# NATIONAL STRATEGY AND ACTION PLAN FOR CLUBFOOT CARE IN BANGLADESH

Sustainable Clubfoot Care in Bangladesh

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Message of the Honorable Minister

Message of the Honorable State Minister

Message of the Secretary, MoHFW

Message of Director General of Health Services

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| | |
|---|---|
| AusAid | Autralian Agency for International Development |
| BCU | British Columbia University |
| BMDC | Bangladesh Medical and Dental Council |
| BNC | Bangladesh Nursing Council |
| BRAC | Bangladesh Rural Advancement Committee |
| B Sc | Bachelor of Science |
| BSMMU | Bangabandu Sheikh Mujib Medical University |
| CBHC | Community Based Health Care |
| CC | Community Clinic |
| CHCP | Community Health Care Provider |
| CHW | Community Health Workers |
| CRP | Centre for Rehabilitation & Paralysed |
| CTEV | Congenital Talipes Equino Varus |
| DFATD | Department of Foreign Aid, Trade and Development |
| DGFP | Directorate General of Family Planning |
| DGHS | Directorate General of Health Services |
| DHIS | District Health Information System |
| DMCH | Dhaka Medical College Hospital |

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|---|---|
| D-Ortho | Diploma of Orthopedics |
| EPI | Expanded Program of Immunization |
| FCPS | Fellow of the College of Physicians and Surgery |
| FWA | Family Welfare Assistant |
| FWV | Family Welfare Visitors |
| GoB | Government of Bangladesh |
| HA | Health Assistant |
| HEP | Health Education and Promotion |
| HRM | Human Resources Management |
| ICMH | Institute of Child and Maternal Health |
| IEC | Information Education and Communication |
| IST | In-service Training |
| LD | Line Director |
| LMICs | Low- and middle-income countries |
| MBBS | Bachelor of Medicine and Bachelor of Surgery |
| MD | March of Dime |
| MNCAH | Maternal Neonatal Child and Adolescent Health |
| MoHFW | Ministry of Health & Family Welfare |
| MoU | Memorandum of Understanding |

| | |
|---|---|
| MRCAH | Maternal Reproductive Child and Adolescent Health |
| MS | Master of Science |
| MSK | Musculoskeletal |
| NGO | Non-government Organization |
| NITOR | National Institute of Traumatology, Orthopedics and Rehabilitation |
| OP | Operational Plan |
| PIU | Program Implementation Unit |
| PMMU | Program Monitoring and Management Unit |
| PMR | Postero-medial release |
| PST | Pre-service Training |
| SACMO | Sub-assistant Community Medical Officer |
| SARPV | Social assistance and Rehabilitation for the Physically Vulnerable |
| SC | Steering Committee |
| SCCB | Sustainable Clubfoot Care in Bangladesh |
| SEARO | South East Asia Regional Office (WHO) |
| UHC | Upazila Health Complex |
| UHFWC | Union Health & Family Welfare Center |

| | |
|---|---|
| USD | US Dollar |
| WfL | Walk for Life |
| WHO | World Health Organization |
| ZCF | Zero Clubfoot |

## EXECUTIVE SUMMARY

Disability poses a major developmental and economic challenge to the victims, due to, in addition to the emotional issue, poverty, that emanate from both physical and mental limitations. This therefore, is a concern to the Government of the People's Republic of Bangladesh.

Clubfoot is a form of congenital deformity of the plantar part of the foot. It is an anathema for the other-wise normal people, especially young women, who are denied a good matrimonial future. It also handicaps a victim's earning capacity, driving him to poverty. This is unfortunate as an effective treatment is available since long, although people in Bangladesh are still unaware of this.

Some international and national non-government organizations and funding agencies, e.g., The Glencoe Foundation of Australia (funding Walk for Life) started providing clubfoot services in Bangladesh, through 32 government health care facilities, with approval of the Directorate General of Health Services, since 2009. Sustainable Clubfoot Care in Bangladesh (SCCB) through a collaborative arrangement of NITOR, Bangladesh Orthopedic Society, BRAC, ICDDR'B and British Columbia University (UBC), funded by DFATD started a pilot project in 2012, with internationally renowned Prof. Shafique Pirani of UBC providing technical support. The Canadian government provided Canadian Dollar 4.32 million for the project.

Bangladesh does not have a scientifically conducted clubfoot prevalence survey yet. An empirical estimate gives a figure of 5,000 clubfoot incidences every year, at rate of 1.2 per 1,000 live births. Recent experience however, put the figure higher. Majority of these patients/ children remain outside the reach of the health system, as clubfoot is not a national priority yet.

Government of Bangladesh has passed 'Bangladesh Persons with Disability Welfare Act in 2001. Subsequently a seminar among the relevant stakeholders, including some professional organizations, adopted 'the Dhaka Declaration on Disability' in 2003. These Act and actions support the cause of disability due to clubfoot quite elaborately and adequately with vision. This document is a further step towards strengthening the services for clubfoot in Bangladesh through a structured approach.

The planned future course of action, towards preventing clubfoot related disability in Bangladesh would aim to ensure that:

1. every child with clubfoot is identified in the community without delay and referred timely for availing treatment;
2. An efficient clubfoot treatment and management systems is available in the country;
3. every child with clubfoot is treated effectively through Ponseti technique.

The activities that will be carried for reaching the objectives, stated above would be:

- Strengthening of the management capacity at NITOR
- Integration of Ponseti technique of clubfoot treatment in the medical, nursing and paramedical course curriculum through a series of discussion with the relevant line directors and other stakeholders and through workshops involving the professionals
- Initiating an educational system for clinicians, nurses and paramedics at graduate and post-graduate levels based on Ponseti technique for clubfoot treatment
- Training orthopaedists, one each in district hospitals and in medical colleges, if they have not been trained yet on clubfoot treatment based on Ponseti technique.
- Initiating a continued training system for community based workers for providing clubfoot related competency based services
- Motivating and organizing social workers, NGO and voluntary organizations to participate in the clubfoot treatment program, i.e., prevention of disability that might occur from clubfoot
- Supplying logistics including communication materials
- Conducting communication interventions for the lay people on the cause and treatment of clubfoot treatment
- Strengthening an early detection and referral system

- Ensuring universal coverage for treatment of clubfoot by identifying appropriate number of clubfoot clinics
- Providing follow up and counselling support at community level
- Ensuring service, educational and training quality through provision of adequate and appropriate educational and training tools and through effective monitoring and evaluation, which would be backed up by developing a monitoring and evaluation framework and its meticulous application
- Strengthening knowledge management (for example, research on cause and treatment) and HMIS
- Establishing an efficient monitoring and evaluation system
- Strengthening governance
- Considering gender perspective is service provision, and
- Establishing an effective coordination and collaboration among all the partners and service providers at every nodal level.

# 1. INTRODUCTION

## *1.1* Definition

The congenital clubfoot is the most common serious birth defect of human bones and joints. Congenital clubfoot, or talipes equinovarus, is a complex *deformity* that is readily apparent at birth and affects the muscles, *ligaments*, bones and joints of the developing foot and ankle. The ankle is rotated downward and the toes point inward towards the opposite leg. All foot bones are usually present, but are out of normal alignment. All of the foot and leg muscles are also present, but some are smaller and weaker than normal. *Tendons* and ligaments are contracted, especially behind the ankle and along the instep.

The deformity is characterized by varying amounts of stiffness secondary to a retracting fibrosis of the soft tissues posterior and medial to the ankle, subtalar and transverse tarsal joints. It is easy to see on a newborn examination. It is a 3 dimensional deformity with four components (cavus, adductus, varus and equinus) that affects the ankle, subtalar, transverse tarsal and cuneiform first metatarsal joints of the foot.

Fifty percent of cases affect one foot, and fifty percent affect both feet. Boys are more commonly affected than girls. Sometimes clubfoot runs in families.

Clubfoot does not show any symptoms at birth or during infancy. It does not affect developmental milestones- sitting and walking. The four fixed deformities seen in clubfoot are:

- Cavus – a term that describes increased height of medial longitudinal arch of the foot.
- Adductus of forefoot – a term that describes deviation of the forefoot towards medial body plane.
- Varus of heel – a term that describes deviation of the heel towards the medial body plane.
- Equinus –a term that describes plantar flexion of foot.

Two types of clubfoot in particular can and should be distinguished at birth, as they may affect management:

- Clubfoot associated with myelomenigocoele – note the posterior midline meningocele;
- Clubfoot associated with Arthrogryposis – showing multiple joint contractures. Typically, the knees and wrists are flexed and the elbows extended. Sometimes the hips are flexed, adducted and dislocated.

## 2. EPIDEMIOLOGY

### *2.1* *Etiology*

Exact cause of clubfoot is unknown. Hypotheses of cause refer to associated transient gene activity, as seen in developmental dysplasia of the hips[1] and lack of foetal movement[2] as a cause of clubfoot. A higher risk among first-degree relatives than among more distant relatives has been noted in several epidemiological studies. Furthermore, the risk among first-degree **rel**atives of female clubfoot cases is higher (4.3%) than that of male clubfoot cases (1.3%)[3]. Studies found smoking in pregnancy has a hi**g**her risk of clubfoot[4,5].

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[1] Ponseti, I., Morcuende, J., Mosca, V., Pirani, S., Dietz, F., Herzenberg, et al. (2005). Clubfoot: Ponseti Management. 2nd Edition. Global-HELP Organization, 2005.

[2] Hester, T. W., Parkinson, L. C., Robson, J., Misra, S., Sangha, H., Martin, J. E. (2009). A hypothesis and model of reduced fetal movement as a common pathogenetic mechanism in clubfoot. Medical Hypotheses 2009;73(6):986–8.

[3] Honein, M. A., Paulozzi, L. J. & Moore, C. A. (2000). Family History, Maternal Smoking, and Clubfoot: An Indication of a Gene Environment Interaction. American Journal of Epidemiology 2000;152:658–65

[4] Reefhuis, J., de Walle, H. E. K., Cornel, M. C. (1998).Maternal smoking and deformities of the foot: results of the EUROCAT Study. European Registries of Congenital Anomalies. (Letter). Am J Public Health 1998;88:1554–5

[5] Cornel, M. C., Erickson, J.D., Khoury, M. J., James, L. M., Liu, Y. (1996). Population-based birth defect and risk-factor surveillance: data from the northern Netherlands. Int J Risk Safety Med 1996; 8:197–209.

It is a second trimester developmental abnormality, usually after the sixteenth week of gestation. It can be seen on antenatal ultrasound examination after eighteenth weeks. It may be associated with myelodysplasia, arthrogryposis of multiple congenital abnormalities. These may engender from abnormality in intrauterine packing, primary germ plasm defect, neuromuscular defect, genetic predisposition with environmental modifiers acting in intrauterine period. Clubfoot may represent a final common pathway for disruption anywhere along the neuromuscular unit including the brain, spinal cord, nerve and muscle resulting in a focal posteromedial retracting fibrosis and consequent tarsal anlagen deformation and malalignment.

### ***2.2*** *Incidence*

Clubfoot is one of the most common congenital anomalies in the musculoskeletal system[6]. It occurs in nearly 1 in every 1,000 live births worldwide, representing a significant burden of disease. The incidence of clubfoot varies widely among different populations, from 0.6 and 2.57 per 1000 live births in the UK and US, with males more affected than females in a ratio of 2:1[7] to 6.8 per 1000 births among the

[6] Dobbs MB, Gurnett CA (2009) Update on clubfoot: etiology and treatment. Clin Orthop Relat Res 467:1146–1153

[7] Cardy AH, Barker S, Chesney D, Sharp L, Maffulli N, Miedzybrodzka Z. Pedigree analysis and epidemiological features of idiopathic congenital talipes equinovarus in the United Kingdom: a case control study. BMC Musculoskelet Disord. 2007;8:62.

natives of Hawaii[8], and 6 to 7 per 1000 births among the Maori population in New Zealand[9]. In Africa a rate ranging from 0.9 to 4 per 1,000 live births was reported with a male: female ratio of 2.4:1.0[6]. The gross estimate is around 80% of all clubfoot cases are born in low and middle income countries [10 , 11] . According to Global Clubfoot Initiative (2014)[12] the incidence of clubfoot is 1 per 1000 live births in USA and 1.4 per 1000 live births in Sweden (Wallander et, al., 2006). In Australia, the incidence is higher among the Aboriginal population than the Caucasian (3.5 and 1.1 per 1000 live births respectively). The incidence is 0.76 per 1000 live births in Philippines and 0.9 per 1000 live births in India (Global Clubfoot Initiative, 2014). Davies (1964) reported that the rate is much lower (about 0.6 per 1,000 live births) among Asians than among Pacific Islanders (more than 6 per 1,000 live births)[13]. A worldwide average

[8] Baker S, Chesney D, Miedzybrodzka Z, Maffulli, N. Genetics and epidemiology of idiopathic congenital talipes equinovarus. J Pediatr Orthop. 2003;23:265–272.

[9] Chapman C, Stott NS, Port RV, Nicol RO. Genetics of clubfoot in Maori and Pacific people. J Med Genet. 2000;37:680–683.

[10] Dobbs, M. B., Nunley, R., Schoenecker, P. L. (2006). Long-term follow up of patients with clubfeet treated with extensive soft-tissue release. Journal of Bone and Joint Surgery. American Volume 2006;88(5):986–96. doi: 10.2106/JBJS.E.00114

[11] Christianson, A., Howson, C. P., & Modell, B. (2005). March of Dimes: global report on birth defects, the hidden toll of dying and disabled children. March of dimes: global report on birth defects, the hidden toll of dying and disabled children.

[12] Global Clubfoot initiative. (2014). Retrieved February 17, 2014 from http://globalclubfoot.org/clubfoot

[13] Davies, R. W. (1964). Family studies and the cause of congenital club foot. J Bone

incidence of about 1-2 per thousand live births is generally accepted as a valid estimate.

About half of the infants with clubfoot have bilateral involvements and unilateral deformity occurs more often on the right side[14,15]. It was found that syndromic CTEV are often more severe and resistant to treatment[16].

The March of Dimes (MD) Global Report on Birth Defects estimates that incidence of birth defects in Bangladesh is 58.6 per thousand live births and it is estimated that out of them, there may be approximately 5,000 children born with clubfoot each year. Majority of these children end up as neglected cases as the formal health care system of Bangladesh lacks appropriately trained human resource and

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Joint Surgery Br1964;46:445-63. Retrieved on February 10, 2014 http://boneandjoint.org.uk/highwire/filestream/10689/field_highwire_article_pdf/0/445.full-text.pdf

[14] Chung, C. S., Nemechek, R. W., Larsen, I. J., Ching, G. H. S. (1969). Genetic and epidemiologic studies of clubfoot in Hawaii: general and medical considerations. Hum Hered 1969;19:321–42.

[15] DeValentine, S., & Blakeslee, T. (1992). Congenital talipes equinovarus. Foot and ankle disorders in children. New York: Churchill Livingstone, 1992

[16] Janicki, J. A., Narayanan, U. G., Harvey, B., Roy, A., Ramseier, L. E., Wright, J. G. (2009). Treatment of neuromuscular and syndrome associated (nonidiopathic) clubfeet using the Ponseti method. Journal of Pediatric Orthopaedics 2009;29(4):393–7.

provision for specialized institutional care.[17] (Global Clubfoot initiative, 2014). Majority of these children end up as neglected cases as the formal health systems of Bangladesh lacks appropriately trained human resource and provision for specialized services. Nguyen[18] et al. reported a higher rate of incidence at lower maternal age (below 25 years) at conception.

### ***2.3*** *Other factors*

The risk varies in different groups, e.g.,

- Gender - Male: Female = 2:1
- Race. Australian aboriginal = 3.49/1000, Australian Caucasian = 1.11/1000, Ugandan Nilotic = 1.2/1000, Mauri = 8.07/1000, Hawaiian = 6.94/1000, Chinese = 3.9/1000, Japanese = 0.87/1000
- Family history
  1. Risk of clubfoot in future pregnancy = 1% for 1st degree relative.
  2. Concordance rate = 33% for monozygotic twins, 2% for dizygotic twins.
- Risk of clubfoot in 1st trimester amniocentesis= 1.3%,

[17] Christianson, A., Howson, C. P., & Modell, B. (2005). March of Dimes: global report on birth defects, the hidden toll of dying and disabled children. March of dimes: global report on birth defects, the hidden toll of dying and disabled children.

[18] Nguyen, M. C., Nhi, H. M., Nam, V. Q. D, Thanh, D. V., Romitti, P., Morcuende , J. A. (2012). Descriptive epidemiology of clubfoot in vietnam: A clinic-based study http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3565392/

- Risk of clubfoot in mid trimester amniocentesis = 0.1%
- Risk of clubfoot with heavy maternal smoking = 0.16%
- Risk of clubfoot with maternal diabetes = 0.24%

## 3. TREATMENT OPTIONS

In high-income countries, in 1948, an evidence-based treatment protocol utilizing sequential plaster casting was pioneered by Professor Ignacio Ponseti, which resulted in excellent outcomes among children treated for this condition. It is a non-operative management for severe talipes equinovarus. This method of manipulative treatment became attractive because long-term outcomes demonstrated the majority of feet were pain-free, planti-grade, and functioning at a high level of activity without evidence of degenerative arthrosis.

A retrospectively review was done on 51 children (31 boys and 20 girls; 72 feet) with idiopathic clubfeet deformity treated with the Ponseti method from January 5, 2002, to January 5, 2007. The median age at treatment was 2 weeks (95% confidence limit, 1–2 weeks); there was no difference in age at presentation between boys and girls. The minimum follow-up was 4 months (mean, 19.8 months; range, 4–48 months). A total of 288 casts were applied (mean, 5.5; standard deviation, 0.92). Successful treatment was defined as a planti-grade foot with a normal hind-foot, mid-foot, and fore-foot on clinical examination. Correction was achieved and maintained in 90% (65 of 72) of the feet; 10% (seven of 72) of the treated feet did not improve and needed subsequent surgery. There was no difference in the proportion of children who had tenotomy or previous

treatment among those who presented with residual deformity or recurrence or had surgery.

In the Ponsetti technique following a plaster cast, a foot brace is worn at night for several years in order to prevent relapse. In 95% of cases, proper treatment results in full correction of the feet. Patients who tolerated bracing not only had lower recurrence rates but underwent less surgery[19]. Treatment methods and results of treatment vary greatly though across low- and middle-income countries (LMICs)[20]. A study found 52 of 67 clubfeet corrected with an average of 6.2 casts and concluded the Ponseti method could substantially reduce the disability burden caused by idiopathic clubfeet[21].

[19] R Baxter Willis, Mazen Al-Hunaishel, Luis Guerra, Ken Kontio. What Proportion of Patients Need Extensive Surgery After Failure of the Ponseti Technique for Clubfoot? Symposium: Clubfoot: Etiology and Treatment. Clinical Orthopaedics and Related Research. May 2009, Volume 467, Issue 5, pp 1294-1297 https://miraclefeet.org/

[20] Luke Harmer and Joseph Rhatigan. Clubfoot Care in Low-Income and Middle-Income Countries: From Clinical Innovation to Public Health Program. 09 November 2013. Int J Surgo

[21] Shafique Pirani, Edward Naddumba, Richard Mathias, Joseph Konde-Lule, J. Norgrove Penny, Titus Beyeza, Ben Mbonye, Jackson Amone, Fulvio Franceschi. Towards Effective Ponseti Clubfoot Care The Uganda Sustainable Clubfoot Care Project. Clin Orthop Relat Res (2009) 467:1154–1163

The Ponseti casting method has become common practice in high-income countries during the last decade and a half[22]. It has changed the treatment of clubfoot so that complex posterior medial release of multiple tendons and joint capsules, which was once the standard, is now rarely needed. This treatment involves sequentially stretching the deformed foot and holding the stretches in a series of casts, mentioned above, to restore the correct alignment of the foot gradually. Following the stretching sequence, a minor surgical procedure, percutaneous tenotomy, as mentioned earlier, is nearly always required but can often be done in an outpatient clinic with local anesthetic. Fewer than 10 % required a surgical procedure beyond percutaneous tenotomy done in the office[23].

The results for patients presenting prior to 3 months of age show satisfactory results 94.4 % of the time[24]. Even in those presenting after 3 months of age, fair or good outcomes were achieved non-operatively in 70 % of cases[**25**].

[22] Dobbs MB, Morcuende JA, Gurnett CA et al (2000) Treatment of idiopathic clubfoot: an historical review. Iowa Orthop J 20:59–64
[23] Ponseti IV, Smoley EN (2009) The classic: congenital club foot— the results of treatment. Clin Orthop Relat Res 467:1133–1145
[24] Richards BS, Faulks S, Rathjen KE et al (2008) A comparison of two nonoperative methods of idiopathic clubfoot correction: the Ponseti method and the French functional (physiotherapy) method. J Bone Joint Surg Am 90:2313–2321
[25] Faulks S, Richards BS (2009) Clubfoot treatment: Ponseti and French functional methods are equally effective. Clin Orthop Relat Res 467:1278–1282

Clubfeet treated with the Ponseti method become normal in shape within a few weeks. With proper adherence to brace wear till age four years of age, feet remain planti-grade, strong, flexible and pain free for decades in most cases. A study of long term outcomes after Ponseti treatment reported that, at mean age 34, 63% showed excellent outcome, 16% were good, and 22% were poor - similar to age and sex matched controls with no history of clubfeet.

Though surgery corrects the deformity, scarring and joint incongruity results in early degeneration of joints, stiffness, pain and disability by early adulthood. Long-term outcomes, after surgical treatment, reported only 4% were excellent and 22% were good, whereas 73% were poor. Surgically treated patients had physical function limitations similar to patients with chronic congestive heart failure, awaiting coronary artery bypass surgery or renal dialysis[26].

Left untreated, the foot remains twisted inwards and becomes painful. The walking child bears weight on the thin skin on the top of the foot. Deformity leads to the downward spiral of disability, dependency, and demoralization. Disabled individuals are rarely productive or valued members of society. Their needs add to the burdens of their families and communities and are a significant cause of poverty. Unattended, clubfoot leads to permanent disability

[26] Bangladesh Ponseti Pocketbook (BPP)

and social downgrading of patients. The situation is further compounded by lack of detection and treatment at birth.

A study[27] revealed that clubfoot correction was obtained in all but 3 patients (98%). Ninety percent of patients required ≤5 casts for correction. Average time for full correction of the deformity was 20 days (range: 14–24 days). Only 4 (2.5%) patients required extensive corrective surgery. There were 17 (11%) relapses. Relapses were unrelated to age at presentation, previous casts needed for correction). Relapses were related to noncompliance with the foot-abduction brace. Four patients (2.5%) underwent an anterior tibial tendon transfer to prevent further relapses.

Serial casting is successful in avoiding extensive postero-medial release (PMR) in only 11% to 58% of patients with idiopathic congenital clubfoot. Ponseti technique claims to avoid PMR in 89% of cases by using the specific technique of manipulation, casting, and limited surgery. A study was conducted on 27 patients undergoing the Ponseti technique (34 feet), matched to 27 control patients (34 feet). All patients underwent serial casting, begun within the first 3 months of life. The parameter studied was the need to perform PMR within the first year of life. In the Ponseti

[27] Jose A. Morcuende, Lori A. Dolan, Frederick R. Dietz, and Ignacio V. Ponseti. Radical Reduction in the Rate of Extensive Corrective Surgery for Clubfoot Using the Ponseti Method. *Pediatrics* Vol. 113 No. 2 February 1, 2004, pp. 376 -380

group, only 1 (3%) of 34 feet required PMR. In 31 (91%) of 34 feet, percutaneous Achilles tenotomy was performed at age 2 to 3 months. The average duration of casting was 2 months. In the control group, 32 (94%) of 34 feet required PMR by the first year of life, despite a longer casting period. Based on the initial success with the Ponseti method, they no longer believe that PMR is required for most cases of idiopathic clubfoot[28]. Foot abduction splints are crucial to avoid recurrence. Longer follow-up will determine whether this matches Ponseti's reported outcomes.

In a comparative study, after an average follow-up of 54.9 months (range 44-68), 35 (57%) clubfeet in group 1 required surgery, while 27 (44%) clubfeet had a residual deformity at last follow-up. In the Ponseti group, 45 (94%) clubfeet were fully corrected at last follow-up (average 29.2 months, range 16-45) while 3 (6%) clubfeet had residual deformity and required surgery. Achilles tendon tenotomy was performed with no complications in 47 clubfeet (in group 2) at an average age of 2.4 months (range 2-4 months)[29].

[28] Herzenberg, John E; Radler, Christo; Bor, Noam. Ponseti Versus Traditional Methods of Casting for Idiopathic Clubfoot. Journal of Pediatric Orthopaedics: July/August 2002 - Volume 22 - Issue 4 - pp 517-521

[29] Segev E, Keret D, Lokiec F, Yavor A, Wientroub S, Ezra E, Hayek S. Early experience with the Ponseti method for the treatment of congenital idiopathic clubfoot. The Israel Medical Association Journal : IMAJ. 2005, 7(5):307-310

The Ponseti casting technique is reported to have a high success rate in the treatment of idiopathic clubfoot. Non-operative treatment of clubfoot provides a lower complication rate, less pain, and higher function as the patient ages than operative treatment. To demonstrate serial post-treatment change in clubfeet over time, three clubfoot rating systems were utilized in the current study.

Patients compliant with the Ponseti technique and treated before the age of 7 months, had a 92% success rate at an early follow-up after casting was completed. It is not the purpose of this article to analyze the long-term clubfoot treatment result but to establish tools which can be used to judge initial success with the Ponseti technique. Complications are few and minor, limited to equipment used and cast technique[30].

The parents of twenty-one patients in another series, did not comply with the use of orthotics. Noncompliance was the factor most related to the risk of recurrence, with an odds ratio of 183 ($p<0.00001$). Parent's education (high-school education or less) was a significant risk factor for recurrence (odds ratio=10.7, $p<0.03$). With the numbers available, no

[30] Lehman, Wallace B.; Mohaideen, Ahamed; Madan, Sanjeev; Scher, David M.; Van Bosse, Harold J. P.; Iannacone, Michelle; Bazzi, Jamal S.; Feldman, David S. A method for the early evaluation of the Ponseti (Iowa) technique for the treatment of idiopathic clubfoot. Journal of Pediatric Orthopaedics B: March 2003 - Volume 12 - Issue 2 - pp 133-140

significant relationship was found between gender, race, parent's marital status, source of medical insurance, parent's income and the risk of recurrence of clubfoot deformity. In addition, the severity of the deformity, the age of the patient at the initiation of treatment, and previous treatment were not found to have a significant effect on the risk of recurrence[31].

Little information exists about the degree of efficacy of the several non-operative treatments, such as manipulation and casting, used in correcting the pathology of the virgin clubfoot deformity. The steps in the correction of the displacements and anomalies of the skeletal components have not been noted. The method reported to have the best long-term results is that of Ponseti. A magnetic resonance imaging protocol was devised to image the described chondro-osseous abnormalities of the virgin clubfoot deformity and to illustrate the changes that occur with the Ponseti method of treatment. Scans were performed at the beginning of, in the middle of, and at the end of treatment. Images obtained with this protocol largely agree with post-mortem studies of clubfeet. All of the major chondro-

[31] Matthew B. Dobbs; J.R. Rudzki; Derek B. Purcell; Tim Walton; Kristina R. Porter; Christina A. Gurnett. Factors Predictive of Outcome After Use of the Ponseti Method for the Treatment of Idiopathic Clubfeet. *J Bone Joint Surg Am*, 2004 Jan; 86 (1): 22 -27

osseous pathology could be visualized in vivo. With Ponseti treatment, all the abnormalities seen on the initial scans either improved markedly or corrected completely. Treatment resulted in correction not only of the abnormal relationships of the tarsal bones, but also of the abnormal shapes of individual tarsal osteo-chondral anlages, probably because of changes in growth resulting from changes in mechanical loading of fast-growing tissues[32].

Early recognition and appropriate treatment of relapse is an important component of the Ponseti technique of clubfoot correction. After correction of a clubfoot deformity by the Ponseti technique, relapse usually involves equinus and varus of the hind-foot. Cavus and adductus rarely recur to a clinically significant degree. Clubfoot recurs most frequently and quickly while the foot is rapidly growing-during the first several years of life. Recurrence of deformity will almost always occur, even after complete correction with the Ponseti technique, if appropriate bracing is not used.

Treatment of clubfoot relapse in infants and toddlers is identical to the original correction maneuver. In a patient approximately 2.5 years of age, a relapse can be treated with anterior tibial tendon transfer to the third cuneiform with

[32] Pirani, Shafique M.B.B.S., F.R.C.S.C.; Zeznik, Laura M.D.; Hodges, David. Magnetic Resonance Imaging Study of the Congenital Clubfoot Treated With the Ponseti Method. Journal of Pediatric Orthopaedics: November/December 2001 - Volume 21 - Issue 6 - pp 719-726

or without Achilles tendon lengthening. The indication for anterior tibial tendon transfer is the presence of dynamic supination during gait. After tendon transfer, bracing is no longer required because the eversion force of the transferred tendon maintains the correction.

In a long-term follow-up study of patients treated by the Ponseti technique, the necessity for anterior tibial tendon transfer did not compromise the outcome with respect to level of pain and functional limitations. Because anterior tibial tendon transfer is joint sparing, the foot retains maximal strength and suppleness. Good long-term results can be anticipated despite clubfoot relapse[33].

A series of 134 feet of 92 patients with Dimeglio grade 2, 3, or 4 deformities was treated with the Ponseti method. Twenty-four percent of feet were of complex deformities at initial presentation to the authors' clinics. *Results*: At a mean follow-up of 46 months (range 24–89) joint release surgery in 97% of feet could be avoided. Sixty-seven percent required a percutaneous tenotomy of the Achilles tendon. Relapse rate was 31% (41 feet). 2 relapses were treated by restarting the use of orthosis, 17 with re-casting, 18 with anterior tibial tendon transfer following a second relapse, and 4 feet with extensive joint surgery.

[33] Dietz FR. Treatment of a recurrent clubfoot deformity after initial correction with the Ponseti technique. http://europepmc.org/abstract/med/16958495. Downloaded on 08 Sept. 2015.

Compliance with the use of orthosis was identified as the most important risk factor ($P$<0.0001) for relapses. Previous unsuccessful treatment attempts by other conservative methods did not adversely affect the results unless the cases had iatrogenic deformities. Cases with iatrogenic deformities from previous treatment had a significantly increased risk of non-compliance and relapse. Experience of the treating surgeon and cast complications were also related to relapses[34].

Esteemed readers have to note the fact at the end of this discussion that, since clubfeet are not all the same, each needs its own treatment protocol and prognosis. It is therefore, useful and necessary to determine the type of clubfoot at presentation for onward actions and prognosis. This however, does not negate the importance and success of the Ponseti technique in any way, as the technique is applicable to all types of clubfoot, albeit with varying degrees of success, based on the type, age of seeking care and compliance with the treatment protocol.

[34] Süleyman Bora Göksan, Ayşegül Bursalı, Fuat Bilgili, Sevan Sıvacıoğlu, and Semih Ayanoğlu. Ponseti technique for the correction of idiopathic clubfeet presenting up to 1 year of age. A preliminary study in children with untreated or complex deformities. Archives of Orthopaedic and Trauma Surgery. January 2006, Volume 126, Issue 1, pp 15-21

## 4. CURRENT SITUATION OF CLUBFOOT TREATENT AND TEACHING IN BANGLADESH

The following section deals on the historical perspective of clubfoot treatment, the mode of present clubfoot service delivery, existing projects and programs, and clubfoot related education in Bangladesh.

### *4.1 Historical perspective*

Before 1971- before the independence of Bangladesh, there was no orthopedic surgeon in the country. Clubfoot care was provided by the pediatricians and general surgeons through serial plasters and surgery. The first specialized orthopedic hospital was established in 1972 through the efforts of Prof. Gharst, the first director of the National Institute of Traumatology Orthopedics and Rehabilitation (NITOR), set up in the public sector, allowing availability of a spectrum of treatments for clubfoot management, mostly surgical as conventional wisdom dictated that non-surgical methods were largely ineffective. Since 2005 the Institute opted for the Ponseti technique for the clubfoot patients.

### *4.2 Mode of clubfoot service delivery in Bangladesh: present projects and programs*

Bangladesh has a network of Ponseti Clubfoot clinics at 44 medical college and district hospitals across Bangladesh, managed by national and international non-government organizations (NGOs). Each clinic operates once or twice a week, and is expected to provide specialized care for

children thought to have clubfoot deformity. These are expected to be staffed with skilled healthcare providers, and should be under the supervision of a specially trained orthopedic surgeon.

Walk for Life (WFL), a local NGO funded by an international NGO, based in Australia, introduced a pilot project adopting the Ponseti method of management of clubfoot care in 2009 in Satkhira district of Bangladesh. Early results from the pilot were encouraging and in 2010, Zero Clubfoot (ZCF) joined in the efforts and started their program in the south eastern districts of the country. Later, other NGOs like LAMB Hospital and CRP Bangladesh started providing clubfoot care in different parts of the country in direct collaboration with WFL. Another NGO named SARPV (Social assistance and Rehabilitation for the Physically Vulnerable) started providing clubfoot care independently from 2011.

A Memorandum of Understanding (MoU) was signed in September, 2011 between the MOH&FW and Glencoe Foundation (parent organization of Walk for Life) to establish a network of clubfoot clinics across Bangladesh at mostly secondary and tertiary hospitals. Based on this MoU, WfL has established clubfoot clinics in several public health facilities across the country, as mentioned above.

Each clinic is managed by a physiotherapist, recruited by the project, who conducts clinical assessment and casting

for clubfoot. The orthopedic surgeon of the corresponding facility is attached to the clinic as the supervising technical expert and responsible to perform tenotomy when indicated. One clinic manager is responsible for 2-3 clubfoot clinics.

The service delivery model of Zero Clubfoot is almost identical to that of the Walk for Life model. However, the LAMB hospital operates the clinic in their own premises utilizing existing resources in collaboration with WfL. SARPV has established a separate bilateral partnership with MoH&FW and utilizes the Upazila Health Complexes to run the clubfoot clinics.

Table 1. Number of health facilities providing clubfoot services

| Level | Type of Facility | # of Facilities | Total facilities | Additional Details |
|---|---|---|---|---|
| **Tertiary Level** | Specialized hospital | 03 | 08 | NITOR, ICMH (autonomous-WfL managed) |
| **Secondary Level** | District Hospitals | 24 | 64 | WfL or ZCF managed |
| | Private health Facilities (NGOs) | 03 | | ZCF, LAMB, CRP |
| **Primary Level** | Upazila Health Complex | 02 | 481 | ZCF or SARPV managed |

| | | | |
|---|---|---|---|
| | Private Facilities | 01 | SARPV independently |
| | **Total** | **44** | |

BSMMU: Bangabandu Sheikh Mujib Medical University,
NITOR: National Institute of Traumatology, Orthopedics and Rehabilitation,
ICMH: Institute of Maternal, Neonatal and Child Health,
WfL: Walk for Life,
ZCF: Zero Clubfoot Foot

Source: WfL, ZCF, SARPV and LAMB informants

Medicine and logistics (plaster of Paris) required for casting are provided by the NGOs operating the clubfoot clinics. They obtain the logistics from local market and maintain the supply chain. In case of stock outs, the patients have to buy the logistics from outside. In case of a tenotomy, the patients have to buy the suture materials, medicines and other logistics from outside.

A brace making industry at Jessore district uses local cobblers to make braces suitable for the Ponseti services. The brace is known as the Steenbeek Foot Abduction Brace, locally these are known as the Bangla Braces. The main raw material- leather, is collected locally; other raw materials are also available locally.

On an average, a cobbler can manufacture 5 to 7 pairs of braces per day. The cost to make each pair varies from 3 to 5 dollars. Each pair is sold between 5 to 10 dollars. Walk for Life and other NGOs procure the braces from these

cobblers and supply to the clubfoot clinics across Bangladesh. Although the NGOs claim to provide all these materials free but on inquiry service seeking families informed that they had to pay for all the logistics.

WfL and other NGOs depend on the grants received from different institutional and personal donors for service delivery and related costs. Rotary International of Bangladesh and AusAid are the largest contributors to clubfoot care in Bangladesh. None of the NGOs has received any financial aid from the government of Bangladesh in the past.

WfL has a monitoring team to check quality of services at its operating clinics. Every clinic receives a supervisory visit by this team once a quarter. In addition, the country managers also pay random visits to these clinics. Walk for Life has/is giving treatment to about 8,000 patients.

Some of the orthopedic surgeons have raised concerns over the role of the physiotherapists appointed by the NGOs for Ponseti technique based clubfoot service, as they sometimes perform tenotomy without any supervision.

The British Columbia University (BCU), with financial support of the Government of Canada (DFATD) started a pilot project on Ponseti technique based services, in NITOR in 2013, BRAC is the collaborating partner, handling all the non-clinical functions. The project will wind up in 2017.

*4.3 Teaching on clubfoot in Bangladesh*

In MBBS course curriculum, clubfoot in mentioned under Orthopedics and Traumatology section. The types, presentation and its treatment options are mentioned. The Ponseti technique however, has not been mentioned as a treatment option in the MBBS course.

The Director of NITOR and the Head of the Department of Orthopedics, Dhaka Medical College opined that the MBBS curriculum is already extensive and does not have scope to include a separate section on the Ponseti technique. However, an orientation for medical graduates on clubfoot care in Bangladesh and the Ponseti technique as the standard of care would be appreciated.

At the post graduate level, there are three courses pertaining to orthopaedics. MS in orthopedics- a five year course offered by BSMMU, NITOR and selected medical colleges; FCPS in Orthopedics awarded by Bangladesh College of Physicians and Surgeons after a period of two years; and a three year diploma course offered by BSMMU, NITOR and selected medical colleges. In the $4^{th}$ and $5^{th}$ years of MS course the Ponseti technique is discussed in detail as a conservative management option including casting, bracing and surgical correction of clubfoot. Treatment of different types of clubfoot is mentioned including the Ponseti technique in Part 2 of FCPS. Year 2 of D-Ortho course deals on the different treatment options of

clubfoot with details on the Ponseti technique, but without any practical.

Director of NITOR, the Secretary General of Bangladesh Orthopedic Society and the Head of Department of Orthopedics from Dhaka Medical College (DMCH) have suggested for hands on training for the post-graduate students to achieve the required skills.

Although the BSc, diploma, or special additional nursing course curriculum mentions clubfoot under Traumatology and Orthopedic section and treatment of clubfoot is discussed with special attention to casts and care of plaster, the Ponseti technique is not mentioned in any of those curricula. The Registrar of Bangladesh Nursing Council opined that the information on clubfoot care is not adequate and there is a need to incorporate more in the curriculum.

Physiotherapy graduation course is offered by the University of Dhaka and NITOR in public sector and 3 other institutions in private sector. The diploma course is offered by many private institutions. Physiotherapy graduation course deals on clubfoot/ congenital foot deformity under Physiotherapy in Orthopedics and Orthopedic Medicine sections. Types and treatment options of clubfoot are mentioned with emphasis on exercise, casting, bracing, etc. However, the Ponseti technique was not mentioned in the curriculum.

There are 20 types of in-service trainings for doctors, nurses and paramedics in public sector, managed by the line director of in-service training of Directorate General of Health Services (DGHS). The duration of these trainings ranges between 1 to 28 days. None of these trainings covers any treatment option related to clubfoot care.

Walk for Life reportedly organized several training sessions by international experts since 2009 and trained 08 local master trainers and other service providers. Since 2013, the trainings are being conducted by the local master trainers. WfL also reported to have trained all the supervising orthopedic surgeons and clinic managers of the 44 clubfoot clinics in Bangladesh.

WfL has developed a training material titled 'Introduction to the treatment of congenital clubfoot using the Ponseti Method' which it uses for training. Dr. Shafique Pirani [an internationally renowned expert in the Ponseti method and an Orthopedics Professor in the British Columbia University (Canada)] has reviewed the document.

### *4.4 Activities for capacity building for Ponseti treatment in Bangladesh*

Ponseti's method of nonsurgical treatment of the congenital clubfoot is now the treatment of choice advocated by the National Institute of Traumatology and Orthopaedic Rehabilitation (NITOR), Bangladesh Orthopaedic Society,

and Bangabandhu Sheikh Mujib Medical University. But two problems mire the capacity of providing this technique based services (discussed below in detail).

WHO SEARO in collaboration with Government of Bangladesh and International Center for Diarrheal Diseases, Bangladesh organized a national workshop on 'Development of National Strategic Plan for Birth Defects Prevention and Surveillance in Bangladesh' in October 2013 aiming to develop the strategic direction and action plans to address major birth defects in the country. The workshop prioritized major eight visible and structural birth defects including clubfoot to be tracked to estimate the disease burden and formulate country-specific action plan to address these health problems.

The Department of Foreign Affairs, Trade, and Development (DFATD) Canada funded the Clubfoot Project in Bangladesh in collaboration with the British Columbia University with the goal to make Ponseti treatment available in Bangladesh. Named as the Sustainable Clubfoot Care in Bangladesh (SCCB), this initiative is focusing on capacity development, health systems strengthening and research capacity in the country. The exclusive community-based identification and referral of foot deformity to manage the clubfoot cases at government facilities provided a unique opportunity to introduce an active community-based

surveillance to estimate the sex-specific incidence of clubfoot in Bangladesh.

The project's methodology is to build capacity through training clubfoot detection and Ponseti treatment in medical colleges and clinics in Bangladesh. The effort to reduce morbidity and disability associated with clubfoot is an important contribution to the economic growth of the country and improvement of the social and economic status of affected individuals.

Through the SCCB project, which will wind up in 2017, 59 master trainer belonging to 23 medical colleges including the Bangabandhu Sheikh Mujib Medical University (BSMMU) and NITOR were trained. Besides this, 33,500 BRAC community based workers were oriented so far. The project also has a plan to orientate 6,000 community clinic staff. Orientation meetings were also held with the relevant faculty members of BSMMU, Dhaka Medical College and Suhrawrdy Medical College. SCCB project also developed training and teaching materials, e.g., Ponseti Care Pocketbook for Bangladesh, with all the necessary illustrations for providing clinical and community based care. This is being revised now to make it further suitable for adoption in Bangladesh. Power point presentations are also available for training and teaching various categories of clinical and non-clinical staff.

The Bangladesh Persons with Disability Welfare Act 2001 included physically crippled, which developed either congenitally or as result of disease or being a victim of accident, or due to improper or maltreatment or for any other reasons; which lead to physical incapacity or loss of mental balance. The Act suggested for formation of national and district committees and ordained for awareness building, identification of cases, treatment, education, health care, rehabilitation and employment, transport facility, social security, and formation of organization by persons with disability.

Persons with Disabilities Rights and Protection Act in Bangladesh, 2013 identified the following types as disability

- Autism
- Physical
- Psychosocial
- Psychosocial refers to schizophrenia or other disabilities such as clinical depression,.
- Visual Impaired
- Speech Disability
- Intellectual Disability
- Hearing Disability
- Hearing-Visual Disability
- Cerebral Palsy
- Down Syndrome
- Multiple Disabilities

A regional symposium on disability held in 2003 and organized by the National Forum of Organizations Working with the Disabled (NFOWD) from 9$^{th}$ -11$^{th}$ December, in

Dhaka dealt on: national policies and legislation, education of people with disabilities, community based rehabilitation, employment and job opportunities, rights of women and children with disabilities, accessibility, self-help movement, information and communication technology, prevention and early intervention, safe environment, social security.

Some of the recommendations given in the NFOWD were: increase in awareness raising activities on cause and availability of treatment and social and clinical services available to the disabled; targeting all of society, including those with disabilities for relevant interventions; empowerment of adults and children with disabilities to encourage them to voice their opinions; providing equal educational opportunities to all children and adults with disabilities; equal employment opportunities through positive discrimination in creating jobs for disabled; inclusion of disabled in all social activities; reflection of the rights for children with disabilities in all children's Acts; targeting for awareness rural and remote areas where communities have less access to information and for provision of services through grassroots level organizations; language sensitivity to avoid negative connotations; further research on all disability issues etc.

## 5. Key gaps in management and service capacity

As of now, Bangladesh is providing Ponseti technique based clubfoot training in 44 medical college and district hospitals. Clinicians of some of these health facilities (23, including NITOR and BSMMU) have received training from both the aforementioned NGOs and also through SCCB Project, as discussed above. Problems however, weaken the efforts taken so far. Some of these problems have been enumerated below, for addressing these:

i. Incoordination among the service providers and service providing facilities and institutions, which created an environment of competition rather than collaboration among the relevant organizations, causing inefficiency in resource utilization;
ii. Weak monitoring and supervisory functions within the management organizations and for the provided clubfoot services;
iii. Poor quality in providing services due to:
    a. poor monitoring and supervision
    b. utilization of inappropriate human resources
    c. absence of service standards;
    d. inadequate capacity development
iv. Inadequacy in covering the whole country evenly and inefficient geographical distribution of resources;
v. Inadequate graduate and post graduate education for medical, nursing and paramedical professionals and for community based workers for providing clubfoot treatment, especially on Ponseti techniques;

vi. No systematic training plan/ program for hospital based clinical service providers and community based workers (for identifying, referring and supporting clubfoot treatment);
vii. Inadequate resources and unclear/ incomplete information about the resource base of different service managing partners, in particular information that is related to training, trainers, training materials and clinically trained personnel;
viii. Weak management structure for addressing Ponseti technique based clubfoot treatment;
ix. No overall strategy and guidelines for assisting clubfoot treatment in Bangladesh.

## 6. Rationale for developing a national strategy and guidelines

In light of the lacunae, mentioned above, it is necessary that a National Strategy and Guideline is prepared and approved by the Ministry of Health & Family Welfare, Government of Bangladesh (GoB). This strategy will explicate the existing weaknesses in the system spanning capacity for managing clubfoot in the country and will suggest ways and means to build the system effectively to provide clubfoot treatment particularly based on the Ponseti technique by strengthening the medical, nursing and paramedic courses, training of community based personnel and strengthening the primary, secondary and tertiary care facilities.

## 7. VISION, GOALS, OBJECTIVES, MAIN ACTIVITIES AND INDICATORS

### 7.1 Vision

No child will suffer from humiliation in the society or suffer economically in Bangladesh due to clubfoot.

### 7.2 Goals

Every child suffering in Bangladesh from clubfoot will be treated effectively.

### 7.3 Objectives

4. Every child with clubfoot will be identified in the community without delay and referred timely for availing treatment;
5. An efficient clubfoot treatment and management systems will be available in the country;
6. Every child with clubfoot will be treated effectively through Ponseti technique.

### 7.4 Activities

1. Strengthen management capacity
2. Integrate Ponseti technique of clubfoot treatment in the medical, nursing and paramedical course curriculum
3. Train and educate clinicians
4. Train community based workers

5. Motivate and organize social workers, NGO and voluntary organizations to participate in the clubfoot treatment program, i.e., prevention of disability that might occur from clubfoot
6. Supply logistics including communication materials
7. Conduct communication interventions
8. Strengthen early detection and referral
9. Ensure universal coverage for treatment of clubfoot
10. Provide follow up and counselling support
11. Ensure service quality
12. Strengthen knowledge management (for example, research on cause and treatment) and HMIS
13. Establishing an effective collaboration and coordination among the relevant partners and service providers at every level
14. Establish an efficient monitoring and evaluation system
15. Strengthen governance
16. Consider gender perspective is service provision

## 7.5 Program Indicators

1. People's attitude towards the cause of Clubfoot.
2. Percentage of Clubfoot cases reporting for treatment
3. Number of clubfoot clinics which have service providers trained on Ponseti technique
4. Number of community based workers trained on Clubfoot care
5. Modifications done in the graduate and postgraduate

medical, nursing and paramedic courses on Clubfoot in particular on Ponseti technique

6. Percentage of parents who follow the clubfoot protocol meticulously
7. Percentage of the children treated with cast who show its side effects
8. Result of treatment among clubfoot children one year after removal of brace

## 8. STRATEGY FOR SUSTAINABLE CLUBFOOT TREATMENT AND EDUCATION IN BANGLADESH

### a. Orientation of public health care policy makers, planners, managers and teachers

Clubfoot treatment, economically speaking, does not appear to give a lucrative rate of return. However, the social and individual benefits that accrue cannot be measured economically. If measured in terms of benefit cost ratio, the social gain would be enormous. The self respect, the stamina, the agility that can be attained from an effective clubfoot treatment and their effect on individual productivity can be substantive, while the amount of investment required for treating a case of clubfoot is astonishingly negligible.

An orientation program will be necessary ab initio for the policy makers, planners, national level program directors and managers. This has to be organized combinedly to let these very important people to know about the importance of Ponseti technique for treating clubfoot. Subsequent to which, they will hopefully agree to and endorse the required budget (to be shown in the line director of hospitals and clinics and line director of pre-service and in-service training of DGHS) for provision of services and for developing and implementing an education/training program respectively. The program directors and mangers would include LD, MNCAH; LD, MRCAH; LD, CBHC and LD, Nursing Services as they are the gatekeepers of the community based workers. For communication interventions

technical and funding, support of the line director (LD) of health education and promotion, i.e., Chief, Bureau of Health Education will also be required, so it is warranted that she also is included in the orientation program. Orientation of program managers will be necessary and useful to obtain their support in catering Ponseti technique based clubfoot treatment by the physicians and their team members at primary health care level.

A second and separate orientation would be required for the clinical teachers. This also needs to include the Nursing Council, and the Medical and Dental Council and the State Medical Faculty. This will have two pronged aims. Firstly, to orientate the teachers, trainers, curriculum developers and approvers to update the relevant course curricula and facilitate Ponseti technique based education and training in relevant teaching and training institutes. Secondly, to encourage and make the clinicians interested to use the Ponseti technique based treatment for clubfoot. This orientation will also have to include the hospital managers.

A third orientation program should be organized for 64 district and about 30 medical college hospital based managers and clinicians to sensitize them and make them interested to make good use of the Ponseti technique based services available in these hospitals for clubfoot treatment.

**b. Communication interventions at the community level**

Lack of awareness, superstition, long travel distance, out of pocket payment and long follow up schedule for patient care have been found to be the main barriers in clubfoot care seeking in Bangladesh, as per a survey conducted by BRAC in 2015; which is akin to findings in some African countries.

People in rural areas consider the birth defects to be a curse of the God. There is reservation in some communities to take a neonate out before 30 days after birth. Lack of awareness in the communities about clubfoot and availability of care also deter people from seeking clubfoot related services.

The above facts will have to be considered when a community based health communication intervention is planned and executed. It will be futile and impossible to attempt to address all the barriers to seeking of clubfoot services. What the system can and should do is, firstly, make family care givers of clubfoot patients understand and believe that clubfoot is a genetic problem and that it is not a curse or punishment of God. It is a developmental problem that relates to the way a child is positioned in mother's womb and may be with the way a pregnant woman has been taken care of during her pregnancy.

Family members of the clubfoot children have to know that effective treatment is available for clubfoot, which can cure almost all cases, if treatment is managed meticulously, with good abidance to the treatment protocol and good follow up. Facts and figures will have to be presented to the family

members through a flip chart as described below.

It will be advisable to impart the above information through interpersonal communication using a flip chart that will show photos of 'before and after treatment effect' among treated clubfoot children and also on the treatment protocols that will be practiced by all parties.

Clarity is called for, even on what the clinicians will do, for confidence building among family members. Instead of mass media interpersonal communication will be more efficient as the uninflected families will hardly be interested other-wise.

### c. Resources required to implement Ponseti treatment pathway

Cost considerations are important from community and family perspectives. In Malawi, one clubfoot program estimated that the cost to treat a clubfoot was about $200[35], when cost of health care workers and indirect costs of building space and administration are added. The clubfoot program in Uganda prescribed the amount of supplies needed for clinics to treat 70 clubfeet in a year[36]. The cost of supplies was about $37.51 for each foot treated. According to the Miracle feet, an average of $250 per child is the cost to pay to transform a child's life[37].

[35] Saltzman HM (2009) Foot focus: international initiative to eradicate clubfeet using the Ponseti method. Foot Ankle Int 30:468–471

[36] Uganda Clubfoot Project (2008) Ponseti clubfoot management: teaching manual for health-care providers in Uganda. Global HELP, Seattle

[37] https://miraclefeet.org/

Treatment methods and results of treatment vary greatly though across low- and middle-income countries (LMICs)[38]. A study found 52 of 67 clubfeet corrected with an average of 6.2 casts through the Ponseti method, which could substantially reduce the disability burden even when caused by idiopathic clubfeet[39]. In Bangladesh, an estimate showed that an amount of Taka 7,000 to sometimes an exceptional amount of 30,000 in a few cases (from USD 100 to USD 400 approximately) may be required for treating clubfoot, including costs of surgery. By and large, it may be said that the amount needed for treating a clubfoot case in Bangladesh will be USD 100 to USD 200. The budget includes cost of plaster of Paris, brace, tenotomy and other surgeries. If an average budget of USD 150 is taken for treatment per clubfoot then for 5,000 patients it should be about USD 750,000 or Taka sixty crores only per year.

Besides cost of treating clubfoot cases there are other facets of expenditure that also needs to be worked out for a complete budget, e.g., orientation, workshop, communication materials, training and orientation materials, training, additional cost for treating other abnormalities independent of clubfoot, physical

[38] Luke Harmer and Joseph Rhatigan. Clubfoot Care in Low-Income and Middle-Income Countries: From Clinical Innovation to Public Health Program. 09 November 2013. Int J Surgo

[39] Shafique Pirani, Edward Naddumba, Richard Mathias, Joseph Konde-Lule, J. Norgrove Penny, Titus Beyeza, Ben Mbonye, Jackson Amone, Fulvio Franceschi. Towards Effective Ponseti Clubfoot Care The Uganda Sustainable Clubfoot Care Project. Clin Orthop Relat Res (2009) 467:1154–1163

renovation, furniture (cupboard, table, chair), automation (computer, printer, photocopier), management cost including budget for travel for monitoring and evaluation and program review, cost for additional human resources, e.g., consultant.

**d. Measures and strategies to fill gaps and manage constraints including policy to support Ponseti technique based clubfoot pathway by MoHFW**

Four gaps exist in the pathway of providing Ponseti technique based clubfoot treatment. Firstly, except the MS graduates no other orthopedist has any skill on Ponseti technique. So those who are already are positioned as orthopedist in district hospitals and medical college hospitals with FCPS and diploma in orthopedics cannot provide Ponseti technique based service for clubfoot. It is obvious therefore that they would require training on the technique. This will require moving the Line Director (LD), In-service Training of DGHS and getting his agreement first; so that he keeps enough fund in his operational plan for this training to these orthopedists on Ponseti technique.

Secondly, clubfoot service is a heavily community and family based intervention. Follow up and community/ family oriented counseling and health communication are necessary. This is a completely blank area now. Filling up gap in this area will require the blessing of the above mentioned line directors in the form of their agreement and provision of fund in their operational plans for this training, if not covered in the OP of LD, IST, DGHS.

The third is intuitively clear, which is, there is a need to include Ponseti technique in the curriculum for FCPS and D-orthopedics to enable the graduates of these courses to provide Ponseti technique based service an effective manner. A similar upgrading of nursing and paramedic curricula should also be useful too. These moves will require blessing of the Bangladesh Medical and Dental Council (BMDC), the Bangladesh Nursing Council (BNC) and the State Medical Faculty. A workshop has been suggested above to get their support in modifying the relevant course curricula.

The fourth is developing a follow up and support service at the community level, which is totally absent now. This would require modification of the job description of the Health Assistants (HA), Family Welfare Assistants (FWA), Community Health Care Providers (CHCPs), Family Welfare Visitors, Sub-assistant Community Medical Officer (SACMOs); as these are the ones who either conduct deliveries at community level or see a newborn first on the part of the health and family planning departments. Hospital based nurses also need modification of their of job description, as they also either conduct, help a physician in conducting deliveries or at least come across a newborn quite frequently. These officials need training to make them proficient to identify and refer the clubfoot cases, after making a differential diagnosis at community level and assist a physician on providing clubfoot services based on Ponseti technique at hospital level.

All the district hospital has an orthopaedist, while some orthpedists are also available at upazila health complexes. Medical college hospitals have a whole department of orthopaedics, with several orthopaedists. But not all of these orthopaedists have any skill in conducting Ponseti technique; as has been stated above, those who obtained FCPS and D-Ortho have not been trained on Ponseti technique. At least one of them needs training in district and medical college hospitals.

Development of 5,000 clubfoot cases per year in the country would mean 78 per district per year or 6 to 7 per month. This would mean that there should be a maximum of one clubfoot clinic per district. If the districts have medical colleges then the clinics should be established in the medical college hospitals, and not in district hospitals. In those districts where there is no medical college hospital than these clinics should be set up in district hospitals.

**e. Measures for including the Ponseti Clubfoot Care pathway in the education system of health care providers in Bangladesh.**

Two types of service providers will be relevant to clubfoot treatment. One type is those who can get education on clubfoot treatment in their pre-service period. Both nurses, SACMOs, other paramedics and doctors fall in this type. The other type is those who have no scope of getting education on clubfoot treatment, in their pre-service period, e.g., family welfare visitors, community health care

providers, health assistants and family welfare assistants and their field supervisors. All they are left with is a scope, if warranted, of getting training on supporting and assisting clubfoot treatment process in their in-service period.

Adequate modifications of the present curricula should be warranted to ensure that enough practical training is arranged for medical students of the post-graduate courses.

Changes in the course curriculum of the nurses and paramedics will also be required. This has to be competency based. This will mainly hinge on their responsibility of providing community and family based counseling; follow up of treatment compliance, protocols and regimens, e.g., how the condition of the plaster is, if there is any side-effect of plastering, how is the child doing with the bracing and how the bracing rules are being practiced, are the caregivers following the clinic visit schedules meticulously etc.

## 9. PLAN OF ACTION

### a. Orientation

1. An orientation intervention is warranted to sensitize the policy makers including the planners of the Ministry of Health & Family Welfare (MoHFW) and those in the health units of the Planning Commission, an orientation program may be warranted for half a day. The other participants of the orientation program would be the relevant line directors of DGHS, MoHFW, i.e., LD, MNCAH, LD-IST, LD, PST, LD, CBHC, LD, HEP, Directorate of Nursing Services and those of the Directorate General of Family Planning (DGFP), e.g., LD, MRCAH, LD, IEC; HRM and Planning unit officials of the Ministry of Health & Family Welfare, and from other ministries, e.g., Directorate General of Social Welfare, and Directorate General of Women and Children Affairs. Involvement of the leaders of the Bangladesh Orthopedic Association will also be warranted.

   The aims of this orientation will be to sensitize the policy makers, planners and national level managers to agree on making provisions in the sectoral plans and the respective operational plans scope for providing Ponseti technique based clubfoot services in a given number of hospitals-medical college hospitals and district hospitals.

2. A second orientation would be for facilitating modification of the existing curriculum of the FCPS and D-Ortho and undergraduate curricula for medical, nursing and paramedic courses; training for those who already graduated from these courses without any skill on clubfoot or Ponseti technique and for the community based health workers for who no such training is available. This orientation has to be participated by the representatives of the Bangladesh Medical and Dental Council; Bangladesh Nursing Council; State Medical Faculty; LD, IST; BSMMU; University Grants Commission, Center for Medical Education, the operational level members of the Bangladesh Orthopedic Association and Pediatric Association.
3. A third orientation program may be arranged for the 64 district and about 30 medical college hospital managers and orthopedists to make them interested to support Ponseti technique based clubfoot treatment.

NITOR will have to take the move and should be the organizer of the orientation program. A consultant may prove to be handy to support NITOR.

The first and the second orientations might include about 30 officials each. A presentation may be made on the cost incurred for providing Ponseti technique based clubfoot

treatment and on the areas of social and individual benefits that are obtained. A public health specialist of repute may be invited for developing and making the presentation.

It is also suggested that a renowned orthopaedic surgeon gives a presentation on the utility of the Ponseti technique – the ease of treatment, the quality maintained, the result obtained with the conditions that a good follow up will have to be ensured, referring to the fact that the follow up would not be a difficult proposition, in light of the manageable number of cases in the community. Enough material in this regard is available in the background section on these.

The orientation sessions may be held in any of the DGHS conference rooms or at NITOR for the second and third orientation. The first orientation should be held in a five star hotel to attract high ups and media.

The first orientation program should be inaugurated by the Honorable Minister, MoHFW. Director, NITOR should be the one to provide the welcome address in these orientation programs. Secretary, DGHS, and DGFP, MoHFW and DGs of the Department of Social Welfare and Women and Children Affairs should also be invited to be Guest of Honor.

Secretary, MoHFW or in his absence DGHS may be the Chief Guest in the other two orientation programs. As alternative, Director, Medical and Allied Education and Director, Hospitals and Clinics may be chief guests respectively in the second and third orientation programs.

**b. Training and adoption of the Standard Operating Procedures of Ponseti Clubfoof Care**

*1.* Training

*i. Modification of course curriculum for graduate and post graduate medical, nursing and paramedic courses*

For inclusion of Ponseti technique in orthopedics courses, the LD of pre-service training has to be convinced that this is an efficient technique for treating clubfoot in children. This may come by if the Director, NITOR moves the line directors, by leading a group to brief them personally. Further impression will be created in the orientation program that has been suggested above for the relevant officials. If the line director and the Ministry of Health and Family Welfare are impressed that the Ponseti technique is an efficient technique then actions should be taken to introduce skill development processes, based on it, at least at all the post-graduate levels, i.e., FCPS, D-Ortho, besides MS degree.

This will require a workshop of all the relevant experts; faculty members; LD, PST, DGHS and the three regulatory councils. This has been described in detail elsewhere in this document. The clinical course curriculum may be developed/ modified based on the Ponseti Pocketbook developed for Bangladesh, as mentioned below and elsewhere in the document.

*The following actions will be taken for modification of course curricula*

- Establish a working/technical group;
- The working/ technical group, with the help of a consultant, assesses and examines the existing orthopedic courses, subject and topic in under and post-graduate medical, nursing and paramedic curricula. This map assesses how clubfoot related topics and Ponseti technique may be a part of the present teaching tools - modules and materials, in these courses;
- A workshop is convened to (i) workout how clubfoot treatment/ Ponseti technique based treatment protocol may be included in the present course curriculum and (ii) develop teaching materials and modules, in light of the assessment and as per competency
- The working/technical group conducts dialogue with the relevant offices and officials (e.g., Director, Pre-service Education, DGHS (LD, PST); Center for

Medical Education; Bangladesh Medical and Dental Council; Bangladesh Nursing Council; State Medical Faculty; Bangabandhu Sheikh Mujib Medical University; National Institute of Traumatology and Orthopedic Rehabilitation) to get their agreement on modification of the relevant course curricula and the relevant processes;

- The group, supported by the consultant develops a training curricula for those who have already graduated and are already providing medical/ health care, without any training on clubfoot treatment in primary or supportive role (e.g., case finding, counseling, follow up, referral), as per competency;
- The consultant prepares a report on inclusion of Ponseti technique in different medical/ nursing and paramedic courses, as per competency and the report is submitted to the LD, PST for adoption, who would forward it to respective Councils for approval and inclusion in the respective curricula
- The group, with the help of a consultant, explores how much, and in which phase/semester/ year Ponseti technique based curricula may be included in the different curricula as per their competency
- Field test is conducted on the developed tools and finalize, print, deliver teaching materials/modules to medical colleges, and nursing and paramedic institutes
- Identify and enlist master trainers trained earlier for

taking classes in undergraduate medical, nursing and paramedic courses.

*ii.* *Training for Ponseti technique based treatment for clubfoot*

Trainings will be needed for those doctors, nurses and paramedics who will be expected to provide Ponseti technique based services (in medical colleges and district hospitals) but who were not trained to do so.

All the public sector medical colleges will have a Ponseti Training Centers and will manage on-job training if and when required, for orthopedists and their team members, e.g., medical officers, nurses and paramedics to assist the orthopedist. This training will be required on job basis, until the fresh medical graduates and fresh post-graduate orthopedists are getting training on clubfoot management, through their revised course curriculum. These centers will be equipped with adequate and appropriate training tools and fund for training based on need. The tools would also include communication materials besides the technical tools and media of training.

- The clinical treatment technique and standard operating procedure for clubfoot treatment by clinicians is available in the Clinical Guidelines for the Management of Clubfoot Deformity using the Ponsetti Methods, Ponseti Int., January 2015,

Version 1.0. This manual may be adapted both for developing course curriculum for graduate and postgraduate medical, nursing and paramedical courses and also for training of different categories of staff from clinicians to community based workers.

- The working group suggested for inclusion of Ponseti clubfoot treatment into the existing educational curriculum, supported by a consultant, develops a training curricula for those who have already graduated and are providing medical/ health care, without any training on clubfoot treatment in district and medical college hospitals;
- The group designs, develops/ produces and/or participates in preparing, printing, developing, procuring educational/ training materials (e.g., audio-visual materials, print materials, dummies etc.). Help is suggested to be taken from the Ponseti Pocketbook;
- The group develops a training schedule
- Line director, In-service Training, DGHS (LD, IST) funds and Director, NITOR (as Program Manager) manages the training program for all relevant categories of personnel (health assistants, family welfare assistants, family welfare visitors, nurses, and sub-assistant community medical officer-all at primary health care level and orthopedists and

nurses at district and medical college hospitals;

- ❖ Enlist the master trainers trained earlier;
- ❖ Conduct graded trainers' training at divisional (medical college) and district (district hospital) orthopedists, with the help of the master trainers;
- ❖ Develop monitoring tools for divisional and district level trainings and services;

- Target: Training of 120 district hospital orthopedic surgeons and medical officers by 2017

*iii. Training for non-clinical/ community based staff*

Bangladesh does not have any cadre of counselors. Clubfoot training like many other non-infectious and non-communicable diseases requires skilled counselors. It is imperatives therefore that nurses, paramedics and community based workers are trained on how to counsel and what to counsel on by the way of clubfoot treatment. The same categories of workers may be involved in follow up of patients under cast to see the effects and practices of casting and bracing and also ensure clinic visits by these patients regularly.

Since they are the first staff often to conduct delivery or come across a newborn they also need to be trained on how to identify a clubfoot case by following a differential diagnosis. They need to refer a reasonably correctly identified case to the health facilities.

A flip book of 15 to 20 pages, will be useful for training community based workers to enable them to perform their clubfoot related services. This should be in four colors, in hard bound glossy paper of 500gm weight/ page. A total of 1,000 copies of such flip book, 18 inches by 12 inches, will be warranted.

The group suggested above, works out a curricula and schedule for training and develops training materials. Fund should come from LD, IST or other relevant LDs, as per the line of staff control.

Targets: (i) 481X2 nurses in phases from upazila health complexes, (ii) 481 upazila health and family planning officers, (iii) 80 BRAC regional and divisional managers, (iv) 55,000 Shashtho Shebikas, (v) 50,000 health and family planning workers at upazila, union and community clinic level.

2. Standard operating procedures for providing service

i. *Provision of care by community level workers:*

Identifying children with clubfoot is best done at the time of birth when the child has contact with medical personnel. The second chance is at the time of immunization. Screening for clubfoot might be integrate with these health care services at the community level. NGO service providers may also be involved in the identification process.

Family and community based health communications need to be based on the family and social scenarios and facts. While organizing and providing a health communication, the communicator needs to keep these, as discussed below, into consideration, to communicate successfully to impact the practicing of clubfoot treatment protocol at family level.

Mothers have to spend more time with the clubfoot children at the expense of other children. Society and the nation carries the burden of clubfoot associated disability and poverty. Females may be less likely to get married and have children. Parents carry the burden of guilt as they may feel that the child was born deformed as the result of a curse on them.

Despite social, family and economic implications stated above, people do not exhibit the level of interest, that is expected of them in reporting for treatment. The main barriers to attending clubfoot clinics, as found in a Uganda study for

example, were: parents caring for other children at home, lack of a family member to provide financial support while away from home receiving treatment, expense of transport from home to clinic, and the distance from home to clinic[40].

While some communications (and counseling, as an extension) need to be taken up at family/ community level by community clinic level workers, some will have to be organized at hospitals, since the provided orientation/ counseling/ advice will have to be applied at home. Before parents leave the clinic, they need to be advised about care of the cast at home. For example, the cast should not become wet. If the cast gets very wet, if child cries inconsolably or if the toes become swollen or discolored then the family caregivers must report to the health care providers.

Once children start walking the deformity causes shoe wear concerns. As they grow older and bigger the deformity becomes painful, and impairs mobility, that limits play and school access, particularly if children have to walk to school. With early adolescence, painful mobility is compounded by cosmetic concerns. In later adolescence and adulthood, limitation of social and employment opportunities leads to demoralization and despair and high risk for poverty.

[40] Kazibwe H, Struthers P (2009) Barriers experienced by parents of children with clubfoot deformity attending specialised clinics in Uganda. Trop Doct 39:15–18

Assess community awareness level on clubfoot – people's and communities' beliefs, practices, family and social support and inclusion and accordingly take up the following activities.

The family care givers need to know that relapse in clubfoot treatment may be quite common, if protocol is not followed meticulously. To prevent relapse parents need to be taught how to use these. Braces are to be worn 23/24 hours a day for the first two months, then when sleeping till the age of 4 years. No braces are needed during the day at this time. Children with clubfeet should attend the clubfoot clinic regularly till age 4 to check the shape of the foot, gait, and to assure the brace fits. This prolonged treatment period can be difficult for parents and children. Community health workers support parents to adhere to the protocol. Children with well-corrected feet can stop wearing the brace on the fourth birthday.

Parents need to be told that every week for usually about five weeks, the child should return to the clinic to have the old cast removed, the foot again manipulated into a better position and recast. The parents will see improvements in the shape of the foot each week and will be more compliant to the subsequent advices given.

The importance of counseling and health communication in clubfoot treatment cannot be overemphasized. One series with good compliance for example, indicated that only 74 % of

parents understood that irregular follow-up and brace use would result in relapse of clubfoot. More concerning was that during the casting phase 79% of parents did not know that they would be responsible to ensure their child's wearing the brace after completion of the casting phase[41]. These results point to a need to improve the education of families about the treatment process and their role in it.

Follow up care in a patient's community by trained community health workers or allied health professionals, is essential to ensure adherence to casting regimens. It also provides psychosocial support to patients and families, and identifies patients with complications early.

It is necessary that community level health workers understand the family background well, e.g. misconceptions of condition, treatment, and results of treatment; poverty; guilt and shame; burden of care for other children and family members; burden of treatment process - getting to hospital (distance, cost)/ at hospital/ at home during manipulation, casting and bracing; long duration of treatment; social, economic and family context of family caregiver of a patient.

Community based health workers will monitor treatment complications and arrange for urgent review if found; will

[41] Kazibwe H, Struthers P (2009) Barriers experienced by parents of children with clubfoot deformity attending specialised clinics in Uganda. Trop Doct 39:15–18

check if the cast becomes tight (which can reduce blood circulation causing the toes to swell and change the color of the toes); check if the cast has become soft/wet/soiled. Clubfoot casts are made of plaster and are not waterproof. Therefore the casts have to be kept dry. If the casts become wet, they can soften and then will not work. If the cast becomes very wet, the skin will also become wet and can suffer damage. They should also:

- Refer the child to the clinic as a routine or whenever required.
- Encourage the parents to complete the casting on time and remind them of the date of the next appointment and ensure their presence to the clinic on due date
- Check if the child is wearing the brace as prescribed. (Sometimes parents think the brace is no longer needed as the foot looks corrected).
- Reinforce the message that bracing is vital to a good outcome and problem solving.
- Ensure that the brace fits well (in case it does not the following may happen: the child's foot gets a sore spot or blister when the brace is on; the parents find it difficult to get the child's foot into the brace; the child's foot escapes from the brace at night; the brace is too small – the toes hang over the edge of the shoe; the child is in pain in the brace and they cry in the brace. Help the parent problem solve why the child is crying. Even if there is no problem with fitting the child might cry. Allow time to the child to get

used to it. After a few days the child settles down). Failing to use the brace - even for one night - is like without the brace.

- Ask the parents to go to the clinic for a brace check to resolve the problem, if any.
- Ensure regular/ scheduled and timely clinic attendance of family care takers and the child patient for clinical checks and other purposes
- Monitor and promote adherence to treatment protocols and maintain a record of their findings.

Before beginning treatment, parents need to be informed, advised, and encouraged to:

- Understand the “cause” of their child’s clubfoot;
- Understand all aspects of the upcoming treatment;
- Openly discuss social, cultural, and financial constraints to treatment;
- Adhere rigorously to the appointment schedule;
- Communicate regularly and openly with clinical staff throughout all phases of treatment;
- Comply strictly with the bracing protocol and follow-up appointments;
- Openly discuss social, cultural, and financial issues regarding brace use;
- Seek support from family, community, health workers, and others, as needed.

People should know that clubfoot responds well to treatment. When treated by medical experts, children with clubfeet without other medical problems will have feet that are capable of normal life. The foot may have been held in a curved position in a crowded uterus; for example, if there are twins, which might cause clubfoot. This positional clubfoot is corrected quicker than idiopathic or syndromic clubfoot. Parents and the society should know that the actual cause of clubfoot is not known and parents do not have to feel at fault, as it is not a curse from the God but due to something else.

Service providers should not draw any rosy picture and should not give false hopes to parents and rather should tell them the complexities of treating clubfoot. Clubfoot has a stubborn tendency to relapse, or come back, after casting correction. Relapses are treated the same way, through manipulation and casts, although casts are applied less frequently and typically correct within fewer castings. Rarely a clubfoot may be resistant. In such a case, your orthopaedic surgeon may recommend surgery, such as a tendon transfer, which would be explained by your surgeon at that time. There may be some discomfort for your baby as he or she adjusts to the treatment, but the process is likely to be more painful for parents as a caring parent than it is for the baby.

Children with clubfeet corrected by the Ponseti Method grow up to have feet that are almost normal in shape and function.

For children with one clubfoot, the corrected foot and calf may be slightly smaller. Children with corrected clubfeet grow normally and participate in most sports or leisure activities. Studies in adults show that patients treated using the Ponseti Method continue to have as strong and as healthy feet as adults born with normal feet.

Parents face many barriers in accessing care for children born with clubfeet, and then in adhering to treatment protocols. One barrier is that Ponseti treatment takes many years. The grass-root staff can help parents in their homes to overcome barriers, improve adherence to treatment protocols and help improve outcomes. Community level workers' activities should include:

- Inquiry whether parents are facing any barriers
- Acknowledging and discussing approaches to overcome barriers, some of which include:
- Raising awareness
- Reassuring of the need for care for good outcomes
- Reassuring that the parents are not at fault. They did not cause the clubfoot. They should not feel guilty or shame of causing the clubfoot in the child.
- Helping parents recruit help from others to assist in the care of children at home whilst they take the child to the clubfoot clinic.
- Reassuring parents that the grass-root workers will visit regularly during treatment to check on the child, during

casting and bracing phases, and help if there are problems

Parents come to the clubfoot clinic full of apprehensions about their child's foot. They worry about what may be wrong, why it happened, if and how it can be treated, and whether they will be able to cope with the financial and practical obligations of the treatment. They worry whether their child will grow up disabled, will go to school, whether their child will be able to participate in society in the same way as others.

Parents may feel their child's condition is their fault, or a curse that has to be lifted first. Therefore it is important to counsel parents, to allay their fears, to inform them the condition is treatable and the outcomes are good. Explain about the diagnosis of clubfoot. Explain that clubfoot is common, and that the cause is unknown. Reassure the parents that the clubfoot is not their fault or a curse.

Historically, clubfeet were treated with extensive surgery. Parents may ask for this. Recommend Ponseti's method of treatment rather that surgery as it is the worldwide standard of care. Research has shown that, with proper adherence to treatment protocols, the outcomes are much better than surgery without the risks of anesthesia. Children grow up and are able to walking and running just like other children. They can wear normal shoes. Adults with Ponseti treated clubfeet continue to enjoy freedom from pain and good function.

Also, take time to describe the interventions - serial manipulation, casting, tenotomy and bracing - so that the parents understand their purpose, risks and benefits. Once informed, parents will be more likely to understand the importance of each stage and be willing to complete the extensive treatment protocols. Reassure that even though Ponseti treatment takes many years and is demanding of the parents. Encourage them that the clinic and community health workers will help them overcome barriers they may face in adhering to treatment protocols.

When parents report to a health facility, they are likely to be anxious, tired and emotional. This is all natural. To minimize stress and make the appointment effective:

- Allow plenty of time to get to the appointment.
- Request parents to bring diapers and any other needs for the baby in case a change is needed.
- Request parents to bring a full bottle for feeding (if not breast-fed).
- Parents might like the community workers to write down the questions for them, so that they do not forget those.
- So take a pen and something to write instructions on.
- Counsel parents to be patient – the office or clinic may be busy with equally important schedule.
- Ready the parents, for they may need a longer parking and/ or waiting time.

- Inform the parents not to keep any plans for later part of the day.

After a cast, advise the parents that if the following are seen in the baby then there is nothing to worry. The baby will/may:

- move his or her legs without discomfort
- have normally-colored, rash-free skin around and near the cast
- have normally-colored toes that are not swollen fuss a bit, but will be consolable

Advise that the parents must see the doctor (if necessary take the baby to the emergency room), if the following are seen in the baby:

- baby's toes are swollen or not normal in color (are blue, black, white or red)
- the cast is wet with urine or other fluid
- baby's skin shows a red rash on the legs, or abnormal color or condition
- an is odor coming from the cast
- baby is crying inconsolably

If the child has residual tightness or weakness in some muscle groups, a physiotherapist may recommend exercises specific to the concern. For younger children, this may include play activities that incorporate climbing, squatting, or walking on different angles or grades to naturally stimulate balanced use

of the muscle groups. Exercises also help your child keep up with age-appropriate motor skill development, improve balance, coordination and walking pattern.

Workers should give the following advices to the parents clubfoot babies/ family care givers

- Clothing: Dress up the baby with clothes with snap buttons that open right up, rather than having to be pulled off over the legs, are most easy to deal with. Stretchy pants with loose fitting legs and an elastic waistband also work well. Sleepers with toes will sometimes fit over the cast, or you can cut off part of the sleeper leg(s) and put a sock or soft bootie on your child to keep the foot or feet warm.
- Bathing: While the baby is wearing a cast, he/she will need sponge-bathing, as the cast is not waterproof and should not become wet. The baby may be placed in the tub or sink and have a bowl of warm water close by. Dip cloth/sponge in the warm water, wring out excess water, and wash the baby. A sponge bath at the edge of the tub works well too. Sit on the edge of the tub with the feet inside and the baby in the lap with a towel over the cast(s). This allows to run the water at a trickle, while baby's hair, face and upper body are washed. Then clean the lower body with a washcloth. Parents have found that bathing this way is faster and less stressful to one's back than bending over the baby or the sink, particularly as babies get heavier!
- Cast removal: If plaster of Paris is used for casting, some

clinics may request the parents to soak the baby's cast at home before bringing the child for recast. Usually a bath or sink will be filled with warm water and the cast completely submersed. A wet towel is wrapped around the cast and leg to soak for 30 minutes. The technician will likely have left a small bump of material on the cast. When this bump can be easily separated from the cast, the plaster is soft enough to unwrap. An explanation is advisable to the parent/child, if s/he understands, what will ensue, and what is to be expected when the case is being removed, so that the child is psychologically ready to face the situation.

Under the brace the baby may be fussy. Advise as follows:

- Providing the brace is fitted well, crying only indicates frustration at not being able to move their legs independently because of the brace. Once babies get used to wearing the brace, they become much more comfortable.
- Babies get used to the brace, usually after the first night or two, and a normal routine is established.
- If the baby is crying and parents are worried that the brace may be inconsolably. Check for signs of skin irritation, such as unusual redness, swelling, bruises, blisters, and sores. If you see these, do not reapply the brace and damaging the feet, remove the brace. (Rarely, the brace irritates the skin, particularly if it is improperly applied. Babies will then cry seek your doctor's advice. Brace

adjustments may be needed). If the skin looks okay, reapply the brace right away. This will prevent your baby from 'learning' that crying will result in parents removing the brace.

- Correctly worn, the brace must be quite tight on the child, especially across the middle of the foot. Red marks in this area may be a common phenomenon. During the hour out of full-time wear these marks will fade. Advise that there is no need to put lotion on these marks as the skin can break down (become macerated).
- Blistering on the heels can be a sign that the shoe was not worn tightly enough. The heel must stay down in the shoe. If blistering is noticed, or there are signs of an infection, a doctor and/or an orthotist should be notified so that this can be corrected as soon as possible. These issues need to be addressed right away to ensure your child's comfort.
- If the baby keeps crying, remove and reapply the brace. This will allow you to check for beginnings of blisters, indicating slipping in the shoes, and is good practice for putting the brace on.
- Child's heels need to be checked for bright red spots, which usually indicate that the shoe was not worn tightly enough. If there is difficulty with this, the orthotist may add a pad above the heel. If red heel marks persist or are severe, contact doctor.
- Train parents/care givers on how to check the length of the bar in the brace by measuring it across the child's shoulders. Too short a bar can be a cause of discomfort.

- Parents should play with the child in the brace to help him or her get used to it. The child cannot move his or her legs independently, so parents need to teach the child that kicking and swinging the legs together is possible. Parents may gently push and pull on the bar to flex and extend the child's knees. Kicking the bar "straight" will help to stretch the tight tendons of a clubfoot. How to do these must be taught by the trained health care workers to the parents.
- The bar of the brace can be padded with a bicycle handle pad to protect the care giver, the child, and household furniture. Training is required on this.
- Occasionally check the bolts which attach the shoe to the bar and ensure that they are tight.
- Make sure baby's socks fit well; poorly fitting socks can bunch up and cause friction or blisters.
- When child goes for nap and at night time put on the brace. The child is less likely to fuss if the brace is a consistent part of their normal nap and bedtime.
- To keep little toes warm, socks can be put over the boots. Buying slightly larger-toed sleepers may be tried and just a slit cut from the last snap can "hook" it over the boot toe.
- Foot Orthotics are custom-made shoe inserts which may be used to support a child's foot to optimize alignment, accommodate a leg-length difference, or support collapsing arches.
- During the correction phase, normal baby stimulation and play is all that is necessary. Although babies should sleep

on their backs, the Canadian Paediatric Society recommends it is also important that they experience 'tummy time' when they are settled and awake to learn how to hold up their head and put weight through their arms. Babies in casts can still be placed on their tummy or on their sides with support. The serving doctor or a physiotherapist need to show the parents various ways of positioning and holding the baby while in casts. Infants in casts can do most things considered normal for their age, except of course, take baths.

- After casting is finished and the baby is in braces, a physiotherapist may suggest some basic exercises to do during the one hour of "off time" from the brace, such as:
    - Heel cord stretches, to maintain the elasticity of the Achilles tendon, and
    - Moving the foot in every direction to maintain a full range of motion.

Other community based activities may be organized, e.g., :

- Create parent support group, and include community leaders
- Orientate the support group members in batches and raise public awareness through mass-media
- Build awareness and provide overview of the Ponseti Clubfoot Care Pathway,
- Information has to be given on roles of parents/CHWs, location of clubfoot referral clinics

Arrange photo exhibition of the treated child before and after treatment, to inform and encourage other victim's / care takers to take treatment.

Routine recognition of foot deformities at birth, early referral to and effective treatment by trained staff are the hallmarks of a successful management of clubfoot, the cycle of which begins at community and domiciliary level. Delayed or missed steps at any stage can jeopardize the outcome. This requires therefore that all the grass root workers screen every child for foot deformities at the first examination, preferably at birth, as a routine. The following procedures should be followed for diagnosing a case of clubfoot at domiciliary/ community level.

- About 3% of all newborns have foot deformities, where the feet look bent or twisted out of shape. Most are due intrauterine crowding and are quite flexible. Some, however, are true congenital malformations and require careful assessment, diagnosis, and treatment to prevent deformity and long-term painful disability. Distinguishing these requires training and experience.
- Nurses and midwives at hospital births, and community level staff at home births should routinely screen the feet of every newborn for foot deformities. The SS/SK should look at all feet and compare them to normal. If the foot does not look normal, they should gently move the foot in different directions, and see if it

moves in a normal fashion. Infants' feet are flexible as most bones are soft cartilage. Feet that look normal and are flexible can safely be left alone. Any foot that has an abnormal shape or does not move freely should be considered possibly abnormal and referred for further assessment. They should also counsel the parents to attend the clubfoot clinic for a medical assessment and reassure that early treatment is very successful, if a problem is present.

- Record the details of pregnancy, delivery, family history of clubfoot, social history, other medical history and treatment of clubfoot to date if any. (Ponseti surgery etc.).
- Conduct a general and musculoskeletal (MSK) exam. Look for signs of other congenital MSK and neurological abnormalities.
- Examine the spine for midline defects.
- Examine other major joints and hands for contractures.
- Examine the hips for instability.

*A decision tree as below may be followed for diagnosing clubfoot cases and deciding on the treatment modality:*

1. Is there a history or clubfoot or does the foot show cavus, adductus, varus and equinus? Yes – continue to decision 2. No - deformity is not a clubfoot

2. Are there any other congenital abnormalities? Yes = diagnosis of Syndromic Clubfoot. No = continue to Decision 3.

3. Is there a history of previous clubfoot treatment. Yes = continue right arm. No = continue left arm (please see the Ponseti Pocketbook for Bangladesh).

4. Is the child walking? Yes = diagnosis of Untreated Walking Clubfoot. Does the foot show cavus, adductus, varus and equinus? No = continue to Decision 5.

5. Is there a complete plantar crease? Yes=diagnosis of Atypical Clubfoot. No=Diagnosis of Untreated Non-Walking Clubfoot

6. Is there a history of clubfoot surgery (apart from tenotomy or tibialis anterior tendon transfer)? Yes = Post Surgical Clubfoot. No = continue to Decision 7

7. Is there any remaining cavus, adductus, varus or equines after treatment? Yes = diagnosis of Persistent Clubfoot. No = the clubfoot is well corrected.

8. When the clubfoot diagnosis by type is confirmed at the clinic, parents need to be counseled about clubfoot and about the need of Ponseti clubfoot treatment.

*Clubfoot related clinical information for community level staff*

1. *Correction.* The Ponseti method uses very specific and gentle manipulations to align the foot in a more normal position, and casting to allow the soft bones to "set". Usually, about five or six weekly casts and a minor procedure to the *Achilles* tendon (tenotomy) are all that is needed to achieve full correction. Difficult clubfeet sometimes need more casts.

2. *Prevention of Relapse.* After correction, a brace is then necessary to prevent relapse. The brace is worn full time (24 hours) for two to three months, and then during nighttime and naps until the child reaches at least four years of age.
3. *Surveillance and follow up.* The clubfoot child will have regular visits until fully grown to monitor how the legs and feet are growing. All children are different and length of treatment may vary. Follow up is rarely needed after the bones stop growing – at around age fourteen for girls and age sixteen for boys.

*ii.* Standard services to be given by the different members of clubfoot clinic care team:

1. Orthopedic surgeon

An ortheopedic surgeon is trained to diagnose and treat a wide variety of musculoskeletal conditions and injuries. Pediatric orthopedists are trained on the unique problems and needs of children. But only trained orthopedic surgeons can provide Ponseti technique based treatment for clubfoot. Only an orthopedic surgeon trained on Ponseti technique will perform tenotomy or surgeries, e.g., tendon transfer/ reconstructive surgery for clubfoot.

2. Physiotherapist

Physiotherapists are health care professionals trained to assess, treat and prevent disease, injury or conditions

that affect the structure and/ or movement of the human body through treatment, exercise and education, provided they have been trained up accordingly, after a general training as a physiotherapist.

The clubfoot treatment needs complete understanding of the planter bones, their independent and inter-related movements, how these can be manipulated to bring these bones into appropriate position and relationship. Additionally, since almost 80% of the cases need tenotomy and about 15% need tendon reconstructive surgery or tendon transfer surgery. About five to seven percent clubfoot cases also exhibit other congenital and developmental problems, with internal organic and neurologic malformations. Based on these, it is expected that physiotherapists are trained in these matters before they provide clubfoot treatment, even under supervision.

3. Orthopedic technologist or cast technician

Orthopedic technologists assist orthopedic surgeons for orthopedic injuries/diseases by applying/adjusting and removing casts, splints, bandages, and ambulatory aids. Until they are trained on Ponseti technique they are not supposed manipulate and put on cast on a clubfoot case.

4. Orthopedic officers/ SACMOs

SACMO will administer all components of Ponseti treatment for the clubfoot under the supervision of a competent orthopedic surgeon, provided they have trained well on manipulating clubfoot cases. Orthopaedic technicians at designated workshops may make Steenbeek foot abduction braces after training.

5. Clinic nurse

A clinic nurse is a registered nurse with knowledge, skill and competence in a specialized area of nursing. For clubfoot, until they receive competency based training or until their course curriculum teaches them to perform competency based clubfoot service, they are supposed to only assist the orthopedic surgeon in clubfoot treatment.

6. Certified orthotist

Certified orthotists are professionals who assess, design, fabricate, and fit "braces" (*orthoses)*. The orthotist will help to 'troubleshoot' if a baby's feet are coming out of the brace or if your baby is experiencing any discomfort with the brace. The orthotist can make adjustments to the brace and educate others on how to apply it properly.

7. Medical students

Medical students are doctors-in-training and participate under supervision in most hospital clinics.

*The function of the clinic staff, as a team:*

- ❖ Evaluate children to confirm a diagnosis,
- ❖ Counsel caregivers about treatment.
- ❖ Manage the clubfoot with the Ponseti method. This can include casting, tenotomy and bracing
- ❖ Care is coordinated with community health workers to help parents and caregivers manage problems in their homes
- ❖ Clubfoot care is taught to medical students and orthopedic surgeons in training.

*3.* Standard distribution of clubfoot clinic

It is important that the clubfoot treatment facility sees a high volume of cases so that the staff members maintain their skills in evaluating and treating it. A health facility that chooses to provide clubfoot care should strive to treat a high volume of children as this lead to deepening knowledge for all members of the team, as "volume supports dedicated teams, tailored facilities, peer feedback, better information technology and the ability to integrate and widen services over the care cycle[42].

A clinic treating one new patient a week also performs about six follow-up cast changes, one tenotomy, and 5-10

[42] Porter ME, Teisberg EO (2007) How physicians can change the future of health care. JAMA 297:1103–1111

abduction brace changes. This clinic schedule would take about 6 hours of time each week. One such clinic should be functional for a population having 30,000 live births annually or a population of 50,000- 100,000 depending on the crude birth rate. This site would likely be at the district hospitals in most cases, so repeat casting or referral to a tertiary care center with an orthopedic surgeon trained in pediatric deformity correction can be made in a timely fashion.

As per Prof. Shafique Pirani, a world renowned authority on Ponseti technique based clubfoot treatment, an efficiently distributed clinic should be the one, which sees 01-03 new clubfoot per week as the minimum. The present distribution translates into two clubfoot cases per union, 20 cases per upazila or 160 cases per district per year. This stands at three cases per week per district. However, population size and case size may not commensurate. Some geographical areas may be more prone to clubfoot problem than others. So pragmatism warrants that the ultimate number of clinics is determined by the prevalence rate of clubfoot by geography.

Identifying and recasting recurrences early may allow complex surgery to be avoided in feet that correct with a second complex surgery to be avoided in feet that correct with a second course of nonsurgical treatment. Upazila level health facilities may also provide weekly recasting after training of the relevant personnel.

4. Standard of the clubfoot treatment

Standard clubfoot treatment should have the following features:

1. 80% tenotomy;
2. Tendon reconstruction in 10%-15% cases;
3. Weekly changing of cast (about 5/6 changes);
4. Bracing for 23/24 hours until the casts are removed and then only at day time until the fourth birthday;
5. Regular follow up at domiciliary level

## c. Project/ Program management structure and functions

*1. Management structure*

1. Establish/ strengthen Project office: Develop a Project Implementation Unit (PIU) with Director, NITOR in the chair.
2. NITOR should form a technical working group, with its Director as the head and a Member Secretary to help him/ her to develop the budget and develop and conduct the orientation programs, provide technical support to district and medical college hospitals. The working group will also move the relevant line directors to include the estimated budget to include in the latter's OPs. The working group should get approval of the formation and ToR from the DGHS (attention LD, PST). Representatives from the BCPS, BSMMU, BMDC, BNC, State Medical Faculty, and relevant LDs will have to be involved. The Orthopedic Association should also be an integral partner of all the functions of NITOR.
3. A Steering Committee (SC) also is required with full fledged terms of reference, for reviewing the functions, results, bottlenecks. Based on these information the SC will advise the program management how the implementation of the planned activities may be made effective and

efficient. The SC has to be formed with heads of the relevant offices. SC should be headed by the Secretary, MoHFW or at least DGHS, to ensure that other heads of offices attend.

2. *Human resources*

The Project Director/ Program Manager may be Director of NITOR but budget-wise the proposed activities have to be included in the operation plan of LD, Hospital Services Improvement; LD, Pre-service and In-service training; LD, MNCAH; LD MRCAH; LD, CBHC and LD, Nursing Services. So office of the Director, NITOR will be reportable to all these LDs. This means that if funding is assured through these LDs, Director, NIPORT will have to be strengthened by adding one position of technical/medical officer, one finance officer, one administrative officer and one computer operator. Provision of fund for these positions will have to be made in the budget of these LDs. One position may be included in one of the LDs each, to save burden on any one.

3. *The program/ project activities*

1. Head office functions

- Conduct dialogue with relevant line directors
- Develop Project Implementation Plan and include it in the next sectoral plan of MoHFW and operational plan of the relevant LDs

- Conduct orientation interventions and workshops for inclusion of Ponseti based course curriculum into the medical, nursing and paramedic course.
- Develop a monitoring and evaluation framework for applying and improving education and training and service provision at all relevant levels
- Set up local partner offices at district level (director, medical college hospital or civil surgeon)
- Conduct quarterly Project Steering Committee meetings
- Conduct monthly Project Implementation Unit meetings
- Ensure timely submission of reports to LDs and PMMU, MoHFW
- Ensure timely dissemination of information to all project stakeholders
- Conduct/ develop baseline and end of project surveys and other required surveys and maps

2. Strengthen clubfoot clinics

- Map institutions, clinics, and health care providers engaged in providing clubfoot service at divisions (medical colleges) and district hospitals by geographical location, skill, resources and heads;
- Develop procurement plan, procure and provide logistics as per the findings (maps);
- Develop clubfoot clinic supervisory tool kit for services and logistics;
- Use the supervisory kits to ensure quality and quantity of service provided

- Improve functioning at clinical and community level by ensuring an effective monitoring and evaluation system.

3. Strengthen tertiary level for treatment, training, supervision, and monitoring

The clubfoot clinics/centers at medical colleges will monitor and provide technical support (supportive supervision) to the services given on clubfoot at district and community levels. Checklists will be developed, updated and modified for monitoring and supportive supervision. The technical group formed at the Project head office will support the medical college units on need basis and will monitor and review services provided at these centers/ clinics.

The centers might need to develop referral slips, in collaboration with the relevant district and upazila officials for use by the CHWs. The referral slip would identify the child screened positive for foot deformity by the CHW, and initiates the referral process.

Staff of these centers will also monitor trainings that will be held at district and upazila levels. Each training center will have a focal point, who would be an orthopedists trained in Ponseti technique and adequate number of staff. The team should be formed locally by the director of medical college hospital. The team would include nurses and paramedics, from among those who are relevant.

Training/ orientation materials suggested to be developed have to be available at these centers to enable these centers for providing technical support and training to all the different types of personnel based on the required competency. It needs to be clear that all sorts of training, whether clinical or non-clinical/ for community based workers, these should be centers to be utilized. It is expected these centers already have master trainers trained through different projects, supported by different NGOs.

These centers will also download and store records of the identified and treated children, treatment outcomes, the list and maps of centers where clubfoot services are given, list and identification of service providers.

For a greater span of identification and referral, the PIU should also hold dialogue with pediatricians and gynecologists. PIU may visit these cadres of clinicians to sensitize them and ensure referral.

To enable the PIU, based in NITOR, it is necessary that NITOR itself is strengthened to be the center of excellence. NITOR already has adequate number of appropriately trained professionals. So establishing a center of excellence at NITOR should not be a difficult proposition. The vision in fact should be to develop a regional center of excellence on clubfoot treatment in NITOR ultimately.

4. Strengthen primary health care infrastructures

Health care providers at upazila health complex, union health and family welfare centers and community clinics belonging to the directorates general of health and also of family planning are the front or fringe level primary health care workers, who are the first service providers in a position to identify clubfoot cases in most of the cases. As suggested above, they need to be trained to identify, refer, follow up and counsel the clubfoot cases and families. To enable them to work as per expectation, they will be trained as per the requirement and competency, as suggested above. They would also require a minor modification in their job description. They also need to be monitored for ensuring their more effective functioning.

Each community clinic also has one community group with about 17 members to manage the CC. There are also three community support groups for each CC, with about 51 members. Although not so active, these supposedly dedicated number of local people are also a great resource to take into consideration, as a great resource for community mobilization for clubfoot.

Strengthening efforts would remain incomplete unless resources are used effectively and efficiently. At the community (primary health care) level there are many other stakeholders, directly involved with provision of health care, e.g., NGOs, local service providers, informal service

providers, local public opinions makers and public leaders. There are workers of other public sectors at the community level, e.g., local government bodies. For improving and to better ensure provision of clubfoot identification, referral, counseling and advise at domiciliary level, it is advisable to conduct communication programs among them, to inculcate skill among them to suspect clubfoot cases and refer them to an appropriate clinics close by. For efficiency it is also necessary to utilize all these forces and allies in a coordinated manner.

5. Referral

A formal referral system would be useful for treating clubfoot children. The channel of referral should be initiated by the health assistants and family welfare assistants, who would refer the cases from domestic level and/or the EPI outreach sites/satellite clinics; by the community health care providers from community clinics; by SACMOs/ FWVs/ medical officers from union health and family welfare centers and upazila health complexes. A slip may be designed for the purpose of referral with provisional diagnosis, birth date of the clubfoot child, economic status of the parents and address.

6. Monitoring and evaluation

Monitoring will be employed as a continuous and ongoing process for quality in care at every applicable level and also for assessing if the goals and targets are being reached.

At the community level quantity (coverage-number of cases identified and referred and followed up effectively), along with counseling (quality) should be monitored. At the clinic level quantity and quality, which should take different form, need to be monitored. Quality of clinical service has to be monitored at process level and also at outcome level, i.e., side-effect of treatment (casting) and abiding by the treatment protocol by the family caregiver, and effectiveness of treatment, i.e., degree of cure.

7. Develop and conduct communication program

Beside a flipbook for training of the community level workers (which they will also use while conducting community awareness interventions) and interpersonal communications and counseling among the clubfoot families, posters and handbills/ handouts will be also useful for awareness building among the masses and opinion leaders.

8. Assist in the development of management information system for clubfoot services

- Design the required administrative, management, clinical and service database
- Develop data collection instrument (recording and reporting forms mentioning important dates, visit schedule, CHW home visit record. Number of patients by location, number treated and outcome)
- Discuss with DGHS-MIS to insert it into the DHIS-2

- Arrange insertion of clubfoot based data into DHIS-2
- Arrange software for data entry into DHIS-2
- Train personnel on data entry and data analysis
- Begin data entry
- Analyze data and prepare online report
- Ensure that the online report is read by the relevant officials, as a means of monitoring and evaluation of performance quality and service coverage
- Check data validity
- Take administrative and management decisions based on the reports.

9. Conduct research into burden, economic analysis, barriers to adherence, and outcomes of treatment.

i. Develop terms of reference for conducting research into the burden, economic analysis, barriers to adherence, and outcomes of treatment;
ii. Contract out the research in to the relevant areas as per the competency of research organizations;
iii. Monitor and assess the quality of the research and findings;
iv. Arrange dissemination of the research findings;
v. Ensure utilization of the research findings in management and clinical decision making and planning.

There is uncertainty in the medical literature on the optimum bracing dosage (time in brace daily, length of duration of brace treatment). Study may be warranted to see if reduced duration of bracing can give equally efficacious results. This could lead to better adherence to the treatment regimen.

Studies will be useful to understand the natural history of untreated clubfoot and consequent gender and age based physical, emotional, and economic impact on affected individuals and their families.

An economic analysis of cost and benefit of Ponseti clubfoot treatment to society will be necessary.

Periodic incidence survey of clubfoot in Bangladesh will be warranted as it remains unknown.

Annual burden of children born with clubfoot is also necessary. No such study was done in Bangladesh yet.

### d. Governance issues

The issue of treating clubfoot should be taken up on a humanitarian ground. Secondly, although treatment of clubfoot does not give a lot of economic return but its social, aesthetic and individual satisfaction, which can hardly be measured economically, is beyond any economic valuation. On the other hand, the investment for addressing clubfoot as an issue is astonishingly low. Matched with financial

investment the social, family and individual benefits are definitely much higher. A due financial allocation therefore should be considered at policy level.

The Ministries of Social Welfare, Local Government, Women and Child Affairs need to emphasize on clubfoot treatment service as a social welfare endeavor.

### e. Gender issues

Girl children still do not get enough care from the family. Since in the society a girls appearance is more important for starting a family, clubfoot may be a curse to their entire life. So clubfoot among them should take priority over those of the boys, not advocating however, that clubfoot among the latter should be overlooked. Parents should be oriented to ensure that girl children with clubfoot are not neglected.

Since education among girls has intergenerational impact it is warranted that girls get proper education to raise the next generation efficiently. On that count also clubfoot among girls should get a priority.

Health workers need to keep it in mind that family care is also in the hand of future wives and mothers. This also necessitates that especial care is given to girls with clubfoot.

### f. Role of the Ministry of Health & Family Welfare

Ministry of Health & Family Welfare, especially its planning wing, has to be exhorted to take up the issue of clubfoot with the degree of seriousness, that it deserves rightly. The Planning Wing is the one which estimates program/ project/ activity budget for the Ministry. The orientation that has been suggested in this document has to ensure participation of the representatives of this wing.

Ministry is the apical organization to approve all the decisions that have been suggested in this document, albeit primary moves will be taken up at the Directorate General of Health Services level. It is usual practice that on technical matters suggestions and requests sent from the Directorate General are not usually turned down by the Ministry.

*The Ministry will approve the following budgets for clubfoot:*

- Budget for strengthening the office of the Project Director (human resources, equipment, furniture)
- Budget for Plaster of Paris (for relevant hospitals)
- Budget for bandage
- Budget for braces
- Budget for communication materials (flip charts and other materials, e.g., posters)
- Budget for workshops for developing communication materials, curriculum development/ updating for post graduate courses and development of training schedules

and materials for physicians, nurses, paramedics and community level workers

- Budget for training (for community workers and for physicians, and nurses)
- Budget for teaching and training materials
- Budget for research
- Budget for physical renovation of clubfoot clinics

## Budget (tentative)

| | |
|---|---|
| Orientation of policy makers, planners and managers | 200,000 |
| Orientation of faculty members, clinicians and hospital managers | 60,000 |
| Orientation of hospital managers and clinicians | 60,000 |
| Production of flipbook (0ne time) | 200,000 |
| Workshop for modification of course curriculum | 60,000 |
| Workshop for upgrading of job description of community workers | 60,000 |
| Provision of Ponseti technique based clubfoot care | 6, 00,000,000 |
| Physical renovation for 30 medical colleges and 34 district hospitals | 6,40,00,000 |
| Furniture and equipment | 1,28,00,000 |
| Training and orientation | 6,64,40,000 |

**Total Approximately eighty one crores**