Scaling up child development centres in Bangladesh

N. Z. Khan,*† R. Sultana,† F. Ahmed,† A. B. Shilpi,† N. Sultana† and G. L. Darmstadt‡ 回

*Department of Pediatric Neuroscience, Dhaka Shishu Hospital, Bangladesh Institute of Child Health, Dhaka, Bangladesh †National Coordinator's Office for "Establishment of Shishu Bikash Kendra in Government Hospitals", Ministry of Health and Family Welfare, Dhaka, Bangladesh, and

‡Division of Neonatal and Developmental Medicine, Department of Pediatrics, Stanford University School of Medicine, Stanford, CA, USA

Accepted for publication 18 September 2017

Abstract

Background Child Development Centres (CDCs) have been established within government medical college tertiary hospitals across Bangladesh. Services entail a parent–professional partnership in a child and family friendly environment with a focus on assessment, diagnosis, and management of a range of neurodevelopmental disorders in children and adolescents 0–16 years of age. Services are provided by a multidisciplinary team of professionals (child health physician, child psychologist, and developmental therapist) who emphasize quality of services over the numbers of children seen. *Methods* In 2008, Dhaka Shishu (Children's) Hospital was given the mandate by the government to conceptualize, train, and monitor CDCs nationwide. Here, we describe the rationale and processes for the establishment of the national network of CDCs and discuss lessons learned on scaling up early childhood development services in a low resource setting.

Results Fifteen CDCs were established in major government hospitals across Bangladesh and have recorded 208,866 patient visits. The majority (79%) of children were from the lowest and middle-income families, and about one third (30%) were < 2 years of age at first presentation. Two thirds of children seen in follow-up demonstrated improvements in functional skills since their first visit, 77% in their adaptive behaviour (i.e., activities of daily living) and 70% in cognitive functions.

Conclusions CDCs are expanding coverage for child neurodevelopment services across Bangladesh through a tiered system of home-based screening, community- and clinic-based functional

assessment, and CDC-based diagnosis, support, and referral. Vulnerable populations—the lowest income groups and younger children—comprised the majority of patients, among whom there is high unmet need for psychological services that is being met for the first time. Innovative human resource development, including a 3-month training for the multidisciplinary teams, enabled wide coverage for assessment and diagnosis of a range of neurodevelopmental problems. Demand for services is growing, especially among non-government and private hospitals.

Keywords

Early Child Development, neurodevelopment, scaling up

Correspondence: Gary L. Darmstadt, Department of Pediatrics, Stanford University School of Medicine, 1265 Welch Road, x155 Stanford, CA, USA, 94305. E-mail: gdarmsta@stanford.edu

Introduction

Bangladesh has achieved a steady decline in under-five child mortality rates over the last 2 decades, from 150 per 1,000 live births in 1990 to 41 in 2013 (UNICEF, 2015). Conversely, rates of childhood neurodevelopmental disorders have risen from 68 per 1,000 in 1988 (Khan and Durkin, 1995) to 185 in 2013 (Survey, 2013). With rising literacy and declining fertility rates resulting in smaller family size (UNICEF, 2015), increasing numbers of parents are seeking services for concerns about their child's neurodevelopment. Until recently, there were no such services within the government healthcare infrastructure in this low-income country of 160 million population.

In 1992, Dhaka Shishu (Children's) Hospital (DSH) established the first multidisciplinary Child Development Centre (CDC; or "Shishu Bikash Kendra" in Bangla), which engaged in research to define evidence-based child development assessment and intervention practices for the country. A key finding was that difficulties in accessing sparse services (McConachie et al., 2001) and the burden of caring for disabled children (Mobarak et al., 2000) were adversely affecting maternal mental health. Despite these challenges, when mothers persisted in bringing their children for regular neurodevelopmental follow-ups, their children showed improved functional outcomes (Khan et al., 2008). Beginning in 1997, due to lack of capacity to provide for the rising demand in child neurodevelopmental services, the DSH started assisting other non-profit hospitals to establish similar services. By 2003, 13 CDCs had been established (Khan and Ferdous, 2003), but evaluation of these services revealed that access by the poorest children was unsatisfactory (Khan, 1998; Khan and Ferdous, 2003).

In 2008, after writing a project proposal to the Ministry of Health and Family Welfare, the DSH was assigned to establish CDCs within all government medical college hospitals (Operational Plan, 2008-2011, 2011-2016). The long-term vision was to ensure optimal development for all children 0-16 years of age in Bangladesh through a tiered system of homebased screening, community- and clinic-based functional assessment, and CDC-based diagnosis, support, and appropriate referral. The tiered-system design became a key mechanism for ensuring wide and equitable reach of the programme. Balance was also sought between providing services for those with developmental disorders and promoting communitybased early mother-child intervention programmes for the broader sector of young children living in extreme poverty. This paper expands on findings in the recent Lancet Series on Advancing Early Childhood Development (Richter et al., 2017) to describe the requirements and processes involved in the scaling up of CDCs within government hospitals, and share early results on the impact of the programme. Applications for scaling up early childhood development services in a low resource setting are discussed.

Methods

The government's operational plan (2008–2011, 2011–2016, 2016–2021)

Through a public-private partnership, the government established a central office and training centre for CDCs at

DSH (a private, non-profit, 500-bed national children's hospital with an academic wing, i.e., the Bangladesh Institute of Child Health) with Professor Naila Zaman Khan as the National Coordinator. The National Coordinator's office was charged with coordinating the conceptualization, training, operationalization, monitoring, and evaluation of CDCs across tertiary government hospitals.

The key objectives of the services are as follows: (a) To establish child and family-friendly centres within key public hospitals across the country; (b) to place and train a core team of multidisciplinary professionals, including child health physicians, child psychologists, and developmental therapists, to provide services within these centres; (c) to apply standardized tools, methodologies, and strategies for early screening, assessment, treatment, and management of the entire range of developmental delays, disorders, impairments, and disabilities; (d) to conduct epidemiological surveys and clinical research to inform the development of a nationwide, evidence-based health service delivery system, and to identify risk factors to address in order to prevent major childhood disabilities; (e) to provide psychosocial services to families and empower parents and primary care providers to optimize their child's development; (f) to provide training and strategies to establish linkages with primary health care services; and (g) to develop a digital data-base of information related to child development and disability across Bangladesh.

Resources

CDCs were financed by the Government of Bangladesh's Development Budget (with a designated line-item). The National Coordinator was given the drawing and disbursement responsibilities for operational costs, repair and maintenance costs, and costs for providing logistical support (i.e., equipment, training, monitoring, and evaluations). The National Coordinator, whose involvement in the programme was *pro bono*, was provided a salaried staff of three trainers and a training coordinator within the DSH.

Human resource development

CDC multidisciplinary team A three-member multidisciplinary professional team is established at each CDC and provided 3 months of specialized training. The *Child Health Physician* is a medical graduate, and the *Child Psychologist* holds a Master's degree in Psychology, preferably with specialization in Developmental Psychology. The *Developmental Therapist* is a "generic" therapist who is further trained in occupational therapy, physiotherapy, and speech and language therapy, within a developmental framework.

CDC administrative team The administrative team is composed of the Office Manager and the Cleaner. The first contact with the child and family occurs through the office manager, who builds rapport (Khan, 1998) and maintains regular contact with the family. He/she maintains digitalized records of the first contact and subsequent visits to clinics within the CDC (Figure 1), including sociodemographic details, types of worries, major findings, and neurodevelopmental diagnosis and profile according to World Health Organization (WHO) or Diagnostic and Statistical Manual of Mental Disorders standards. The office manager must have a college degree (e.g., Bachelor of Arts) and good computer and writing skills in both English and Bangla. In addition, data basing and Information Technology skills are strengthened through a 1-week training at the National Coordinator's office. The cleaner maintains a level of fastidiousness after each clinic attendance that allows children to play safely on the mat with toys, books, and all objects used during assessments.

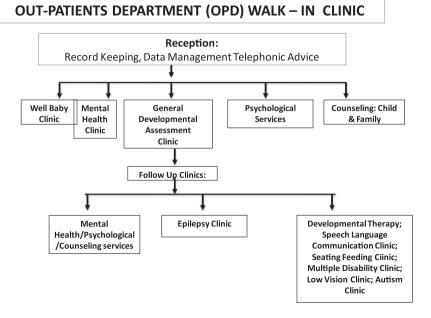
Training

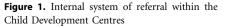
The structure of the 3-month training provided to the multidisciplinary team at DSH is shown in Table 1. A fundamental concept of the CDC assessments is based upon functional neurodevelopment of children and their delays,

deviances, and disorders, adapted from the International Classification of Impairments, Disabilities and Handicap (WHO, 1980) and the International Classification of Function (WHO, 2001). During tutorials, the processes involved in recording every child's neurodevelopmental profile are highlighted, including determination of a diagnosis of their underlying neurodevelopmental disorders according to an adapted version of the International Classification of Diseases (WHO, 1990).

The importance of applying validated tools, scales, and procedures is emphasized in the tutorials for each of the specific clinics within the CDCs. Evidence-based practices related to each of the clinical services are outlined in Table S1. In the course of the 3-month training period, Child Health Physicians and Developmental Therapists are provided a 2-week, hands-on training in applying the Rapid Neurodevelopmental Assessment, an assessment tool developed and validated by the Bangladesh Protibondhi Foundation in collaboration with DSH (Khan et al., 2010; Khan et al., 2013; Khan et al., 2014; Muslima et al., 2016) for neurodevelopmental assessment of children ages 0-16 years. This training provides a comprehensive overview of normal development, delays, and disorders and is especially useful for newly engaged professionals. Child psychologists are trained in psychometric tests with more emphasis on cognitive, behavioural, and psychomotor functions.

Child protection and family counselling are integral to the training and are emphasized for each child. Stress of the mother and the family of children with neurodevelopmental concerns is another important aspect that these tutorials





| | Physician | Therapist | Psychologist |
|-----------------------|---|---|--------------------------------|
| Months 1 and 2 | | | |
| Case discussions | Daily, 8–9 am, on cases seen the day befo | re, in-depth discussion on any 1 | |
| Clinical placements | OPD, IPD, GDA, WBC, | OPD, IPD, WBC, nRNDA, | PA, BSID, SBIS, WIPSI, |
| am–1:30 pm | nRNDA, EC, CAMH, Assist: | SLC, MDC, AC, LVC, DT, | WISC, IBAS, ADOS, |
| | SLC, MDC, AC, LVC, DT | Assist: GDA, EC, CAMH | Assist: GDA, CAMH |
| utorials 1:30–2:30 pm | Five introductory tutorials; 42 specific tuto | rials, some common | |
| NDA 2 weeks: | Normal and delayed development. Hands- | on assessment | PSC, CAMH, Tests. |
| am–5 pm | of children 0–16 years of age | | Report Writing |
| 1onth 3 | | | |
| hild Development | Work with the local | Work with the local | Work with the local |
| Centres: 2 weeks | child health physician | developmental therapist | child psychologist |
| ield trips: 2 weeks | Inclusive and special schools, rehabilitation and autism; urban and rural CBR. | e centres, for example, for vision or hearing o | disorders, motor difficulties, |

 Table 1. Contents of a 3-month training of the multidisciplinary team of professionals at the Department of Pediatric Neuroscience, Dhaka Shishu

 Hospital, that is, the National Coordinator's training centre

Note. OPD = Out-Patients Department Walk-In Clinic; IPD = In-Patients Department, referrals of admitted children; GDA = General Developmental Assessment Clinic; WBC = Well Baby Clinic; nRNDA = Neonatal Rapid Neurodevelopmental Assessment Clinic; EC = Epilepsy Clinic; CAMH = Child and Adolescent Mental Health Clinic; SLC = Speech, Language and Communication Clinic; MDC = Multiple Disabilities Clinic; AC = Therapeutic Interventions for Autism Clinic; LVC = Low Vision Clinic; DT = Developmental Therapy Clinic; PA = Psychological Assessment Clinic; BSID = Bayley Scales for Infant Development; SBIS = Stanford Binet Intelligence Scale; WPPSI = Wechsler Pre Primary and Primary Scales of Intelligence; WISC = Wechsler Intelligence Scales for Children; IBAS = Independent Behaviour Assessment Scale; ADOS = Autism Diagnostic Observation Schedule; PSC = Psychosocial Counselling Clinic; CBR = Community Based Rehabilitation. Please see Table S1 for evidence-based tools, scales, and procedures applied in the above clinics.

highlight, including the importance of an empathetic parent– professional partnership. Experiences of providers and lessons learned are shared regularly in order to improve service provision.

Visits to nationally recognized institutions for investigations, inclusive education, and rehabilitation are organized to widen the multidisciplinary team's comprehension about the networks they can build within other health, education, and social services when considering placements of the children beyond CDCs. An example from the Bangladesh Protibondhi Foundation's Kalyani Inclusive School is provided in Box 1.

Box 1: Bangladesh Protibondhi Foundation (BPF)

BPF is a non-governmental organization that runs early mother–child programmes (for newborns to 3-year-olds), inclusive pre-primary and primary schools, vocational training, community-based rehabilitation, sports, cultural and economic empowerment programmes, and an Institute of Special Education. It was established in 1984 to work with children with developmental disabilities. BPF has pioneered the development of evidence-based tools, scales, and procedures for screening, assessment, and early intervention of children with a range of neurodevelopmental disabilities (see Neuroepidemiology, Rapid Neurodevelopmental Assessment, Multiple Disabilities Clinic, sections of Table S1, where tools copyrighted by BPF are marked), including programmes for child protection against sexual, physical, and emotional violence, abuse, and neglect (Bangladesh Protibondhi Foundation, 2015). It has 11 schools, 3 in Dhaka city, each in close proximity to a CDC (numbers 1,2, and 3, see Figure 2) and 8 others across Bangladesh that are close to CDCs (numbers 5, 12, and 14, see Figure 2).As there are over 100 NGOs in Bangladesh working with children with disabilities, the link between government-run CDCs and BPF schools and services provide a good example of the coordinated expansion of multisectoral services across Bangladesh, to ensure social and educational participation of children with special needs, when diagnosed.

Logistics

The space for CDCs ranges from 500 to 1,500 sq. feet, depending upon availability, divided into the reception area and two private areas for the multidisciplinary team. One area is designated for psychometric testing by the child psychologist or for family counselling. Another area is designated for the child health physician and developmental therapist to run several clinics, sometimes with the child psychologist joining in, especially for comprehensive child assessment, that is, the General Developmental Assessment. Several pieces of equipment are needed for functioning of the CDCs. Copyrighted standardized psychometric tests are purchased from the respective companies (Text S1). Other tests (e.g., Independent Behaviour Assessment Scale and Rapid Neurodevelopmental Assessment) developed by the National Coordinator's team are made available to the CDCs at minimal cost.

Monitoring and evaluation

Records of all services are digitalized, and data are entered in an SPSSpc software programme. Data are centrally monitored every month by the National Coordination team at DSH and uploaded monthly on the government's website (GOB website, n. d.), where information and data are regularly updated for public awareness, dissemination of information, and accountability.

Monitoring activities include recording the overall developmental course of each child at follow-up visits, for which standard operational definitions are followed (Text S2). The National Coordination team undertakes monthly review and discussion of process data (e.g., clinic visits) with each CDC and makes site visits to CDCs at least once vearly. National Coordination team visits include confidential assessments of performance of each multidisciplinary team member. In addition, tracking is maintained by multidisciplinary team member participation in clinical and academic activities of the respective Department of Pediatrics and in national workshops and training programmes, presentation of CDC work in local and national conferences, and publication by team member(s) in peer-reviewed journals. The National Coordinator, in conjunction with the head of the respective paediatrics departments, is empowered to make decisions pertaining to the CDC personnel, including job termination if quality of work is deemed to be unsatisfactory.

Ethical considerations

All children's personal information is kept confidential. For individual research information or video or photographic images, written parental consent is sought.

For each child, a minimum of 20 min is expended at the first contact to the Outpatient Department Walk-in Clinic; 1 hr or more is devoted to comprehensive assessment by the multidisciplinary team; and a follow-up visit takes about 40 min. This results in fewer children being seen per day compared to other outpatient services of the hospitals, thus favouring quality of service over numbers of children seen. For example, a CDC team can see a maximum of 10 children in its various clinics, compared to over 50 children seen per day by a physician in the paediatric outpatient services. Unless there is an ongoing pathology (e.g., uncontrolled seizures or a regressive disorder), each child is seen for a maximum of six visits at 4- to 6-week intervals. Nutrition, daily functioning, and stress management are emphasized, and educational, rehabilitative, social, or any other appropriate placements for the child within the community are negotiated by the CDC team with the primary care providers. These arrangements are deemed mandatory to develop a positive parent–professional partnership and allay anxiety in already highly stressed families (Khan et al., 2008; Mobarak et al., 2000).

Results

Geographical locations (GOB website, n.d.) and number of attendances

Fifteen CDCs have been established thus far, all in urban centres (Figure 2). The number of child attendances to various clinics within the CDCs is shown in Table 2. Of the total 208,866 attendances up to March 2016, 42% (n = 86,796) were first contacts, among which two thirds (68%) took place in the Walk-in Clinic. Of the 122,070 follow-up clinic attendances, one third of visits were to the Developmental Therapy Clinic (32%), one fourth (23%) to the Walk-in Clinic (23%), and 16% attended the Epilepsy Clinic (16%).

Sociodemographics of attending children

Of the total first attendances in the Walk-In Clinic (n = 58,766, Table 2), 36% and 43% were from the lowest and middleincome families, respectively. The definition of ultra-poor by the World Bank is earnings of \leq \$2 per day. CDCs recorded families as "low income" if family income was < \$4 per day; "middle income" if between \$4 and 12 per day; and "higher income" if >\$12 per day. Nearly two thirds (62%) of attendees were male children. About one third (30%) were under 2 years of age, one third (36%) were between 2 and 5 years of age, 22% were 5–9 years of age, and 12% were 10–16 years of age. However, the age group was older for children attending the Mental Health Clinic, where one third (34%) were in the 5- to 9-year-old age group.



Figure 2. Fifteen Child Development Centres in medical college hospitals in Bangladesh (established: 1–5 in 2009; 6–10 in 2011; 11–15 in 2014). [Colour figure can be viewed at wileyonlinelibrary.com]

Qualitative outcomes

Clinical notes from follow-up visits at the 15 CDCs revealed substantial improvements in child neurodevelopmental function. Levels of improvement, as recorded by the child health physicians, were 77% in the Walk-in Clinic, 74% in the Epilepsy Clinic, 66% in the General Developmental Assessment Clinic, and 58% in the Mental Health Clinic. Improvement levels, as recorded by the Developmental Therapists, were 66% in the Developmental Therapy Clinic; 64% in the Speech, Language, and Communication Clinic; 60% in the Low Vision Clinic; 77% in the Seating and Feeding Clinic; 57% in the Multi-disability Clinic; 70% in the Autism Clinic; and 70% in the Well Baby Clinic. Improvements, as recorded by the child physicians, were 77% in adaptive behaviour (i.e., activities of daily living, gross motor functions, socialization, and communication) and 70% in cognitive functions.

CDC replication in private autonomous hospitals and in other countries

Since 2008, alongside the establishment of CDCs within government hospitals, the DSH team has strengthened the

CDCs in five non-governmental hospitals in Bangladesh and assisted in the establishment of new CDC services in one army hospital within Dhaka and in one private hospital in Dhaka (Child Development Centre, Apollo Hospital Dhaka, n.d.).

There were marked differences in the types of complaints among children who presented to the private hospital compared to those who presented to one of the busiest CDCs, that is, the Dhaka Medical College Hospital. In the private hospital, 45%, 41%, 36%, and 31% of children needed comprehensive General Developmental Assessment, Psychological Assessment, or referral to the Mental Health Clinic or Autism Clinic, respectively, compared to 12%, 22%, 8%, and 7%, respectively, in Dhaka Medical College Hospital.

Since the establishment of a CDC within the private hospital, the DSH team has trained professionals from several other private hospitals who are planning to establish similar services. There are also queries to the DSH team from other regional countries as well as from Latin American and African countries requesting assistance with establishment of child developmental services.

| Name of | | First c | First contact by clinic | clinic | | | | | | | Follov | Follow-up clinics | S | | | | | |
|---|--|---------------------------|-------------------------|--------|---------------------------|--------------------------|---------------------|---------------------|------------------------|----------------------|--------------------------|------------------------|------------------------|--------------------------|---------------------------|------------------------------|----------------------------|---|
| meaicai college hospital | OPD | РА | WBC | Q | Total | GDA | AC | MDC | S + F | Ę | SLC | Ы | EP | PA | QPD | HW | Total FU | Grand Total |
| Dhaka | 7,166 | 1,552 | 579 | 1,534 | 10,831 | 1,405 | 467 | 128 | 837 | 1,046 | 3,352 | 4,238 | 3,277 | 724 | 1,645 | 461 | 17,580 | 28,411 |
| Suhrawardi | 4,024 | 1,837 | 290 | 1,819 | 7,970 | 874 | 113 | 82 | 53 | 98 | 593 | 696 | 965 | 504 | 995 | 290 | 5,536 | 13,506 |
| Salimullah | 3,982 | 1,729 | 121 | 1,721 | 7,553 | 1,267 | 157 | 57 | 130 | 245 | 765 | 2,231 | 3,157 | 936 | 1,180 | 185 | 10,310 | 17,863 |
| Sylhet | 7,093 | 1,321 | 60 | 1,304 | 9,778 | 2,028 | 185 | 25 | 73 | 270 | 366 | 3,480 | 216 | 181 | 674 | 55 | 7,553 | 17,331 |
| Barisal | 3,230 | 1,199 | 66 | 1,194 | 5,722 | 866 | 130 | 81 | 266 | 435 | 277 | 3,567 | 380 | 2,217 | 3,485 | 161 | 11,865 | 17,587 |
| Chittagong | 6,218 | 1,473 | 128 | 1,449 | 9,268 | 642 | 133 | S | 260 | 315 | 677 | 5,916 | 6,078 | 851 | 3,349 | 24 | 18,250 | 27,518 |
| Rajshahi | 7,692 | 689 | 61 | 677 | 9,119 | 209 | 168 | 113 | 50 | 105 | 159 | 5,877 | 2,674 | 679 | 5,941 | 155 | 16,130 | 25,249 |
| Khulna | 3,394 | 665 | 15 | 651 | 4,725 | 206 | 43 | 25 | 17 | 69 | 66 | 2,064 | 1,174 | 492 | 825 | 7 | 4,988 | 9,713 |
| Rangpur | 4,405 | 573 | 112 | 569 | 5,659 | 302 | 20 | - | 7 | 10 | 309 | 1,827 | 106 | 379 | 449 | 11 | 3,421 | 9,080 |
| Mymensingh | 4,994 | 689 | 101 | 675 | 6,459 | 418 | 142 | 37 | 270 | 696 | 977 | 4,959 | 917 | 362 | 5,811 | 25 | 14,887 | 21,346 |
| Dinajpur | 1,073 | 213 | 30 | 205 | 1,521 | 260 | 24 | 93 | 40 | 45 | 94 | 2 | 82 | 75 | 967 | £ | 1,688 | 3,209 |
| Faridpur | 727 | 243 | 4 | 231 | 1,205 | 187 | 53 | 71 | 26 | 13 | 80 | 2 | 63 | 121 | 540 | 0 | 1,156 | 2,361 |
| Comilla | 1,928 | 356 | 151 | 348 | 2,783 | 208 | 74 | 45 | 0 | 89 | 113 | 2,650 | 180 | 107 | 1,104 | m | 4,573 | 7,356 |
| Bogra | 1,975 | 513 | 17 | 503 | 3,008 | 242 | 60 | 43 | 12 | 51 | 94 | 1,001 | 172 | 407 | 1,001 | 0 | 3,083 | 6,091 |
| Cox's Bazar | 865 | 166 | 4 | 160 | 1,195 | 136 | 14 | 63 | 7 | 17 | 81 | 274 | 35 | 73 | 345 | S | 1,050 | 2,245 |
| Total= | 58,766 | 13,218 | 1,772 | 13,040 | 86,796 | 9,250 | 1,783 | 869 | 2,048 | 3,777 | 8,003 | 39,060 | 19,476 | 8,108 | 28,311 | 1,385 | 122,070 | 208,866 |
| <i>Note</i> . GDA = General Developmental Assessment, OPD MDC = Multi-disability Clinic; S&F = Seating and Feeding; Development Centres | General De isability Cli Centres | velopment nic; S&F = (| al Assessm | | = Out-Patie LV = Low V | ents Depē /ision; SLC | artment; = Speec | PA = Ps h, Langu | ychologic Iage & Co | al Assess mmunica | iment; WE ation; DT = | 3C = Well = Develop | Baby Clir mental Th | nic; IPD = erapy; EPI | ln-patien I = Epileps; | s depart y; MH = <i>l</i> | ment; AC = Mental Healt | = Out-Patients Department; PA = Psychological Assessment; WBC = Well Baby Clinic; IPD = In-patients department; AC = Autism Clinic; LV = Low Vision; SLC = Speech, Language & Communication; DT = Developmental Therapy; EPI = Epilepsy; MH = Mental Health; CDC = Child |

Table 2. Number of child CDC attendances by clinic up to March 2016 Attendances of first 5 CDCs: Since Aug 2009; Second 5 CDCs: since Sept 2010; Third 5 CDCs: since Feb 2014

Piloting a tiered system of referral

In 2013, a country wide survey of neurodevelopmental disorders, including autism, was conducted by the Directorate of Non-Communicable Diseases under the health ministry, coordinated by the National Coordinator's office in collaboration with the established CDCs. A tiered system of referral was successfully applied, from home-based screening by government Health Visitors, to community-based assessment by community healthcare providers, to diagnosis at subdistrict hospitals by CDC professionals. Details of the methods and findings are available at the government's website (Survey 2013).

Discussion

A Bangladesh government programme to scale up child development services within CDCs in government tertiary hospitals has been successfully implemented for the past 8 years. Plans to extend the services to secondary and primary care hospitals are underway (Operational Plan, 2016–2021). Successes and challenges of the present programme are discussed.

Reaching the unreached

Providing high-quality services to disenfranchised families seeking help for children with neurodevelopmental concerns was the main impetus for establishing the CDCs. A tiered system of referral from home-based screening to community- and clinic-based functional assessments to CDC-based diagnostic workups and comprehensive services was piloted in 2013 and is in the process of being scaled up (Survey, 2013). Building regional "centres of excellence" and using these hubs to spread services out to the community and family level is central to the scale-up strategy. Simultaneously, linkages are forged with frontline health and education providers to create community, and in some cases, population-based, screening, and referral pathways. It is anticipated that this strategy will further extend the reach of the CDC network into rural communities.

Geographical locations of the 15 centres of services has ensured coverage across the 8 administrative divisions of the country. Additional CDCs have been established in strategic locations to further extend the reach (e.g., Cox's Bazaar in the deep south east, where indigenous tribal populations are a majority; Bogra in the central part of the country, and a major highway junction; and Comilla, Faridpur, Rangpur and Dinajpur in the far northwest). As approximately one tenth of the country's 160 million population live in Dhaka city (UNICEF, 2015), three CDCs were established in the three major tertiary hospitals in north Dhaka (Suhrawardy Medical College Hospital), central Dhaka (Dhaka Medical College Hospital), and south Dhaka (Salimullah Medical College Hospital). Over the past two decades, DSH has also assisted in the development of similar services in major specialized hospitals in Dhaka city (i.e., the Institute of Pediatric Neurodevelopment and Autism; Bangladesh Institute of Rehabilitation for Disorders of Endocrinology and Metabolism; and Combined Military Hospital Dhaka), Chittagong (Chittagong Ma O Shishu Hospital), and Matuail (Institute of Mother and Child Health).

Over one third of attending children were from the lowest income families, followed by the middle-income families, which comprised almost half of the children. Cost of transportation, loss of a day's wages, and cultural barriers for young mothers travelling long distances were some reasons for attrition in follow-up in previous studies (McConachie et al., 2001). The present services are designed to overcome these problems, mainly by providing services closer to homes.

Almost one third of first contacts in the Walk-in Clinics were children < 2 years of age. This may reflect the "baby friendliness" of the services, including a clean environment, empathetic staff, and a reassuring multidisciplinary team that conveys to the family both functional strengths and weaknesses in every child seen, no matter what the nature of the parental worries or assessment outcomes. This approach is also meant to encourage families to bring their children for evaluation, no matter the nature or severity of the concern or risk factors present. Thus, services are designed to address the needs of children with disabilities, as well as normo-typically developing children, whose families are provided anticipatory guidance aimed to optimize the development and achievement of the full potential of all children.

It is also important to note that a significant minority of attendees belonged to the adolescent age group, whose problems often remain unrecognized. In an analysis of 300 children attending the Mental Health Clinic in DSH, 16% were >10 years of age (Islam et al., 2011). The latter children "fall through the gap" as there are no specific services designed to accommodate their problems. The CDC welcomes this age group to its services as the multidisciplinary team is trained to address issues relating to child and adolescent mental health (Muslima et al., 2016).

Human resource development

Finding common ground that empowers the multidisciplinary team to work together in synergistic ways that meet the holistic needs of families of children with developmental impairments and disabilities and significant risk factors for suboptimal development (e.g., extreme poverty) is a challenging and important component of the training, a fact that is acknowledged by countries with well-established services (Parr et al., 2013). Beyond the evidence-based practices that are followed based on the practical experience and research of DSH, the protocols followed are also based on the international standards and procedures followed by the WHO, including the International Classification of Impairments and Disabilities (WHO, 1980) and the International Classification of Function (WHO, 2001). The practically observable activities incorporated into the protocols used in the CDCs have been shown to promote multidisciplinary teamwork (Watter et al., 2008), provide a summary profile of children at each visit, and encourage parents to find creative ways to improve their child's functional deficits.

Clinical services

Embedding the CDCs within the health infrastructure of medical college hospitals ensures free access for families with at-risk children from the newborn period through adolescence. This also enables linkages with and referral to a wide range of departments outside of paediatrics that provide critical elements of care for families with children who have disabilities and impairments. In addition to health and nutrition, child protection services are also integral to the programme.

First contact with the CDCs occurred primarily through the Walk-in Clinics, although almost one fifth of families sought direct access to Psychological Services. This suggests that there is high unmet demand for child psychological services within public hospitals, which is corroborated by a 2013 government survey that found that of the 185 per 1,000 children with neurodevelopmental disorders, 85% were for cognitive impairments (Survey, 2013). The need for psychological services is being met for the first time in Bangladesh through this programme.

Provision of follow-up services centred on the Developmental Therapy Clinic, where about one third (32%) of followup visits occurred and where intervention strategies were provided by the developmental therapist (e.g., activities of daily living, play, diet, and nutritional advice) for a range of comorbidities that accompany the most common neurodevelopmental disorders, including epilepsy, cerebral palsy, encephalopathies, cognitive difficulties, and behavioural disorders. In contrast to the CDCs, specialty clinics for these disorders are often limited in their mandate and do not address broader issues of daily living. Substantial functional improvement occurred when a cohort of high-risk newborns was followed up by developmental therapists within a CDC in a non-profit children's hospital in Dhaka city (Banu et al., 2015). The developmental therapist's effective, holistic approach to the child's functional limitations and individualized intervention strategies highlights the need for innovative human resource development in many low- and middle-income countries, and for formal training, including the granting of degrees in developmental therapy within academic institutions. Moreover, the substantial functional improvements recorded on follow-up visits to specific clinics of the CDCs are due to the efforts of the entire multidisciplinary team and their administrative staff. Systematic prospective studies may be needed to validate these positive preliminary outcomes.

Replication of services in private hospitals

The 2013 "Epidemiological Survey of Neurodevelopmental Disorders and Autism" (Survey, 2013) conducted with technical expertise provided by the CDC network showed that there were significant differences in the prevalence of neurodevelopmental disabilities and impairments by wealth quintile. In both rural and urban populations, there were higher rates of behavioural disorders, mental health conditions, disorders of vision and hearing, genetic syndromes, and particularly for Autism Spectrum Disorders within the highest wealth quintiles. Among rural children, Autism prevalence was 0.68 per 1,000 compared to 30 per 1,000 in urban children, all among higher income families. Further research is needed to understand the reasons for this difference, which may lead to new insights into risk factors and targets for intervention. These statistics prompted the DSH team to approach private hospitals catering to higher income groups to establish CDCs with their assistance. The differences in the types and volume of conditions that children seek services for in a higher income private hospital compared to a CDC within a busy public hospital within Dhaka city is evidence of the unrecognized need for addressing problems in children from higher wealth quintiles. These needs go beyond borders, as private hospitals from neighbouring countries are also showing interest in establishing services. It must be recognized, however, that although there is an important need to tailor systems and services to the needs and interests of higher income communities, the need for services for children with a wide range of risk factors and developmental disabilities and impairments is also acute in more remote, poor, rural sectors of Bangladesh.

Challenges

A major challenge of the programme of CDCs in Bangladesh is how to continue programme expansion and ensure sustainability. The services provided by the CDCs have already become an integral part of the services of the respective paediatrics departments. Processes are underway to include the multidisciplinary posts within the government's revenue budget, under a new discipline called Child Neurology and Development. Postgraduate courses have been approved and initiated, that is, Fellow of the College of Physicians and Surgeons and Medical Doctor courses. In a resource-poor country, combining training in child neurology and child development is necessary if human resources are to be best applied. CDCs are expected to be placed under this discipline of Child Neurology and Development so that the quality of services can be maintained and improved, and research and development to find innovative technologies can be continued.

Lessons learned for scaling up

Establishing early child development services within the health sector enabled rapid and extensive reach, especially to poor children early in life, because families were already attending health services. This reach can be extended deeper into rural communities through nationwide epidemiological surveillance systems made possible in part through the development of capacity for child developmental assessment and management by multidisciplinary teams of a child health physician, child psychologist, and developmental therapist at CDCs throughout the country. Thus, the CDCs are designed to meet the referral needs of regional populations, who are further serviced through frontline health clinics and village-based services and through teachers who are trained in screening for neurodevelopmental disabilities and impairments and who in turn promote nurturing care of all children. The CDCs also provide training and capacity building in child developmental services of undergraduate and postgraduate students, who are now responsible for knowledge of child development as part of national medical examinations. Ultimately, however, extension of services beyond the CDCs requires the development of paraprofessional and professional expertise within all local administrative hospitals, so that neurodevelopmental surveillance can be provided to every child. This can be administered through a tiered system of referral, from home-based services to community- and clinic-based assessments and interventions to hospital-based diagnosis and appropriate referral and interventions for the breadth of neurodevelopmental disabilities. Surveillance data revealed that many children from privileged backgrounds, especially children with Autism Spectrum Disorder, were failing to avail services in the public

system. Thus, to achieve greater equity of service provision, it was necessary to also establish services within private health facilities where higher income level families receive care.

As services were developed within CDCs, we focused on quality of care rather than numbers of children seen and found that this is important for sustainability. Establishment of public–private partnership has also been critical to success. Governmental funding and facilities have been necessary for achieving national scale, while research, managerial, and technical inputs from DSH, an academic institution, and Bangladesh Protibondi Foundation, an implementing organization, have ensured that services are evidence-based, are meeting the needs of families, and that quality is maintained.

Multisectoral linkages beyond health and nutrition to education, social protection, and child protection is critical to impact and sustainability. The Bangladesh Protibondi Foundation has established community-based early mother– child intervention programmes and inclusive schools offering school meals adjacent to several of the CDCs where children are referred for education and rehabilitation purposes. This is a model for integration of health, nutrition, education, and social protection, as well as for linking communities with facility-based services, which the programme is striving to replicate system-wide. This is a central strategy for expanding the coverage and impact of services to widely address risk factors and mitigate impairments population-wide.

Key Messages

- Establishing early child development services within the health sector enabled rapid and extensive reach, especially to poor children early in life.
- Institutionalization of early child development services within departments of paediatrics was critical to programme sustainability.
- The need for psychological services is being met for the first time in Bangladesh through this programme.
- Training of an innovative, multidisciplinary professional team composed of a child health physician, a child psychologist, and a developmental therapist was critical to meeting a wide range of medical and psychosocial needs of at-risk children and their families, and enabled the building of capacity for child development services among medical undergraduates and through in-service training.
- As services were developed within CDCs, we focused on quality of care rather than numbers of children seen, and found that this is important for sustainability.

- Many children from privileged backgrounds, especially children with autism, were failing to utilize services in the public system. Thus, to achieve greater equity of service provision, it was necessary to also establish services within private health facilities where higher income level families receive care.
- A tiered system of referral from home-based screening to community- and clinic-based functional assessments to CDC-based diagnostic workups is in the process of being scaled up, and is necessary to extend the reach of the CDC network into rural communities and to reach all children with preventive and therapeutic services.

Acknowledgements

We acknowledge the hard work and dedication of all child health physicians, child psychologists, developmental therapists, and office managers of the CDCs in the 15 medical college hospitals. We would also like to thank all children and their care providers for making each CDC a useful and utilized service within their community. We would like to thank the Line Director, Hospital Services Management, Ministry of Health and Family Welfare, Directorate General of Health Services, Ministry of Health and Family Welfare, Government of Bangladesh, for financial and administrative support to the programme.

References

- Bangladesh Protibondhi Foundation (2015) Shishu Shurokkha Shikkha Shohayika (Child Protection Educational Assistance; 3 booklets). Save the Children Bangladesh.
- Banu S. H., Salim A. F. M., Ara R., Akhter R., Khan N. Z. (2015) Neurodevelopmental evaluation in full-term newborns with neonatal hypoxic ischemic encephalopathy (HIE): A case control study. *Bangl J Child Health*, **39** (1), 6–13.
- Child Development Centre, Apollo Hospital Dhaka. Available at: http://www.apollodhaka.com/child-development-centre/
- GOB website (n.d.). Shishu Bikash Kendra. Available at: https://www. hsmdghs-bd.org/ShishuBikashKendro_ChildDevelopmentCenter.htm
- Islam, F., ParveenM, P. R., Khan, N. Z., et al. (2011) Child psychiatric disorders presenting to a tertiary multidisciplinary child development service in Bangladesh. *Bangladesh Journal of Child Health*, 35, 84–89.
- Khan, N. Z. (1998) Best resource use for disabled children. World Health Forum, 19, 47–52.
- Khan, N. & Durkin, M. (1995) Framework: Prevalence. In: *Disabled children and developing countries* (eds P. Zinkin & H. McConachie),

Clinics in Developmental Medicine No. 136, pp. 1–9. MacKeith Press, London.

- Khan, N. Z. & Ferdous, S. (eds) (2003) *Paediatric neurosciences:* Services and research in Bangladesh. Shishu Bikash Network, Dhaka.
- Khan N. Z., Muslima H., Bhattacharya M., Parvin R., Begum, N., Jahan, M., Begum, D., Akhtar, S., Ahmed, A. S. M. N. U. & Darmstadt, G. L. (2008) Stress in mothers of preterm infants in Bangladesh: Associations with family, child and maternal factors and children's neurodevelopment. *Child: Care, Health and Development*, **34** (5), 657–664.
- Khan, N. Z., Muslima, H., Begum, N., Begum, N., Shilpi, A. S., Batra, M. & Darmstadt, G. D. (2010) Reliability and validity of a structured tool for neurodevelopmental assessment of 0–24 month olds for use by multiple professionals in Bangladesh. *Pediatrics*, 125, e755–e762 Epub 2010 Mar 22.
- Khan, N. Z., Muslima, H., Shilpi, A. B., Begum, D., Parveen, M., Akter, N., Ferdous, S., Nahar, K., McConachie, H. & Darmstadt, G. L. (2013) Validation of rapid neurodevelopmental assessment for 2to 5-year-old children in Bangladesh. *Pediatrics*, **131**, e486–e494.
- Khan, N. Z., Muslima, H., El Arifeen, S., McConachie, H., Shilpi, A. B., Ferdous, S. & Darmstadt, G. L. (2014) Validation of a rapid neurodevelopmental assessment tool for 5 to 9 year-old children in Bangladesh. *Journal of Pediatrics*, **164**, 1165–1170.
- McConachie H., Huq S., Munir S., Kamrunnahar, A. N., Ferdous S. & Khan N. Z. (2001) Difficulties for mothers in using an early intervention service for children with cerebral palsy in Bangladesh. *Child: Care, Health and Development*, **27** (1), 1–12.
- Mobarak R., Khan N. Z., Munir S., Zaman S. Z. & McConachie H. (2000) Predictors of stress in mothers of young children with cerebral palsy in Bangladesh. *Journal of Pediatric Psychology*, **25** (6), 427–433.
- Muslima, H., Khan, N. Z., Shilpi, A. B., Begum, D., Parveen, M., McConachie, H. & Darmstadt, G. L. (2016) Validation of a rapid neurodevelopmental assessment tool for 10- to 16-year-old young adolescents in Bangladesh. *Child: Care, Health and Development*, 42, 658–665.
- Operational Plan, 2008-2011. "Establishment of *Shishu Bikash Kendra* in 14 Medical College Hospitals". Operational Plan, 2008–2011. Hospital Services Management, Directorate General of Health Services, Ministry of Health and Family Welfare, Government of Bangladesh.
- Operational Plan, 2016-2021. "Establishment of *Shishu Bikash Kendra* in Secondary and Tertiary Hospitals". Operational Plan, 2016–2021. Hospital Services Management, Directorate General of Health Services, Ministry of Health and Family Welfare, Government of Bangladesh.
- Parr, J. R., Jolleff, N., Gray, L., Gibbs, J., Williams, J. & McConachie, H. (2013) Twenty years of research shows UK child development team provision still varies widely for children with disability. *Child: Care, Health and Development*, **39**, 903–907.
- Richter, L. M., Daelmans, B., Lombardi, J., Heymann, J., Lopez-Boo,
 F., Behrman, J. R., Lu, C., Lucas, J. E., Perez-Escamilla, R., Dua, T.,
 Bhutta, Z. A., Stenberg, K., Gertler, P. & Darmstadt, G. L. (2017)
 Investing in the foundation of sustainable development: Pathways to

scale up for early childhood development. *Lancet*, **389** (10064), 103–118.

- Survey (2013) Survey of Autism and Neurodevelopmental Disorders in Bangladesh. Directorate General of Health Services, Ministry of Health and Family Welfare, Government of Bangladesh. Available at: http://www.hsmdghs-bd.org/SKB15/SKB-0403.pdf
- UNICEF (2015) State of the World's Children. New York, USA. Available at: sowc2015.unicef.org/
- Watter, P., Rodger, S., Marinac, J., Woodyatt, G., Ziviani, J. & Ozanne, A. (2008) Multidisciplinary assessment of children with developmental coordination disorder: Using the ICF framework to inform assessment. *Physical Occ Pediatr*, **28**, 331–352.
- WHO (1980) International Classification of Impairments, Disabilities, and Handicaps. World Health Organization, Geneva.
- WHO (1990) International Classification of Diseases World Health Organization, Geneva. (ICD10 updated version 2016)
- WHO (2001) International Classification of Functioning, Disability and Health. World Health Organization, Geneva.

Supporting information

Additional Supporting Information may be found online in the supporting information tab for this article.