for 2-4 years. The function of the brace is to maintain the extreme foot abduction (70 degrees) in children with treated clubfeet. The brace is necessary to maintain this correction (more information on the braces in the essential medical products [part]).

» **Monitoring to maturity**: Regular follow up of the feet is necessary to monitor the possible occurrence of relapse, the foot should maintain the correction over the years. If any of the deformities are present; a relapse might be present and further treatment might be required.

⚠️ **Attention point**

“Failure to achieve correction of the foot following repeated casting and tenotomy might indicate inappropriate manipulation and casting and/or incomplete tenotomy, and additional consultation should be sought at a specialized center” (Ponseti guidelines).
Activities to integrate rehabilitation system within the health system

In order to put in place such a system and to ensure the 8 steps are established and working fluently and in close coordination, there will be the need for an integrated health system. This has different definitions and different meaning for different actors, here a short description of the actors involved and the meaning of integration to them in this particular subject.

<table>
<thead>
<tr>
<th>ACTOR</th>
<th>MEANING OF INTEGRATION</th>
<th>SAMPLES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Users</td>
<td>Continuity of care, friendly user</td>
<td>The paramedical health worker that does the follow up of the new born does also the screening for clubfoot, the referral to specialized services if clubfoot is detected and the follow up of the bracing protocol when back home; this way users can skip numerous visits and number of faces to reach outcomes</td>
</tr>
<tr>
<td>Professionals</td>
<td>Multidisciplinary approach</td>
<td>Child traumatologist, physiotherapist and an orthoprothesist visiting together a child that has a relapse</td>
</tr>
<tr>
<td>Providers</td>
<td>Separate specific service providers are closely coordinated</td>
<td>Close coordination between the first health post that identifies, the clubfoot clinic at the provincial level and the specialist treating complicated cases at the 3rd level</td>
</tr>
<tr>
<td>Organizational</td>
<td>There are merges, contacts or strategic alliances between different institutions</td>
<td>For instance, the Ministry of Health at local level and the collaboration between a specialized INGO such as miracle feet and Handicap International in Bolivia</td>
</tr>
<tr>
<td>Decision makers</td>
<td>Clubfoot programs can be included in to early childhood programs, this way decisions on policies, regulation and financing can be handled easier and quicker</td>
<td>For instance, the person responsible for the early detection program can at the same time regulate and monitor the clubfoot program in collaboration and coordination with the person responsible for the rehabilitation</td>
</tr>
</tbody>
</table>
Handicap International is frequently at a position to play a role of catalyzer at the organizational level. The alliance of different institutions will bring an alliance on know-hows and resources. In order to do that first step a mapping of actors is needed in the local context. There is a significant number of actors specialized in clubfoot treatment with whom HI already has contact for some projects. These actors have developed high expertise in the clinical approach and in the management of the system to be implemented, frequently though they have less presence in the field than HI. HI is also perceived by them as an interesting actor that is already working within the local system and with the local partners. Collaboration with these actors (when possible) is envisaged in order to maximally and efficiently use the resources and know-how available.

⚠️ Attention points
Define from the beginning the role and budget of each actor in the process, for each step and as detailed as possible.

**The actors that can be involved in our activities**

15 Extracted and adapted from the policy paper [Physical and Functional Rehabilitation](#), Handicap International, 2013, p. 48
A list of the main organizations working on the clubfoot thematic exists and can help teams to facilitate a local mapping.\(^\text{16}\)

\(^{16}\) [http://globalclubfoot.com/about-gci/partner-organisations/](http://globalclubfoot.com/about-gci/partner-organisations/)
There are also numerous local initiatives that are already in place, supported by smaller foundations or personal initiatives, but for sure worthwhile exploring in every local project aiming to start clubfoot activities. For example, in Ethiopia, there is a residential home in the capital of Addis Ababa that welcomes children from all over the country during their clubfoot treatment. Adherence to treatment is 100% guaranteed through them for children that otherwise would need to travel many days to change casts\textsuperscript{17}.

**Indicators**

- Availability
- Access
- Comprehensiveness
- Quality of services.

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**Logic of intervention (How I start / what do I need) – Checklist of areas to pay attention to before to launch clubfoot activities**

- Identify what is already in place for clubfoot treatment (clinical treatment but also national laws...).
- Identify partners:
  - Local partners: MoH, clinics, CBR...
  - Technical partners: Miracle feet...
- What do I need besides partners:
  - Human resources
  - Training resources
  - Infrastructure
  - Budget
- Processes to put in place (Integrated within the local continuum of care):
  - Identification and referral
  - Registration (International registration and database) and data management
  - Treatment (manipulation and casts, tenotomy, braces and referral to third level when needed)
  - Production or import of braces
  - Follow up (outreach, CBR, SMS system from Rehab service...)
  - Advocacy.

\textsuperscript{17} \url{http://www.alemachen.cbiset.com/en}
2. The workforce

A well-performing **health workforce** is one which works in ways that are responsive, fair and efficient to achieve the best health outcomes possible, given available resources and circumstances. I.e. there are sufficient numbers and mix of staff, fairly distributed; they are competent, responsive and productive.

**Specific objective**

The health staff at different levels is trained and motivated to organize clubfoot services and to identify, refer, counsel, treat and follow up children with clubfoot.

**Description**

The success of projects and treatment of clubfoot depends highly on the knowledge, skills, motivation and engagement of the people responsible for organizing and delivering health services. The human factor is a crucial one. Health staff is frequently not familiar neither trained on clubfoot identification and treatment and the subject is not included in their planning of duties. To conduct a clubfoot treatment efficiently and qualitatively requires appropriate planning, management and development of the human resources needed. Training enables the persons involved in one phase or another of the clubfoot treatment to develop and enhance their personal skills, knowledge and behaviors, and enhances their competencies to practice in their functions. The good news is that there are plenty of training resources available on clubfoot, directed to a diverse public, from surgeons to parents. This, in turn, advances practice, service delivery and ultimately outcomes for the children.

**Activities**

The profiles of professionals we work with at the rehabilitation projects are various\(^{18}\). Most important is that they are reliable and committed to the work with children with a clubfoot.

In clubfoot treatment, we will need to get involved in the planning and capacity building of health staff to fulfill the following roles (underline in blue in the figure above):

- Midwifes and primary health care staff: identification and referral
- Doctor: case manager, tenotomy and complicated cases

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\(^{18}\) See the [Physical and functional rehabilitation](#) policy paper, Handicap International, 2013, p. 54
Physiotherapists or paramedical staff: manipulation and casts
P&O in case of local production of braces as well as other support to physiotherapist or paramedical staff
Receptionist: registration, database management
Social work or community worker: education of parents.

As mentioned above, training resources are available, but it is important to keep in mind that the training should be conducted by an experienced Ponseti trained professional from local or international level, with a preference to an institutional partner. Here comes the big opportunity to work in alliance with specialists on the thematic (INGOs working in the field of Clubfoot treatment have already developed very interesting tools and resources).

In Senegal and in Bolivia, HI teams are currently using a streaming down training strategy. Both programs selected a doctor, already working on clubfoot, who has been sent to a regional training of trainers (ToT) organized by our partners specialized in clubfoot (Mobility Outreach International, Miracle Feet and Cure International). After coming back from the ToT, these doctors will train the staff in the existing rehabilitation projects to include clubfoot

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19 Such type of professional could be identified through this link to resource professionals per country: [http://www.ponseti.info/ponseti-doctors-by-location.html](http://www.ponseti.info/ponseti-doctors-by-location.html); or by looking for national staff who has the potential and will to be trained on the Ponseti method, who will then function as the focal person in country and could then even train others
management in their services. In addition to that, HI and the partners signed agreements that specify the role of each actor in the development of clubfoot services.

Always with a long term sustainability approach and the maximum impact possible in mind, it is also very important to seek the possibility of including training of human resources to the university curriculums of certain professions, to continuous education organized by professional associations, local teaching institutes, or any other local institution that will potentially replicate and sustain the trainings.

### 3. Information system and research

A well-functioning **health information system** is one that ensures the production, analysis, dissemination and use of reliable and timely information on health determinants, health systems performance and health status.

**Specific objective**

Generation of information that enables decision-makers at all levels of the health system to identify progress, problems and needs related to clubfoot, make evidence-based decisions on health policy and allocate resources optimally.

**Description**

The health information system provides the foundations for decision-making and advocacy. Record keeping and Data management need to be carefully planned from the beginning of the project. It is important to analyze well with our local partners how the record keeping will be complementing the record system already in place. Ideally we would set-up the International Clubfoot Registry Portal (ICR) either online or offline, and train the persons that will use it. After that a specific plan for data collection needs to be elaborated or modified if already in place for other activities. Compilation, analysis and use of this information have to also be formally organized.

As mentioned before there is nowadays no international agreement on one set of data collection for clubfoot, right now, GCI is surveying the existing tools to position a one tool for all.
Activities

Data collection at the rehabilitation services is always a work in progress. It is a dynamic attempt where managers and rehabilitation professionals strive for constant improvement. For its clarity, here it will be exposed in 4 big groups of activity.

a) Data generation

Data generation is frequently associated with monitoring and evaluation. Here we suggest a much broader scope where data is also generated for advocacy to include clubfoot in national strategies, for research on clubfoot treatment, etc. It is for all these reasons that data generation has to be well defined from the beginning, finding the balance between workload of the person registering the data and quantity/quality of data is always challenging. A review of the existing system and a good analysis of the information needed will provide the gaps in this system and will be a good baseline. From there one can decide whether it will be necessary to enrich existing tools with the information targeted for clubfoot. The aim should not be to modify national tools already existing in the system, but a good strategy could be to test the modifications in your projects and then show your results at the national level, if you started with the tools already existing the possibility of appropriation is much higher.

b) Compilation

Not all data collected at the clubfoot clinic need to be submitted to higher levels. Identification of data which need to be disseminated and the determining on how frequently this must be done, to whom and in which form will guarantee efficiency.

Assess also the advantages and disadvantages of incorporating emerging technologies in the data generation and compilation. In case of deciding for it, the same process of pre-test and validation as mentioned before applies.

See Toolbox and in particular GCI data form: 2015 data

c) Analysis and synthesis

The goal of this analysis is not to focus on what is wrong and condemn it, it is to highlight the positive aspects of the service that works, as well as to identify what is going wrong as a basis for improving the services, generating tools for advocacy, changing planning and budgets, etc.
d) Communication and use

An effective way of motivating data producers is to constantly provide feedback to the person doing the data collection (positive and negative). Determine the most effective way of disseminating the data considering the following factors: needs of the target group, best format, budget and project priorities.

Clinical Scoring: There is already some existing clinical scoring used broadly

The Pirani scoring system can be used to monitor improvement during the initial casting phase. It is a 0-6 point scale; the higher the score, the more severe the deformity. The Dimeglio scoring is a 0-20 points scale comprising range of movement measures and four observational features; the higher the score, the more severe the deformity.

Having said all this about data collection we want to point out that HI is in favor to include data on Club Foot treatment in already existing databases, done through the existing health system in each country of intervention. Example Senegal, the data should theoretically be collected from maternity, pediatric and rehabilitation registries and it would be up to our partner and us to see if this is the case before entering in to any activities.

HI will at the same time see with the Global Clubfoot Initiative how to collect data in one single database, using an already existing database within the structure of the ministry of health. It is desirable that all this data collection is in line with the GCI, the MoH and the partner we work with on the ground. In this case the Global Clubfoot Initiative can provide the guidance needed for this process.

The Global Clubfoot Initiative is currently involved in a number of innovative projects with the aim to improve treatment quality and outcomes of patients with clubfoot. One of these projects is to review the different clubfoot databases being used globally, to identify weaknesses and limitations and make recommendations for data collection and management tools that meet clinician, patient educator and organizational needs and to make data collection and usage easier. At the time of publication of these guidelines surveys are being carried out. Results should provide guidance and an agreement should follow among the main implementing partners in order to be able to use only one database and therefore be able to share and unify data for research and advocacy purposes.

The American NGO Miracle feet, intervening in Senegal, will want to implement this project as soon as it is ready, most likely around fall 2017. A lot of indicators collected are taken from the International Clubfoot Registry (ICR) which is a University of Iowa data base. The mobile app based database (by dimagi, a platform called commcare) is an attempt to make data collection more end user friendly.
For Senegal miracle feet will start on paper collecting certain indicators from the ICR and as close to the commcare indicators as possible to then be able to switch over to the commcare platform when the database is finished.

The platform is meant to be shared and used globally. It is a GCI project but miracle feet is spearheading it.

**Indicators**

- A national (or piloting local) set of indicators targeting clubfoot services is agreed among partners
- Uniform data is generated and compiled
- Dissemination plan for the data.

**4. Essential medical products and technologies**

A well-functioning health system ensures equitable access to **essential medical products, vaccines** and **technologies** of assured quality, safety, efficacy and cost-effectiveness, and their scientifically sound and cost-effective use.

**Specific objective**

Ensure equitable access to the products of quality needed for the clubfoot treatment.

**Description**

Ponseti treatment of clubfoot needs basically plaster and serial foot abduction braces. There will be also a need for general consumables which are normally already in place in a health facility: for the minor surgery it needs devices for the tendon section and local anesthesia, and for the general running it needs buckets, towels, and equipment to remove plaster...

This section will focus on the braces as it is the only specific product for clubfoot treatment, specific and absolutely necessary. It is important to keep in mind that we cannot skip this part of the treatment. If braces are not available it is better not to start with the treatment.
Braces must be placed right after the last cast and the use of the brace during the first week supervised. Monitoring access to braces is closely intertwined with at least two other building blocks: service delivery and governance. As a support to the advocacy for access to braces, the list of WHO priority assistive products is a good tool\(^\text{20}\).

See Toolbox

Activities

Braces of different sizes need to be available at all times, with assured quality, and at a price (if any) that users in your local community can afford. The brace consists of two shoes attached to a bar at a specific angle. The clubfoot brace (sometimes called a Foot Abduction Brace [FAB], or Dennis Brown) is an extremely important part of the Ponseti method. It holds the correction of the foot and helps to prevent relapse.

Once the foot is corrected to 70º external rotations, the child’s feet will be measured to ensure that the correct size shoes are fitted once out of the final cast. These shoes are always attached to an adjustable bar that holds them at the correct angle to maintain correction.

There are a few brace types available. The Steenbeek brace (SFAB) designed in Uganda by Michiel Steenbeek, and endorsed by Dr. Ponseti, is an effective low-cost option for developing countries.

The production of the braces is normally accessible at orthopedic workshops; if not at reach in your program there is the possibility to train the local shoe maker in the community to do it\(^\text{21}\).

See Braces section on Toolbox

Indicators

- Availability of the braces (availability of raw material)
- Quality of the braces (availability of technical skills, good and sufficient training).

\(^{21}\) A good resource for that is: http://global-help.org/products/steenbeek-brace-for-clubfoot-type-ii-brace-patterns/
5. Health care financing

A good **health financing system** raises adequate funds for health, in ways that ensure people can use needed services, and are protected from financial catastrophe or impoverishment associated with having to pay for them.

**Description**

As mentioned in the principles of intervention, Handicap International promotes the Universal Health Coverage (UHC), UHC aims to ensure that every child with clubfoot, everywhere, can access quality clubfoot treatment services without the family facing financial hardship as a result. Every year 100 million people are pushed into poverty and 150 million people globally suffer financial catastrophe annually because of out-of-pocket expenditure on health services (WHO, 2012). Financial protection is at the core of UHC and improving financial protection is a central focus of health financing policy.

**Specific objective**

Clubfoot services are sustainable, financially accessible for families and they do not lead families to financial hardship.

**Activities**

The activities relevant here can vary a lot from context to context, in this paper we will focus on two big packets, one is advocacy with health authorities towards UHC and financial access to clubfoot treatment and the other is the financing of the group of activities needed to implement the pilot clubfoot treatment locally.

Handicap International developed a methodology to analyze the financial system related to rehabilitation services in each country. The main objective is to provide Handicap International field teams, and their local partners, with all the data required to understand the economic system for physical and functional rehabilitation, and thus identify ways of

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improving the funding, and the supply and demand for rehabilitation services in low and middle income countries.

On the other hand it is also interesting and practical to look at the expenses it will bring to add a component of clubfoot to an already existing rehabilitation project. The expenses might vary a lot from one context to another and also depend a lot on the partnerships we might be able to establish and therefore the logic repartition of expenses. Here is a list of possible activities to be funded by any of the partners.

| Identification and referral | • Inter-programmatic health coordination meetings: for instance meetings with disability responsible, new born responsible...
• Practical Training of primary health care professionals: 1 day training with children with Clubfoot and practical sessions.  
• Development and printing of written materials for general information of the population and/or for daily screening of primary health care workers. |
|-----------------------------|------------------------------------------------------------------------------------------------------|
| Clinical treatment          | • Registration of children: train local staff already registering the data in the local health facility.  
• 3 days training, normally, of clinical professionals: with practical sessions so it will require the material stipulated for the clinics below. Minimum one doctor as case manager and for the tenotomy, and one Physiotherapist or paramedical staff for the manipulation and casting. There is the possibility to have a rotating doctor assisting more than one clinic.  
• Equipment of clinics:  
  - General equipment for any basic clinic: buckets, running water, cleaning products, chairs...  
  - Specific to clubfoot: plaster, tubular bandage (small sizes). |
| Braces                     | • Practical training of local professionals (for sustainability).  
• International purchase or supply (rapid response).  
• Generate a local bank of devices as they are usable from one child to another. |
| Follow-up of families and parents support | • Field visits by the clinical staff to follow up families (ideally and depending on existence of CBR to refer...).  
• Ideally, and depending on the context, there is the need of human resources to accompany the families (social work, psychology, CBR worker or similar). |
| Coordination                | Human resources that can coordinate the integrated system. |
6. Leadership and governance

Description

Leadership and governance involves ensuring strategic policy frameworks exist and are combined with effective oversight, coalition-building, the provision of appropriate regulations and incentives, attention to system-design, and accountability.

Specific objective

Participate (at all the levels) to the building of strategic policy frameworks for clubfoot and its implementation.

Activities

Activities in this topic should occur in a big range of setting and levels, starting from inside HI in our local teams until the international level joining the advocacy efforts of GCI. Here are some samples of possible activities to launch.

a) Reinforce our internal capacities to participate more and better in the advocacy actions undertaken in the country:
   - Introduction to clubfoot for local staff and identifying a clubfoot focal point for the program
   - Train country staff on advocacy and use of data and testimonies
   - Organize presentations and debate events internally
   - Create and disseminate reference documents
   - Accompaniment of the partners, with for instance coaching and organizational development on the subject, or support to specific initiatives.

b) Build advocacy plan based on our projects’ outputs and evidences:
   - Document the different aspects (data collection, cultural perception, stakeholders involved, policy/regulations existing, project/programs existing, opportunities for advocacy at local and national level).
   - Liaise with key stakeholders and governing bodies so that they are informed and acknowledge HI’s expertise on clubfoot: participate to all relevant meetings, conferences, professional and multi-actor networks at local and international level.

• Collect testimonies to be shared with decision-makers and media, and promoted via HI’s communication tools including social media.

**Indicators**

• Existence of a national clubfoot strategy
• Existence of a national assistive devices strategy that includes clubfoot orthosis
• Inclusion of clubfoot data in national collection.
And now it’s time to act

This Policy Paper presents how HI projects and programs can address the care/management of the clubfoot.

It is a call to (re)mobilise all our country teams to be part of a global initiative aiming to eradicate the clubfoot, a malformation which is not a fatality. We still can be involved in ending the clubfoot disability.

We encourage HI countries/programs to study the situation and existing stakeholders in their countries of intervention.

All together we can be part of a global dynamic, in line with the World Health Organisation Rehabilitation 2030 Call to Action, the Lancet Commission on Global Surgery 2030 and the UN Sustainable Development Goals 2030: the Runfree 2030. Under the umbrella of the Global Clubfoot Initiative (GCI), of which HI is a member, the ambition is to ensure that by the year 2030 at least 70% of children born with clubfoot in lower and middle countries can access treatment. (Currently, less than 15% of children in these countries access treatment that would prevent a lifetime of disability.)

Today, amongst around 50 HI projects in Rehabilitation, only a few of them (Bolivia, Sri Lanka, Sierra Leone, Togo and Burkina Faso coming up) are working on the prevention and cure of the clubfoot.

It is a pathology linked to many of our sectors of intervention: maternal and child health, early detection and intervention, technical devices (the club foot braces is within WHO’s 50 priority technical aids), education.

Our new strategy steers us to work for the tangible improvement to the living conditions of persons with disabilities and vulnerable populations, using innovation, appropriate approaches and organisational agility. And more specifically to strengthen our leadership on access to services specific to persons with physical incapacities and to expand our activities on primary prevention of impairment and chronic disease.

Our intervention methods are proven and recognised efficient, the needs are considerable, yet our interventions are close to none. Only a few rare components of clubfoot care are implemented.

We are regularly asked to be part of the GCI governing structure, yet we will not consider having the legitimacy until we massively implement projects curing the clubfoot. So let’s do it!
APPENDICES

1. Factsheet clubfoot (Nepal)

   ➔ See Toolbox

2. Global clubfoot initiative (GCI) 2015 data collection form

   ➔ See Toolbox

3. Resources

   • Global clubfoot initiative
     http://globalclubfoot.org/

   • Ponseti international
     http://www.ponseti.info

   • World Health Organization - Priority Assistive Products List (APL)
4. Glossary of terms

**Abduction**: Movement of a limb away from the midline (middle) of the body.

**Achilles Tendon**: The tendon that joins the bone of the heel to the calf muscle.

**Adhesion**: Abnormal union of bodily tissues restricting movement.

**Anterior**: At, or towards the front.

**Arthrogryposis**: Children born with one or more joint contractures have abnormal fibrosis of the muscle tissue causing muscle shortening, and therefore are unable to perform passive extension and flexion in the affected joint or joints.

**Bilateral clubfoot (BCF)**: Both feet are affected.

**Clubfoot** (also known as *talipes equinovarus*): When clubfoot occurs the foot is twisted inward and down, and this condition occurs during development in the womb. Physicians have observed that fetuses that develop clubfoot start with a normal foot and then the foot begins to turn inward around the third month. Most children born with clubfoot are not missing any bones, muscles, or connective tissue. It is a congenital condition, meaning that when it occurs it is always present at birth. It is one of the most common congenital deformities. One or both feet may be affected and the affected feet can range from relatively flexible to stiff and rigid. The condition is not painful for the new born, though when a child gets to walking age, walking with an uncorrected clubfoot can be very painful and difficult, if not impossible.

**Congenital**: A condition that is present at birth.

**Deformity**: A condition where some part of the body is drastically different from normal in terms of size, or shape.

**Dorsal**: Top of foot.

**Dorsiflexion**: When referring the ankle, dorsiflexion is the ability to bend at the ankle, and move the foot upward.

**Eversion**: Turning the sole of the foot outward.

**Fibrosis**: Fibrosis is the formation of excess fibrous connective tissue in an organ or tissue in a reparative or reactive process.

**Foot Abduction Brace (FAB)**: A Foot Abduction Brace consists of an adjustable length aluminum bar with adjustable footplates onto which shoes attach. It is recommended that an adjustable bar is used instead of a fixed length bar because the child will quickly outgrow the fixed length bar.

**Idiopathic**: Of unknown cause.

**Inversion**: Turning the sole of the foot inward.
**Ligament**: Connective tissue binding bone to bone.

**Manipulation**: Manually stretching the foot into an over-corrected position.

**Prosthetist/Orthotist**: Health professional that manufactures orthosis and prosthesis.

**Orthosis**: Brace or splint used for support.

**Plantar Surface**: Sole of foot.

**Ponseti**: Is an effective low-cost foot abduction brace option for developing countries.

**Relapse**: When the foot returns to being a clubfoot after being corrected.

**Tenotomy**: Surgical procedure that slices the tendon to lengthen the muscle.

**Unilateral clubfoot**: Only one foot is affected by with clubfoot.

**Valgus**: Directed away from the midline of the body.

**Varus**: Directed towards the midline of the body.

### 5. Acronyms

- **APL**: Assistive Priority Products
- **BCF**: Bilateral Clubfoot
- **CBR**: Community Based Rehabilitation
- **FAB**: Foot Abduction Brace
- **GCI**: Global Clubfoot Initiative
- **ICR**: International Clubfoot Registry
- **IDA**: International Disability Alliance
- **IDDC**: International disability and development consortium
- **IEC**: Information, Education and Communication
- **MNCH**: Mother New born and Child Care
- **MoH**: Ministry of Health
- **PHC**: Primary Health Care
- **P&O**: Prosthetics and Orthotics
- **ToT**: Training of trainers
- **UCH**: Universal Health Coverage
- **WHO**: World Health Organization
Handicap International’s interventions related to clubfoot

The treatment of clubfoot requires the work at different levels and from different actors. This work is exposed in this document.

Handicap International does not aim at working in all the activities exposed in this paper in one program.

The aim is to present the scope of work that need to be implemented in order to set up accessible, sustainable and quality clubfoot services that need to be implemented by a range of coordinated actors.