

**TRAINING MANUAL FOR
THE ESTABLISHMENT OF CHILD DEVELOPMENT AND
DISABILITY SERVICES IN BANGLADESH**

VOLUMES - I & II



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BPF

Bangladesh Protibondhi Foundation

Dedicated to the memory of
Professor Emeritus Sultana Sarwatara Zaman
a pioneer in the cause of children with disabilities

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Editors: Naila Zaman Khan and Humaira Muslima

FOREWORD

This manual is the outcome of almost three decades of experience, since 1992, gathered by Professor Naila Zaman Khan and her team (including Dr. Humaira Muslima, who joined her in 1998) in developing multi-professional expertise and establishing Child Development Centers (CDCs) (Shishu Bikash Kendra in Bangla) across Bangladesh. The main objective of these centers has been to assess, identify, diagnose and appropriately manage children, from newborn to 18 years, presenting with a wide range of neurodevelopmental delays, impairments and disabilities; within a child-friendly and family-friendly environment; and by a team of multidisciplinary professionals.

The first CDC was established within the Dhaka Shishu Hospital (DSH) in 1992 by Professor Khan, after her return to Bangladesh having completed a fellowship training and subsequently obtaining a doctoral degree from the Neurosciences Unit, Great Ormond Street Hospital for Children, Institute of Child Health, London, UK. Subsequently, utilizing the experiences gathered over several years, from 1997 onwards initiatives were taken to establish similar services under the pediatrics departments of various government and government-managed national hospitals such as the Chattagram Ma O Shishu Hospital (CMOSH), Bangladesh Institute for Rehabilitation of Disorders of Endocrine and Metabolism (BIRDEM), Bangabandhu Sheikh Mujib Medical University (BSMMU), Institute of Mother and Child Health (ICMH) Matuail, Dr. MR Khan Children's Hospital and Institute of Child Health (DMRKCH), Combined Military Hospital Dhaka (CMH), Center for Women and Child Health (CWCH) Ashulia; and some private hospitals such as Apollo Hospital Dhaka, and Square Hospital Dhaka.

The contents of the manual and the quality of the multi-professional training was validated when Professor Khan was given the responsibility of establishing CDCs within government tertiary medical college hospitals across Bangladesh through the Directorate General of Health Services, Ministry of Health and Family Welfare, Government of Bangladesh, as the National Coordinator, in 2008. She and her team of dedicated professionals carried out this responsibility meticulously till 2018, having established 15 CDCs within government medical college hospitals across the country.

There is still much to achieve. Given the numbers of medical college hospitals, both within the government and not-for-profit privately owned ones, and other private hospitals providing services to children, only a handful have fully established CDC services. Beyond Bangladesh also there are many countries where such services are still very rudimentary. I believe the contents of this manual will provide a rich source of training materials for those who want to train professionals in establishing similar services. I congratulate Professor Khan, Dr. Humaira Muslima and their team for publishing such a timely manual. I hope it brings benefits for children within and outside Bangladesh.

Professor Najmun Nahar
Dhaka
May 2019



Date: 28 November, 2020

NOTE FROM THE EDITORS - IN - CHIEF

Services for children at risk of, or those who have developed neurodevelopmental disorders and/or disabilities are hard to reach where they are most needed, ie, within hospitals, where most families seek initial help. To bridge the gap we have assisted, and hence gathered experience, in the establishment of services across Bangladesh, called Child Development Centers (CDC) (Shishu Bikash Kendra, or SBK, in Bangla) within non-government and government hospitals. This manual is a comprehensive document which provides information and training materials for setting up CDCs within hospitals and similar facilities.

The manual comprises of 8 modules. Module 1, ie, the introductory module, will be equally beneficial for policy makers, hospital administrators, and the professional team. It provides the rationale for establishing such a service; elaborates the specific qualifications and composition of the service providers; provides evidence on how to make the service child and family friendly; and describes the physical structure and materials required to establish a basic service. Module 2 comprises of lectures on basic neuroanatomy and neurophysiology, and their correlation with developmental functions. It is recommended at a 'generic' and 'essential' set of lectures all professionals. Modules 3, 4 and 5 comprise of specific tutorials, tools and annexed information on common neurodevelopmental disorders and mental health conditions which will lay the foundation for establishing specific clinics within the CDCs. Although module 3 is meant for Child Health Physicians (CHPs), module 4 for Child Psychologists (CPs) and module 5 for Developmental Therapists (DTs), and brackets in the Contents pages indicate their usefulness either for these individual professionals, or as a 'generic' tutorial for all. Module 6 provides a comprehensive description about the responsibilities of the CDC administration (mainly the Office Manager) to keep records, communicate with clients, and provide both continuity and transparency to the service. It describes how to maintain an Appointments Diary, CDC Records by ID number, and Forms and Files for each specific clinic. It also provides data entry software development information so that all children's attendances can be digitized. A template for clinical audit by week, month and year is included; as well as a template for financial auditing. A template for writing a full report about a child, which is often requested by the family will also be found to be useful. Lastly, it provides a tutorial on all the above-mentioned aspects of a CDC administration, to train Office Managers. Module 7 describes the ideal placements for every trainee outside the training institution so that a comprehensive idea of common disorders leading to childhood disabilities, and their rehabilitational, educational, and social implications can be put into perspective. It should also provide the trainee with an idea of what kinds of supports are available and 'best available practices' within our country and by region. Model 8 is the annexures section that provides lists of tests, scales, and forms related to, and referenced by a particular Clinic or Tutorial.

We would like to see this project as a 'work in progress', bearing in mind that human knowledge, the social milieu, resource availability, and demand for services are ever-changing. We hope that this manual will be considered a template upon which newer knowledge and information will continue to be added; while eliminating some which might become redundant. We hope newer CDCs will continue to be established, while those already established will continue to grow and flourish.

The post Covid19 world is in a flux. Social distancing has rendered many services to become 'non essential'; and face-to-face training a risk. In this virtual world we have given priority to publishing the electronic version of the manual. In the hope that online training and demonstrations will reduce the infection risk considerably, both of trainers and trainees. The best outcome of this manual will be to see new services emerge with its help.

Naila Zaman Khan and Humaira Muslima



Date: 28 November, 2020

ACKNOWLEDGEMENTS

This document is the result of experiences acquired over three decades in the field of child neurology, childhood development and neurodisability, from our base within the Department of Pediatric Neuroscience, Bangladesh Institute of Child Health, Dhaka Shishu (Children's) Hospital (DSH). DSH authorities and our working colleagues over the years, have provided unstinting support to the slow, and, often painful, development of CDC services especially as more often than nought we had to think and act 'out of the box'. Starting from 1991, it was a pioneering service within Bangladesh, and DSH continued to keep faith in our work. We sincerely acknowledge their support.

The best interest of children and families has always been our compass to go by as to the validity and sustainability of the service. Towards this objective we have continued to search for evidence-based 'best practices' across the world, or to surmise from our own evidence-based research outcomes. Key institutions across the world have assisted us in this matter. We are especially grateful to three such partners, ie, the Neurosciences Unit, Institute of Child Health, Great Ormond Street Hospital for Children, London, UK; the Fleming Nuffield Unit for Child and Adolescent Mental Health, New Castle, UK; and the Gertrude Sergievsky Center for the Epidemiology of Brain Disorders, Columbia University School of Public Health, New York, USA.

Bangladesh is a resource-poor country where any kind of partnership requires financial support, be it in research, clinical placements in countries outside Bangladesh, post graduate training and degrees from abroad, or to support visits to our country by international experts. We remain grateful to British Council Bangladesh, for providing support over the years. Many of our experiences have been the outcomes of outreach programs and community-based projects, which have provided us with a blue-print for the future, ie, to reach every child born within our country to optimize their neurodevelopment. The two key trusts who have given us their financial support are the Child Care Trust, UK; and the Banyan Trust, UK and the Netherlands. We cannot thank them enough for their support.

Institutions are only as good as the inspiring professionals they nurture. We are thankful to Late Professor Kenneth Holt, late Professor Brian Neville, Dr. Patricia Sonksen, Professor Helen McConachie, Professor Zena Stein, Professor Leslie Davidson, Professor Maureen Durkin, Professor Gary Darmstadt, Dr. Stewart Boyd, Dr. Matthew Pitt, Alison Wisbeach, Nicola Jolleff, Dr. Melanie Adams, Namita Jacob, Professor Abbey Berg, Professor Maureen Black, late Dr. Anula Nikapota, and many others who remain in our hearts, for their time, efforts, ideas and encouragements. Which continues till today.

We are indebted to the Bangladesh Society for Child Neurology, Development and Disability (BSCNDD) (bscndd.org) for providing a regular platform for dissemination of the scientific and social messages and information periodically through various scientific meetings, seminars and conferences for over a decade.

Our final and most vital acknowledgement and continuing prayers are for late Professor Emeritus Sultana Sarwatara Zaman, whose indomitable spirit, insight and vision for services for every child with a disability in Bangladesh since the early 1970s has remained a beacon of inspiration till today. The Bangladesh Protibondhi Foundation (bpfbd.org), which Professor Zaman founded in 1984, remains a frontline organization for technological and social development and research, and our hope for the work ahead.



Contents of Eight Modules

MODULE 1

INTRODUCTION:

1.1 RATIONALE FOR ESTABLISHING CHILD DEVELOPMENT CENTERS (CDCS)

1.1.1 Epidemiology: (1.1.1. LECTURE: EPIDEMIOLOGY)

- i. ICF International Classification of Function (ICF, WHO) (ICIDH; ICF; 'F' WORDS)
- ii. Prevalence within rural and urban communities; by wealth quintile; and other risk factors and severity.
- iii. Rising incidence of NDDs and NDIs in hospitals (government, semi-government, private)
- iv. Neurodevelopmental Impairments (NDIs) rising in inverse proportion to declining child mortality rates.
- v. Rising demand for services: some reasons are lower fertility rates, smaller family sizes, rising parental literacy, increased access to information, declining hard-core poverty, increased mobility.
- vi. Quality of Child Survival: Sustainable Development Goals (SDGs)

1.1.2 Why CDC within hospitals?: early diagnosis, early intervention, best outcomes (1.1.2.LECTURE: EVIDENCE BASED PRACTICE)

1.2 MULTIDISCIPLINARY TEAM (TERMS OF REFERENCE) (ANNEXURE)

- 1.2.1 Child Health Physician: degree, training, role
- 1.2.2 Child Psychologist: degree, training, role
- 1.2.3 Developmental Therapist: degree, training, role
- 1.2.4 Office Manager: degree, training, role
- 1.2.5 Cleaner: degree, training, role

1.3 CHILD AND FAMILY FRIENDLY SERVICE

- 1.3.1 Parental stress reduction (Tutorial-Generic)
- 1.3.2 Emotional stabilization (Tutorial-Generic)
- 1.3.3 Parent Professional Partnership (Tutorial-Generic)
- 1.3.4 Individualized child-oriented service (Tutorial-Generic)
- 1.3.5 Number of visits (Tutorial-Generic)
- 1.3.6 Behavior Change Communication (BCC) (Tutorial-Generic)
- 1.3.7 Positive Parenting (Tutorial-Generic)
- 1.3.8 Child Protection (Tutorial-Generic)

1.4 STRUCTURE OF A CDC AND MATERIALS (ANNEXURE) General (Toys, Play Materials, Reference Books)

1.4.1 Area within the hospital

- 1.4.1.a Space Planning (diagram)
- 1.4.1.b Furniture

1.4.2 Equipment, Tests and Tools, Forms, Toys, Medical Equipment

- 1.4.2.a General (Toys, Play Materials, Reference Books)
- 1.4.2.b For Child Health Physician (Forms, Tests, Medical Equipment)
- 1.4.2.c For Child Psychologist (Forms, Tests, Tools)
- 1.4.2.d For Developmental Therapist (Forms, Tests, Tools, Toys/Materials)

1.4.3 Storage

1.4.4 Cleanliness

1.4.5 Maintaining a quiet environment

1.4.6 Waiting area

1.4.7 Computer, IT support , cell phone, video camera (Table)

1.4.8 Library (Table)



MODULE 2

THE NERVOUS SYSTEM AND ITS CORRELATION WITH DEVELOPMENTAL FUNCTIONS:

- 2.1** Brain development, morphology by function, neurodevelopment from conception, neuroplasticity, neuroprotection, windows of opportunities, use it or lose it, use it as much as you can. (2.1. LECTURE: NEUROBIOLOGY)
- 2.2** Neuroanatomy.(2.2 LECTURE: NEUROANATOMY)
- 2.3** Developmental Domains: Gross Motor, Fine Motor, Vision, Hearing, Speech Language Communication, Cognition, Behavior. With examples of various functional limitations: severity ratings, single vs. multiple etc. (2.3.LECTURE : DEVELOPMENTAL DOMAINS)

MODULE 3

CLINICS WHERE KEY PROFESSIONAL IS THE CHILD HEALTH PHYSICIAN:

3.1 OUT PATIENTS DEPARTMENT (OPD) CLINIC

- **3.1.1** Play and Toy Selection (Tutorial-Generic)

3.2 GENERAL DEVELOPMENTAL ASSESSMENT (GDA) CLINIC

- **3.2.1** Neurochemistry (Tutorial-CHP)
- **3.2.2** Neuropharmacology (Tutorial-CHP)
- **3.2.3** Neurodegenerative and Neurometabolic disorders (Tutorial-CHP)
- **3.2.4** Neuronal migration disorders (Tutorial-CHP)
- **3.2.5** Neuroradiology (Tutorial-CHP)
- **3.2.6** Sleep Disorders in Children (Tutorial-CHP)
- **3.2.7** Embryology of Nervous System (Tutorial-CHP)
- **3.2.8** Neuromuscular Disease in Children (Tutorial-CHP)
- **3.2.9** Congenital anomalies of CNS (Tutorial-CHP)
- **3.2.10** Movement disorder (Tutorial-CHP)
- **3.2.11** Neurodevelopmental Assessment (NDA) Form (Annexure)
- **3.2.12** Data Entry Sheet (Annexure)
- **3.2.13** Developmental Therapy Form (Annexure)
- **3.2.14** International Classification of Disease -10 criteria for Autism (Annexure)
- **3.2.15** DSM-V criteria for Autism (Annexure)
- **3.2.16** Modified checklist for Autism in Toddlers (M-CHAT) (Annexure)
- **3.2.17** Social Communication Questionnaire (SCQ) (Annexure)
- **3.2.18** International Classification of Disease -10 and 11 (ICD-10, ICD-11) (Link)
- **3.2.19** Diagnostic and Statistical Manual-IV and V (DSM IV and DSM V) (Link)

(Annexure:Adapted Codes from ICD 10 and DSM IV and DSM V) (Razia: GDA, OPD, Motor, Epilepsy, Other neurological disorders, Selina: Epilepsy, Farzana: Mental Health, TIA, Bipasha: Psychological disorders , Sharmeen: Psychological disorders, Shilpi, Nasreen: SLC, Motor, Multiple Disability

3.3 EPILEPSY CLINIC (EC)

- **3.3.1** Epilepsy (Tutorial-CHP)
- **3.3.2** Epilepsy - Treatment (Tutorial-CHP)
- **3.3.3** Neurophysiology - Normal EEG (Tutorial-CHP)
- **3.3.4** Abnormal EEG (Tutorial-CHP)
- **3.3.5** Seizure Pro-forma (Annexure)

3.4 CHILD AND ADOLESCENT MENTAL HEALTH (CAMH) CLINIC

- **3.4.1** Overview of Child & Adolescent Mental Health (Tutorial-Generic)
- **3.4.2** Attention Deficit Hyperactivity Disorder (Tutorial- Generic)
- **3.4.3** Behaviour modification strategies (Tutorial- Generic)
- **3.4.4** Conduct Disorders (Tutorial- Generic)
- **3.4.5** Oppositional Defiant Disorders (Tutorial- Generic)
- **3.4.6** Strengths & Difficulties Questionnaire (SDQ- Bangla version) (Annexure)
- **3.4.7** Conner's Parent Rating Scale (short form) (Annexure)



MODULE 4

CLINICS WHERE KEY PROFESSIONAL IS THE CHILD PSYCHOLOGIST AND COUNSELOR:

4.1 PSYCHOLOGICAL ASSESSMENT AND COUNSELING (PAC) CLINIC

- 4.1.1 Bayley Scales of Infant and Toddler Development (Bayley III) (Manual, Tool Kit, Tutorial)
- 4.1.2 Wechsler Preschool and Primary Scales of Intelligence III (WPPSI III) Junior and Senior version (Manual, Tool Kit, Tutorial)
- 4.1.3 Wechsler Intelligence Scales for Children IV (WISC IV)(Manual , Tool Kit, Tutorial)
- 4.1.4 Stanford Binet Intelligence Scale (SBIS) (Manual, Tool Kit, Tutorial)
- 4.1.5 Reynell Zinkin Scale for young visually handicapped and multiply disabled children (RZS) (Manual and Took Kit, Tutorial)
- 4.1.6 The Independent Behavior Assessment Scale (IBAS) (Manual, Tool Kit, Tutorial)
- 4.1.7 Autism Diagnostic Observation Schedule (ADOS), Module 1, 2,3 (Manual , Tool Kit, Tutorial)
- 4.1.8 Cognition (Tutorial-CP)
- 4.1.9 Learning Difficulties and Dyslexia (Tutorial-CP)
- 4.1.10 Emotional Intelligence (Tutorial-CP)
- 4.1.11 Executive Function (Tutorial-CP)
- 4.1.12 Basic Counseling Skills (Tutorial-CP)
- 4.1.13 Counseling approach (Tutorial-CP)
- 4.1.14 Family Counseling (Tutorial-CP)
- 4.1.15 Attachment Theory (Tutorial-CP)
- 4.1.16 Cognitive Behavior Therapy (Tutorial-CP)
- 4.1.17 Eye Movement Desensitization and Reprocessing (EMDR) (Tutorial-CP)
- 4.1.18 Transactional Analysis (Tutorial-CP)
- 4.1.19 Intervention protocol (Tutorial-CP)
- 4.1.20 Interventional Strategies of Communication (Tutorial-CP)
- 4.1.21 Interventional Strategies of Socialization. (Tutorial-CP)
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- 4.1.23 Schooling.(Tutorial-CP)
- 4.1.24 Strengths and Difficulties Questionnaire (SDQ) (Tutorial-CP)
- 4.1.25 Strengths and Difficulties Questionnaire (SDQ- Bangla version) (Annexure #3.4.6.)
- 4.1.26 Conner's Parent Rating Scale (short form) (Annexure #3.4.7.)
- 4.1.27 Psychological Assessment Form (Annexure)

MODULE 5

CLINICS WHERE KEY PROFESSIONAL IS THE DEVELOPMENTAL THERAPIST

5.1 MULTIPLE DISABILITY CLINIC – MOTOR (MDC-M)

- 5.1.1 Cerebral Palsy (Tutorial-Generic)
- 5.1.2 Gross Motor Function Classification System (GMFCS) (Tutorial-DT)
- 5.1.3 Multiple Disability and Management (Tutorial-DT)
- 5.1.4 Movements of joints (Tutorial- DT)
- 5.1.5 Assistive device (Tutorial- DT)
- 5.1.6 Activities of Daily Living (Tutorial- Generic)
- 5.1.7 Multiple Disability Clinic Form (Annexure)
- 5.1.8 Gross Motor Function Classification System (GMFCS) (Annexure)

5.2 MULTIPLE DISABILITY CLINIC – SEATING AND FEEDING (MDC – S AND F)

- 5.2.1 Normal Feeding (Tutorial-Generic)
- 5.2.2 Seating & Feeding (Tutorial-DT)
- 5.2.3 Dietary Management (Tutorial-DT)
- 5.2.4 Seating and Feeding Form (Annexure)
- 5.1.5 Assistive device (Tutorial- DT)
- 5.2.6 Record of height and weight to measure wasting and stunting status (Annex: Growth Charts/ Link)



5.3 DISABILITY CLINIC – VISUAL IMPAIRMENT (MDC – VI)

- 5.3.1 Visual impairment (Tutorial-Generic)
- 5.3.2 Cortical Visual Impairment (Tutorial-Generic)
- 5.3.3 Multiple Disability Clinic Form (Annexure # 5.1.7)

5.4 THERAPEUTIC INTERVENTION FOR AUTISM (TIA) CLINIC

- 5.4.1 Autism Spectrum Disorders (Tutorial-Generic)
- 5.4.2 ASD: More Than Words (MTW) and other intervention strategies (Tutorial-DT)
- 5.4.3 Sensory Processing and Intervention (Tutorial- Generic)
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- 5.4.5 TIA Form (Annexure)
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- 5.4.7 Parent Interview for Autism-Clinical Version (PIA-CV Bangla version) (Annexure)

5.5 SPEECH, LANGUAGE, AND COMMUNICATION (SLC) CLINIC

- 5.5.1 Working with children with SLC needs (Tutorial-Generic)
- 5.5.2 Hearing Impairment (Tutorial-Generic)
- 5.5.3 Attention and listening (Tutorial-Generic)
- 5.5.4 Speech, Language and Communication History Form (Annexure)
- 5.5.5 Speech, Language and Communication Checklist (Annexure)

5.6 WELL BABY AND NEONATAL CLINIC (WBC)

- 5.6.1 Normal Development (Tutorial-Generic)
- 5.6.2 Early Intervention (Tutorial-Generic)
- 5.6.3 Rapid Neurodevelopmental Assessment (RNDA) (Manual, Tool Kit, Video, Link)

MODULE 6

OFFICE AND ADMINISTRATION:

6.1 PROCEDURES FOR MAINTAINING PATIENT INFORMATION:

- 6.1.1 Appointment Diary
- 6.1.2 Early Intervention (Tutorial-Generic)
- 6.1.3 Rapid Neurodevelopmental Assessment (RNDA) (Manual, Tool Kit, Video, Link)

6.2 PROCEDURES FOR MAINTAINING PATIENT INFORMATION:

- 6.2.1 Normal Development(Tutorial-Generic)
- 6.2.2 Registry Book – ID, Date, Referral Information, Name, Age, Sex, Siblings, Address, Information on Parents, Socioeconomic Status, Diagnosis.
- 6.2.3 Forms and files by Clinics

6.3 DATA MANAGEMENT

- 6.3.1 Data entry software

6.3 CLINICAL AUDIT: weekly, monthly, yearly.

6.4 FINANCIAL AUDIT

- 6.4.1 Audit of equipment
- 6.4.2 Audit of expenditure

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6.6 AN OVERVIEW OF OFFICE MANAGEMENT (Tutorial-OM)



MODULE 7

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- 7.1** Community Based Rehabilitation (Urban and Rural)
- 7.2** Day Care, Pre School and Schools (Special and Inclusive)
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MODULE 8

ANNEXURE

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- **1.4.2.a** General (Toys, Play Materials, Reference Books)
- **1.4.2.b** For Child Health Physician (Forms, Tests, Medical Equipment)
- **1.4.2.c** For Child Psychologist (Forms, Tests, Tools)
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- **3.2.11** Neurodevelopmental Assessment (NDA) Form (annexure)
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