2016 Situation Assessment of Autism and Neurodevelopmental Disorders in Bangladesh

Non Communicable Disease Control Programme
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With Technical Assistance of
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Situation Assessment of Autism and Neurodevelopmental Disorders in Bangladesh

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Institute for Community Inclusion at University of Massachusetts Boston

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List of Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
ADI-R	Autism diagnostic interview revised
ADOS	Autism Diagnostic Observation Schedule
AHI	Assistant health inspector
APSC	Annual Primary School Census
AWF	Autistic Welfare Foundation
BANBEIS	Bangladesh Bureau of Educational Information & Statistics
BCC	Bangladesh Computer Council
BHTPA	Bangladesh Hi-Tech Park Authority
BKSP	Bangladesh Krira Shikkha Protishtan (Bangladesh Institute of Sports)
BMRC	Bangladesh Medical Research Council
BMTTI	Bangladesh Madrasa Teachers Training Institute
BSMMU	Bangabandhu Sheikh Mujib Medical University
CABS	Clancy Autism Behavior Scale
CBR	Community-based rehabilitation
CC	Community clinic
CCA	Controller of Certifying Authorities
CDC	Child development center
CDD	Center for Disability & Development
CP	Cerebral palsy
CRP	Centre for the Rehabilitation of the Paralysed
CSO	civil society organizations
CWD	child/children with disability
DAWBA	Development and Well-Being Assessment
DGHS	Directorate General of Health Services
DMS	Data management system
DPE	Directorate of Primary Education
DPO	Disabled persons' organization
DRRA	Disabled Rehabilitation and Research Association
DSHE	Directorate of Secondary and Higher Education
DSM-IV (V)	The Diagnostic and Statistical Manual
DSQ	Developmental Screening Questionnaire
DYD	Department of Youth Development

ELC	Early learning center
ELCD	Early Learning for Child Development
ELDS	Early Learning and Development Standards
ESD	Essential service delivery
GDA	General development assessment
GDP	Gross Domestic Product
GoB	Government of Bangladesh
HA	Healthcare assistant
HF	Household Form
HI	Health inspector
HIES	Household Income and Expenditure Survey
HRD	Human resource development
HSTTI	Higher Secondary Teachers Training Institute
ICD-10	International classification of diseases
ICDDRB	International Centre for Diarrhoeal Disease Research, Bangladesh
ICF	International Classification of Functioning: Disability and Health
ICI	Institute for Community Inclusion (University of Massachusetts Boston)
ICTD	Information & Communication Technology Division – Ministry of Posts, Telecommunication & Information Technology
IEC	Information, education and communication
IEP	Individualized Education Plan
ILO	International Labour Organization
IQ	Intelligence quotient
IMCC	Inter-Ministerial Coordination Committee
IPNA	Institute for Pediatric Neurodisorder and Autism
IDSC	Integrated disability service center
IST	In-service training
JMS	Jatiyo Mohila Sangstha
JPUF	Jatiyo Protibondhi Unnayan Foundation
LGD	Local Government Division – Ministry of Local Government, Rural Development & Cooperatives
LMIC	Low- middle-income countries
MBBS	Bachelor of Medicine, Bachelor of Surgery

MCF	Mother-Child Form
M-CHAT	Modified Checklist for Autism in Toddlers
MDGs	Millenium Development Goals
MoCA	Ministry of Cultural Affairs
MoE	Ministry of Education
MoF	Ministry of Finance
MoHFW	Ministry of Health & Family Welfare
MoI	Ministry of Information
MoLE	Ministry of Labor & Employment
MoPME	Ministry of Primary & Mass Education
MoSW	Ministry of Social Welfare
MoWCA	Ministry of Women & Children Affairs
MoYS	Ministry of Youth & Sports
MTV	Mobile therapy van
NAAND	National Academy for Autism & Neurodevelopmental Disorders
NAC	National Advisory Committee (for Autism & Neurodevelopmental Disorders in Bangladesh)
NAEM	National Academy for Education Management
NAPE	National Academy for Primary Education
NCDC	Non-Communicable Disease Control (DGHS)
NCSAND	National Steering Committee for Autism and Neurodevelopmental Disorders
NCTB	National Curriculum & Textbook Board
NDD	neurodevelopmental disorder/disability
NFOWD	National Forum of Organizations Working with the Disabled
NGO	Non-governmental organization
NGOAB	NGO Affairs Bureau (PMO)
NILG	National Institute for Local Government
NIMH&R	National Institute of Mental Health & Research
NINS	National Institute for Neurosciences
NITOR	National Institute of Traumatology and Orthopaedic Rehabilitation
NSDC	National Skill Development Council
PFDA	Parents Forum for Differently Able
PMO	Prime Minister’s Office

PS	Primary school
PTI	Primary teachers Training Institute
PWD	Person with disability
RCHCIB	Revitalization of Community Health Care Initiatives in Bangladesh
RN**D**A	The Rapid Neurodevelopmental Assessment
ROSC	Reaching Out-of-School Children
SAAN	Southeast Asian Autism Network
SACMO	Sub-assistant community medical officer
SCAPAND	Strategic and Convergent Action Plan for Autism & Neurodevelopmental Disorders
SCQ	Social communication questionnaire
SDG	Sustainable Development Goal
SEARO	South East Asia Region Office
SS	Secondary school
SWAC	Society for the Welfare of Autistic Children
SWID	Society for the Welfare of the Intellectually Disabled
TGC	Technical Guidance Committee
TOR	terms of reference
TOT	Training of trainers
TTC	Technical training center
TQP	Ten Questions Plus
UCEDD	University Centers for Excellence in Developmental Disabilities Education, Research, and Service
UHC	Upazila health complex
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
USEO	Upazila Secondary Education Officer
WAAD	World Autism Awareness Day
WHA	World Health Assembly
WHO	World Health Organization
YTC	Youth training center

Glossary

zila	District
upazila	Sub-district
parishad	Council
shishu bikash kendro	Child development center
protibondhi	Person with disability
uthan boithok	Courtyard meeting
madrasa	Islamic parochial school
kishore	Teenaged/adolescent boy
kishori	Teenaged/adolescent girl

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EXECUTIVE SUMMARY

Addressing the inclusion of persons with disabilities is an integral part of government-implemented strategies for sustainable development. Inclusion is predicated on principles of universal human rights as outlined in the UN Convention on the Rights of Persons with Disabilities and upheld by the social and human rights models of disability. These core values (outlined below) are central to and provide a framework for the interpretation of this report and its findings.

- **Inclusive and Equitable Development**: Persons with disabilities have the right and should be included within all government programs and policies. The development of segregated institutions, including schools, is neither cost effective nor efficient or respectful of the dignity and rights of persons with disabilities.
- **Individualized**: Persons with disabilities, including those with neurodevelopmental disabilities, are individuals with different wants and needs. All programs should be conceptualized with an ethos of valuing diversity of its participants and meeting the individual's needs when designing and delivering services.
- **Participatory**: Adopting the international disability rights community's mantra of "nothing about me without me" is key for all initiatives related to those with disabilities. Any action should be planned with their involvement as key stakeholders in program design, implementation, and evaluation.
- **Affordable and Community-based**: Persons with disabilities are more likely to live in poverty due to the adverse economic impacts of disability. Affordable community-based services allow for persons with disabilities to remain with their family and local community and participate fully in community life. All efforts should ensure local community-based supports to ensure community independence.
- **Coordinated and Accountable**: National, regional and local initiatives should be coordinated to reduce redundancy and ensure persons with disabilities are offered coordinated disability supports. Implementation of effective

monitoring and evaluation plans, which include consumer feedback loops, are key to ensuring accountable and successful interventions.

The “Situation Assessment of Autism and Neurodevelopmental Disorders in Bangladesh” (herein referred to as “Situation Assessment”) was prepared for JDTAF project No. TA/083 and funded by Crown Agents LTD. Data was collected from November 15, 2015 to March 3, 2016 in collaboration with the Shuchona Foundation and ICDDRb. In addition to data collected by on the ground partners, the Institute for Community Inclusion conducted two site visits, one in December 2015 to Dhaka and one in February 2016 to Dhaka and the surrounding area. Throughout the data collection process, team members engaged stakeholders, including opinion leaders, service providers, policy makers, partners, parents, and potential beneficiaries through in-depth interviews, focus group discussions, community dialogue, and small group discussions.

The purpose of the situation assessment was to execute a situation analysis for Autism and Neurodevelopment Disorder (NDD) in Bangladesh, in purview of the previous situation analysis reports completed by MOHFW and other ministries, divisions and stakeholders to be used later to develop a national-level strategy and action plan. The situation assessment covers the following areas: a review of the scale and prevalence of NDD with trends of the disorder in the recent past in Bangladesh (see page 17); estimation of likely disease burden in the near future (see page 27); assessment of the social response to NDD in Bangladesh (see page 67); overview of the support and services required by persons with NDD (see page 79); an inventory of service providers working with NDD in Bangladesh (see page 85); an assessment of the adequacy of the existing services and support available for addressing NDD in country (see page 97); an overview of the role and preparedness of MOHFW and other stakeholders in addressing NDD in Bangladesh (see page 108); recommendations for monitoring, supervision and reporting mechanisms for NDD services at the national level (see page 167); and recommended key activities that should be undertaken by the Health and other relevant ministries in the short and medium term (see page 167). The report provides an overview of recommendations from many stakeholders and as such the reporting of these findings are included in the report text. Investigators have summarized key strategic recommendations for consideration at the conclusion of the report.

1 INTRODUCTION

1.1 Problem Statement

There is sufficient evidence researched all over the world that indicates that persons with disabilities (PWDs) are often more prone to suffering economic and social difficulties and at a greater risk of poverty.[1] In addition to constraining their lives, exclusion of PWDs has a debilitating effect on their societies as well. Aside from being a major issue of human rights abuse, studies have been conducted to gauge the severity of the impact of this exclusion on economies. For instance, the World Bank estimated in 2008 the annual cost of disability in Bangladesh (computed from the forgone income of PWDs and their caregivers as a result of missing out on educational and employment opportunities) to be USD 1.2 billion – about 1.7% of GDP.[2] Similarly, the International Labour Organization (ILO) estimated based on a study of ten low- and middle-income countries (LMICs) that 3-7% of GDP is lost each year because of exclusion of PWDs from the workforce, partly due to a lack of education opportunities for them in those countries.[3]

Employment opportunities for PWDs are often very limited in number and restrictive in nature (such as informal jobs). Rather, they are more likely to be "underemployed" – with low salaries, part-time jobs and a minimal scope for career advancement. As a result, in comparison to non-disabled persons, it is extremely challenging for PWDs to secure full-time employment, making them "economically inactive" members of society.[4] Within the disability group, this is even truer for persons with Autism and NDDs, because of the complexity and significant variations in the manifestation of the disorders.

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[1] World Health Organization and World Bank Group, *World Report on Disability*, 10 (2011).

[2] The World Bank, *Project Appraisal Document on a Proposed Credit to the People's Republic of Bangladesh for a Disability and Children-at-Risk project* (2008).

[3] Buckup, S. (2009). ILO Employment Sector Working Paper No. 43, *"The price of exclusion: The economic consequences of excluding people with disabilities from the world of work"*.

[4] Global Campaign for Education, *Equal Right Equal Opportunity: Inclusive Education for Children with Disabilities* (2013). Available from: www.campaignforeducation.org/en/campaigns/education-and-disability

The result is that in most countries, disabled people are among the poorest of the poor. Adults with disabilities typically live in poorer than average households: disability is associated with approximately a ten-percentage-point increase in the probability of falling in the two poorest quintiles. According to World Bank estimates, one in every five of the world's poorest people has a disability.

The situation was similar in Bangladesh, until the government under the leadership of the Honorable Prime Minister Sheikh Hasina and advice from experts brought about changes in the lives of people with disabilities.

In July of 2011 in Dhaka, the Government of Bangladesh (GoB) hosted the largest and most high-profile international conference that has ever been held for a single psychological disability, which resulted in the passing of the Dhaka Declaration on Autism Spectrum Disorders and Developmental Disabilities. This event sparked the development of an inter-ministerial committee on neurodevelopmental disabilities (NDD), a situation analysis (2014) mapping existing resources and gaps in services for NDD, and the formation of a Strategic and Convergent Action Plan on Autism and NDDs (SCPAND) that addresses the life-cycle needs of persons with these disorders. This is a critical period in Bangladesh and it is vital that appropriate planning and suitable action take place. Programs must be based on culture, social expectations, financial and professional resources, and existing infrastructure within Bangladesh.[5]

Implementation of the Master Action Plan requires strategic planning and cross-sector collaboration between ministries, non-governmental organizations, and community members. The GoB should, through policies and programs, strive to provide timely and evidence-based services and supports to those with NDD and their families through the provision of educational and health-related services. This includes monitoring and regulation of services currently being provided in country, the training of professionals and family members for service delivery, and the development of higher education programs to serve as centers for professional development.

However, current efforts to develop supports and services for those with NDD and their families have been hindered by disjointed coordination at the government level

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[5] Global Autism Public Health Initiative in Bangladesh, *One Year Progression on Autism in Bangladesh* (2012)

and a lack of clear ownership over NDD and the Master Action Plan. Despite the existence of a Steering Committee for NDD – comprised of all the relevant government ministries – services and programs continue to be developed in an uncoordinated and sometimes redundant manner. In addition, the lack of a professional body mandated to develop service providers in country has significantly hindered the training of competent services providers.[6] This has led to a gap in services[7] for those with NDD and their families in Bangladesh. Currently, families have little to no access to high-quality health or educational[8] services for their children. Those with NDD are excluded and denied access to services needed. This exclusion creates significant stigma and isolation for those with NDD and their families, as well as financial detriment to the family unit.

1.2 Definition of Population

According to the DSM-V,[9] neurodevelopmental disorders are a group of conditions with onset in the developmental period, and continue throughout an individual's lifetime. The disorders typically manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning. These brain function deficits can affect a person's emotions and memory, as well as his or her ability to learn, socialize, and maintain self-control. The range of developmental deficits varies from very specific limitations of learning or control of executive functions to global impairments of social skills or intelligence.

The category of neurodevelopmental disorders, as set out in the DSM-5, includes attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), communication disorders, intellectual developmental disorder, motor disorders, and specific learning disorders. It's not unusual for these disorders to co-exist. While there are no known cures for neurodevelopmental disorders, medication and therapy treatments do exist that can help a child or adult.

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[6] Global Autism Public Health Initiative in Bangladesh, *Situation Analysis of Autism and Neurodevelopmental Disabilities in Bangladesh* (2012)

[7] Global Autism Public Health Initiative in Bangladesh, *Situation Analysis of Autism and Neurodevelopmental Disabilities in Bangladesh* (2012)

[8] Global Autism Public Health Initiative in Bangladesh, *Situation Analysis of Autism and Neurodevelopmental Disabilities in Bangladesh* (2012)

[9] American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders: DSM-5. Washington, D.C: American Psychiatric Association.

ICD-10[10] classifies autism and neurodevelopmental disorders under mental and other behavioral disorders. This block comprises a range of mental disorders grouped together on the basis of their having in common a demonstrable etiology in cerebral disease, brain injury, or other insult leading to cerebral dysfunction. For the purposes of this analysis, sections F70-79 (mental retardation) and F80-89 (disorders of psychological development) are most applicable. Section F80-89 includes speech disorders, learning disorders, motor disorders, and pervasive developmental disorders.

Autism Spectrum Disorder

Under the DSM-5, autism is characterized by persistent deficits in **social communication** and interaction across multiple contexts, as well as **restricted, repetitive patterns of behavior**, interests, or activities. These deficits are present in early childhood, typically before age three, and lead to clinically significant functional impairment. Sample symptoms include lack of social or emotional reciprocity, stereotyped and repetitive use of language or idiosyncratic language, and persistent preoccupation with unusual objects. The disturbance must not be better accounted for by Rett syndrome, intellectual disability or global developmental delay. ICD-10 (2010) uses essentially the same definition, but continues to break autism into subtype (childhood autism, atypical autism, childhood disintegrative disorder, Rett Syndrome, Asperger Syndrome, Pervasive Development Disorder, etc.) while the DSM-5 has a combined definition of autism and assesses severity of symptoms.

1.3 Scale and prevalence of Autism and Neurodevelopmental Disorders

The world's knowledge of the general status of children living with disabilities is shamefully scant. It is impossible to generate global estimates based on national data that is outdated, inconsistent or unreliable, thus resulting in an unclear picture internationally due to the difficulty of sourcing globally comparable data.[11] Data on

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[10] *ICD-10: International Statistical Classification of Diseases and Related Health Problems: Tenth Revision*. World Health Organization. 2007. Archived from the original on 21 April 2013. Retrieved 10 January 2016.

[11] UNICEF, *The State of the World's Children 2013: Children with Disabilities* (2013). Available from: www.unicef.org/sowc2013/report.html

autism is even scarcer, compounded further by the complexity of identifying the disorder by laypersons.

A combination of social, technical and practical factors are the main reasons behind such paucity of data on disability, which makes it very difficult to collect accurate, usable national data. In Bangladesh, for instance, families raising CWDs abstain from reporting their children out of fear of being ostracized by society, due to a misperception that a disability is a "punishment" for parents' wrongdoings. Technical factors such as differing definitions (based on the importance given to different aspects of disability), classifications and categorizations of disability prevent the collation of cross-country comparable data. Practical difficulties include a shortage of trained personnel to conduct disability detection surveys in rural areas, which ultimately leads to lower reporting of disability prevalence.[12]

Countries reporting higher disability prevalence tend to collect their data through surveys and apply a measurement approach that records activity limitations and participation restrictions in addition to impairments, and are based on the **International Classification of Functioning: Disability & Health (ICF)**[13]. In addition, these countries also have well-defined and agreed-upon disability categories, as well as a set procedure for their identification. Like many other LMICs, no such definition, process of identification or medical record keeping exists in Bangladesh, and a part of the reason for that is because disability is not embedded within the health system. Therefore during the data collection process, disability categories are based on the functions and their impact, which are largely defined by the purpose of the study and the researchers' education background. This deficiency in Bangladesh urgently needs to be addressed, because the ensuing result thereof is a lack of accurate national data, which in turn leads to inadequate planning of service provision from the government. Ultimately, the disabled population – particularly those with NDDs – end up not receiving the support they need to live content, comfortable lives in society. After all, how can one make effective, feasible policy decisions when one doesn't have a gauge of the extent of the national problem?

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[12] Global Campaign for Education, *Equal Right Equal Opportunity: Inclusive Education for Children with Disabilities* (2013). Available from: www.campaignforeducation.org/en/campaigns/education-and-disability

[13] ICF is a WHO framework of health and health-related domains designed for measuring health and disability metrics at both individual and population levels.

Bangladesh, like many countries in the region, has reported high variations in prevalence between the 2010 HIES[14] and MoSW's Disability Detection Survey (precisely for the aforesaid reasons), with HIES using the method of disability data collection formulated by the *Washington Group on Disability Statistics*. Figure 1 illustrates that variance for even just one sub-category of disabilities across the world.

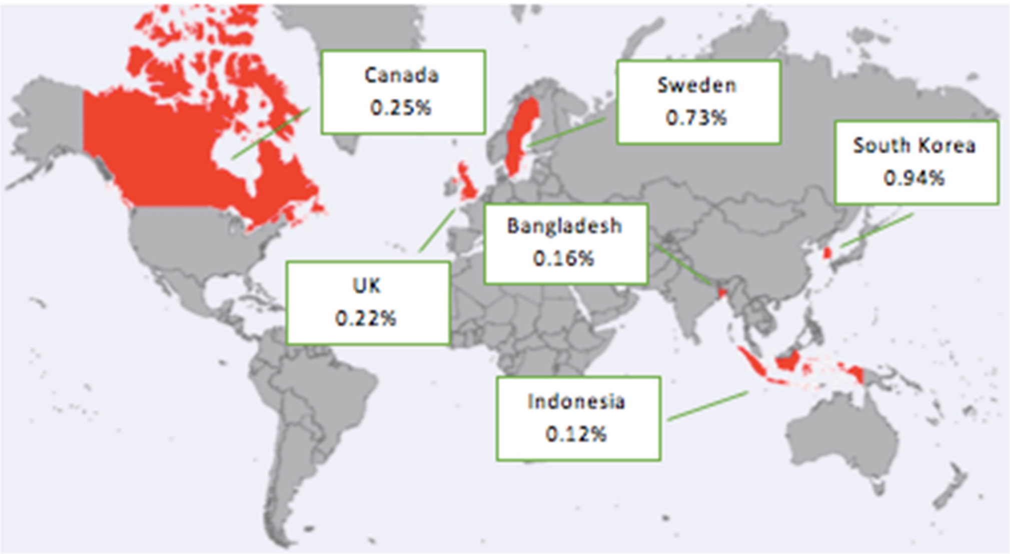

Figure 1 – Comparison of prevalence figures of ASD from various regions[16]

UNESCAP chose to present the HIES finding (~9.07%[15]) as the prevalence figure for Bangladesh ahead of all other findings available at the time (Figure 2). Yet this figure is 50% higher than what UNESCAP reported back in 2008, which was just under 6%.[16] Such volatility of data suggests that disability detection is a constantly evolving science that involves a multitude of variables – some that can be accounted for and others that cannot – thus making the task of determining an accurate prevalence figure for any given country all the more difficult.

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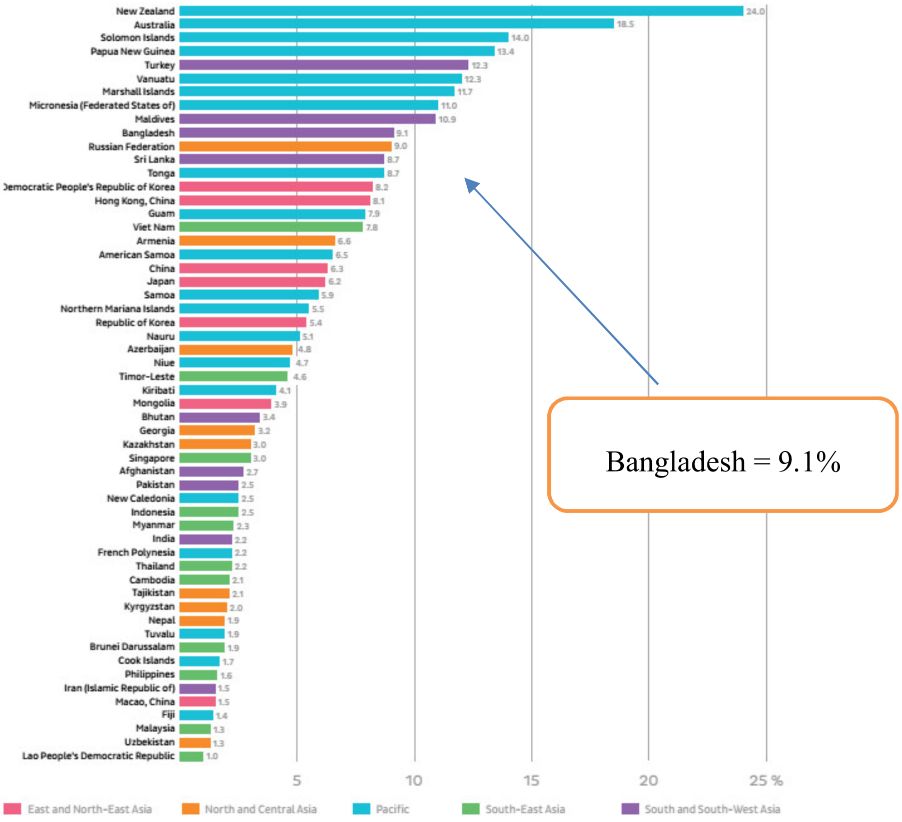
[14] Household Income & Expenditure Survey

[15] Bangladesh Bureau of Statistics, *Report of the Household Income & Expenditure Survey 2010*. Available from: www.bbs.gov.bd/WebTestApplication/userfiles/Image/LatestReports/HIES-10.pdf

[16] United Nations Economic and Social Commission for Asia and the Pacific, 2008.



Bangladesh = 9.1%

Figure 2 – Disability prevalence figures of countries in the Asia-Pacific region as of 2015[17]

As mentioned earlier, data on autism and other NDDs is even more difficult to procure, but some studies in Bangladesh are worth mentioning.

Table 1 – Epidemiology of autism in Bangladesh

YEAR	TYPE	CONDUCTOR	PREVALENCE	LIMITATIONS
2005	Epidemiological	Mullick & Goodman	0.2%	Very small sample size Rural areas not covered
2009	Community-based (sub-district	WHO & NIMH&R[18]	0.84%	Very small sample size Rural areas not

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[17] United Nations Economic and Social Commission for Asia and the Pacific, *Disability at a Glance 2015*. Available from: www.unescap.org/resources/disability-glance-2015-strengthening-employment-prospects-persons-disabilities-asia-and.

[18] National Institute of Mental Health & Research, Dhaka

	level)			covered
2013[19]	Epidemiological (8 sites, one per division)	DGHS (NCDC[20]) MoHFW (RCHCIB[21]) BMRC[22] Shishu Hospital (Dept. of Pediatric Neuroscience)	0.155% 0.07% (rural) 3% (urban)	Major discrepancy between rural and urban data, which contradicts international trends Inter-rater reliability in doubt

The disorders listed in Table 2 below are some of the more frequently cited NDDs. If the prevalence figures for these disorders are added together, it results in an estimate global prevalence of 3.5% for NDDs. The actual prevalence would, of course, be higher when other NDDs such as sensory disorders, cerebral palsy, and learning and behavioral disorders such as ADHD are included.

Table 2 – Global prevalence figures for common NDDs

DISORDER	YEAR	SOURCE	PREVALENCE
Autism spectrum disorders	2013	WHO[23]	0.625%
Down syndrome	2015	WHO[24]	0.095%
Intellectual disorders	1980-2009	Maulik et al.[25]	1.037%

Autism is growing at a faster rate (Figure 3), even more so than even cerebral palsy in the US as evidenced by the findings of an NDD surveillance program for 8-year-olds

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[19] This 2013 survey of ASD and NDDs in Bangladesh by Khan et al. is the most comprehensive and scientifically diligent effort to date, involving 7,280 children aged 0-9 years using a three-stage deisgn involving two screening phases and one psychological diagnostic workout. Available at: www.hsmdghs-bd.org.

[20] Non Communicable Disease Control

[21] Revitalization of Community Health Care Initiatives in Bangladesh – a project of MoHFW

[22] Bangladesh Medical Research Council

[23] World Health Organization. Retrieved from: http://www.who.int/features/qa/85/en/

[24] World Health Organization. Retrieved from: http://www.who.int/genomics/public/geneticdiseases/en/index1.html

[25] Maulik, P. K. et al. (2011). Prevalence of Intellectual Disability: A Meta-Analysis of Population-Based Studies. *Research in Developmental Disabilities*, 32(2), 419-436

in metropolitan Atlanta, Georgia.[26] However, this may not be true in the Asia-Pacific region where a large number of deliveries are still being done at home where there is greater risk complications during the birthing process, such as birth-asphyxiation, particularly in remote areas with limited access to medical facilities. Such data indicate the dire need for action to address this rising global health concern.

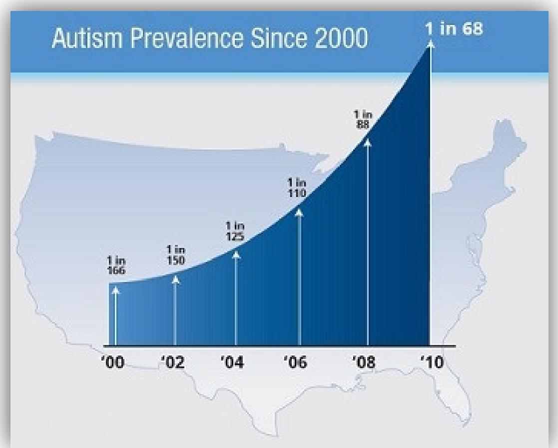

Figure 3 – Prevalence figures of ASD in USA since 2000[27]

Childhood Disability as a Public Health Problem

The burden of childhood disability as a public health problem in developing countries remains unrecognized. It is not uncommon in Bangladesh as well. The child survival rate in Bangladesh has improved, but that is being off-set with the increasing rates of non-communicable conditions such as childhood disabilities. According to GoB surveys in 1982, 1986, and 1998, the prevalence rate of disability has been identified at 0.64%, 0.05%, and 1.60% respectively. Bangladesh Protibandhi Kallayan Samity (BPKS) records the disability prevalence rate at 7.8%; Action-Aid Bangladesh and Social Assistance and Rehabilitation for the Physically Vulnerable put the figure at 8.8%. One study conducted by Handicap International (HI) and NFOWD on disability among 13,205 people all over Bangladesh showed the disability rate at 5.6% (Alam, Bari, & Khan, 2005).

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[26] Van Naarden Braun, K. et al. (2015). Trends in the prevalence of autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, and vision impairment, metropolitan Atlanta, 1991-2010. *PLoS One*, 10(4): e0124120.

[27] Sourced from: Center for Disease Control and Prevention, USA

There are no exact statistics on how many children are affected with autism in the country. About 10% of Bangladesh's people have a disability ; of those, 1% is estimated to be autistic, amounting to around 150,000 people (Shegufta Yasmin, 2012). While autism and neurodevelopmental disabiliites are commonly recognized in developed countries, this is comparatively new concept in Bangladesh. There is a need to explore the epidemiology of NDD in Bangladesh to find out the exact statistics to help facilitate an appropriate program and intervention plan to rehabilitate those with NDD. The section below outlines an extensive literature review assessing the current and previous global data on NDDs.

Systematic Review Methodology

The research team conducted a systematic literature review using databases such as PubMed and Google Scholar. Search terms included each of the following terms: “autism”, “neurodevelopmental disorder (NDD)”, “neurodevelopment impairment”, “prevalence of autism”, ‘‘Autism disorder’’, “Situation Assessment of Autism”, “prevalence of motor”, “Prevalence of cerebral palsy” and “ADHD”. The literature search was conducted in three contexts of Global, Asia, and Bangladesh. Researchers also located and reviewed article reference lists to identify the prevalence study.

Inclusion criteria

The following inclusion criteria were used in selecting articles: studies that included data regarding prevalence rates of overall NDD, different types of NDD and association between demographic data and NDD, and diagnostic studies using different tools, e.g., Strengths and Difficulties Questionnaire (SDQ), Development and Well-Being Assessment (DAWBA), General Health Questionnaire 60 (GHQ-60), ten Questions (TQ), Behavior checklist (BCL), and Rapid Neurodevelopment Assessment (RNDA). Data was extracted from each study that met inclusion criteria, including first author; year of publication; country, region, and area of study; screening strategy and information source; diagnostic criteria and strategy; age of diagnosis; size of population; and reported prevalence estimate of NDD.

Reviewed articles

A total of 41 articles on autism and neurodevelopmental disorder (NDD) were reviewed. Among them 20 articles were specific to Bangladesh, 12 to Asia, and nine were worldwide. Thirteen articles were acceptable in relation to trends and estimated prevalence of NDD in Bangladesh and were published between the years of 1990 and 2015. Seven studies covering six countries were identified in Asia ranging from the years of 1992 to 2016. Four articles were reviewed from a global perspective; among them were two studies found on autism spectrum disorder (ASD) and another two study found on both ASD and neurodevelopmental disorder (NDD).

Results

Data extracted from literature addressed several different thematic areas:

Demographic situation

Most of the studies in Bangladesh were community-based. Nine studies were conducted in urban areas, five studies included both urban and rural areas, and four studies focused on the rural context in Bangladesh.

Study Design and Diagnostic Tool

Studies reviewed sought to identify the prevalence of NDD, the situation of NDD, association of factors with NDD, and prevalence in different local (urban, rural, community/hospital based) and demographic contexts (age, sex) throughout Bangladesh and Asia, as well as globally. Most of these studies were executed through cross-sectional design followed by desk review, a series of different stakeholder meetings, retrospective study and cohort study. Some of the studies were conducted using standardized diagnostic tools for validation of the tool to identify NDD. Most of the studies used Ten Questionnaire Plus (TQP), behavioural checklist (BCL), the Diagnostic and Statistical Manual (DSM-iv), or the International Classification of Diseases (ICD-10), which are more or less similiar or context-specific for excution of first stage of study of identifying the positive cases. For autism identification the most common diagnostic tool was the Autism Diagnostic Observation Schedule (ADOS).

Bangladesh Studies

As there were differences in study designs, tools, population, context, culture and type of AND, the data on prevalence of autism and neurodevelopmental disorder varied across the studies, making it difficult to estimate the exact statistics of NDD in Bangladesh.

In the context of Bangladesh, the prevalence sample population ranged from 300 (hospital-based study) to 12,051 (community-based). Prevalence rates ranged from 1.6% - 30.8 %(Zaman & ,et al., 1990 Tabib, 2009). Most of the studies found a higher prevalence rate in boys than girls)2.4:%1) (%Islam ,2012(,)6 :%5.1(% (Titumir & Hossain, 2005(,) 3.5:%2.6(%)Tabib, 2009(,)7.7:%5.9) (%Zamanet al., 1990 (.

One study showed the prevalence rate of differents types of NDDs, such as vision 0).9% ,(hearing 1).9% ,(learning 0).7%and no speech (0 ,(.9%) (Zamanet al., 1990 (. Another fifteen-year study assessing prevalence, knowledge, and attitudes)n=1200(showed the overall prevalence of disability to be 5.65% in Bangladesh.Individual disability categories included hearing)18.6%(,visual) 32.2(%, speech)3.9%(and , intellectual)6.(%5)Titumir & Hossain, 2005 .(Another study showed the prevalence of motor).096(%, speech)1.63%(,hearing)0.7(%, vision)0.61%(,cognitive)1.11 (% and learning)0.85%(and cerebral palsy ,).061with a male and female ratio of ,% .prevalence of 068.0 :%55) (%Tabib, 2009) .According to government survey on NDD/NDIconducted in 2013 ,, the overall prevalence of ASD is 0.155% 0).3% in .Dhaka and 0063 %in rural areas(It also showed a higher rate of NDDs related to . cognition)15.8(%, followed bylanguage)5.6(%, fine motor) 4.5(%, .and CP (04 .(%

Some associations were found between NDD and demographic charecteristics, such as socio-economic status (SES). One study showed that the prevalence of psychiatric disorders was significantly higher in richer respondents than poorer with a significant association (x2=5.4, p=.02) (Islam, Ali, Ferroni, Underwood, & Alam, 2003).

Asia Studies

In Asia, the reviewed articles represented ages 0 – 12 years old with a sample size range among the studies from 30 (Japan) to 55,266 (South Korea). The different study design, sample size, screening instruments, and diagnosis tools of the studies made it difficult to compare the study results and estimate the prevalence.

The prevalence of ASD in this review ranged from 0.12% to 9.3 (Wignyosumarto, Mukhlas, and Shirataki, 1992; Kim, Y.S. et al., 2011; Sun, X. et al., 2015). Higher prevalence of ASD was found in China (9.3%) (Sun, X. et al., 2015), and lower prevalence was found in Indonesia (0.12%) (Wignyosumarto, Mukhlas, & Shirataki, 1992). Additional studies showed the prevalence of NDD to range from 31.6% to 87% (Chattopadhyay, N. & Mitra, K., 2015; Hatakenaka, Y. et al., 2016) with a higher prevalence in Japan (87%) (Hatakenaka, Y. et al., 2016) and lower prevalence in India (31.6%) (Chattopadhyay, N. & Mitra, K., 2015). Another study showed a prevalence rate of NDD as 50% in urban areas in India (Modi, Patel, & Mishra, 2016). The incidence rate of ASD increased from 0.01% to 0.07% between 1998 and 2002 (Plubrukarn, Piyasil, Moungnoi, Tanprasert, & Chutchawalitsakul, 2005).

The results of two studies using the same diagnostic tools--the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R)--showed that prevalence of ASDs was higher in China (9.3 %) than South Korea (2.64%) (Kim, Y.S. et al., 2011; Sun, X. et al., 2015). One study used CAST (Childhood Autism Spectrum Test) for screening and validated using ADOS and ADR-I. Other studies used the Childhood Autism Rating Scale (CARS), the Amiel-Tison method of tone assessment, and the Bayley developmental screening tool (Wignyosumarto, Mukhlas, & Shirataki, 1992; Chattopadhyay, N. & Mitra, K., 2015; Modi, Patel, & Mishra, 2016).

Global Studies

Globally the prevalence of NDDs ranged from 11.3% to 16.1% (Baio, 2012; Boyle et al., 2011; Dealberto, 2011; Baird, 2006). A higher prevalence of ASD was found in the UK, (Baird, 2006, Baio, 2012). But other studies showed rates of 12.84% to 15.04% (Boyle et al., 2011), 0.65 for autism and 1.22 for NDD (Dealberto, 2011). Most of the studies estimated the sex-specific prevalence as higher for boys (Baio, 2012; Dealberto, 2011).

In 2006, ASD prevalence in the United States was found to be significantly lower in Florida ($p<0.001$) and Alabama ($p<0.05$), and higher in Arizona and Missouri ($p<0.05$) (Baio, 2012).

Limitations

Studies varied by population and population size, culture, and context, which led to inconsistent results. Some studies were conducted in limited areas due to lack of resources not allowing for an adequate representation of the population of Bangladesh. Methodological differences contributed to varied findings and a number of studies omitted prevalence figures. These factors made it difficult to analyze the trends and prevalence of NDDs in Bangladesh.

Recommendations

NDDs are an important public health concern and should be regarded as a priority area for government action. Data shows that the number of children with certain developmental disabilities has increased, requiring more health and education services which are bearing on the need for health, education, and social services, including the need for more specialized health services: mental health services, medical specialists, therapists, allied health professionals, etc. Research is needed to ascertain the risk factors associated with NDDs in order to develop effective public health programs and essential supports for persons with NDDs, their families, and communities to improve long-term outcomes.

Disease Burden

In order to crate a strategic and effective effort to respond to the needs of individuals with NDD, it is critical that every effort be made to fully understand the prevalence of NDD within Bangladesh. Icddr,b took the primary responsibility for this objective by conducting an extensive review of existing incidence and prevalence data in Bangladesh.

Methodology

Data was collected from the 1990-2015 surveys for children aged 2 to 9 years. Reported diagnoses of the following were included: attention deficit hyperactivity disorder; intellectual disability; autism; learning disorders; communication disorder;

speech disorder. All included studies were required to meet the following selection criteria: (a) cross-sectional that provided the prevalence of NDD in Bangladesh; (b) based on population samples and clinical settings; and (c) the study being representative of the community or national populations. Exclusion criteria were (i) review articles, commentaries; (ii) articles repeating data which had already been included; and (iii) studies based on special populations or study sites.

Results

From an extensive review of literature only four studies reported the prevalence of NDD according to the screening tool TQP (Appendix 1 – Table-1) and one study reported prevalence of NDD according to the confirmatory diagnosis tools ADOS (Appendix 2 – Table-2). The prevalence rate of NDD cases by year varied from 3,600 to 18,655 per 100,000 children from 1990 to 2013, and one study reported that 4% of children had confirmatory NDD cases. Based on existing data, the prevalence rate of confirmatory diagnosed NDD cases was 136 to 746 per 100,000 children from 1990-2013. The estimated diagnosed NDD cases for males were 56 to 260 per 100,000 cases, and for females were 52 to 244 per 100,000 cases. In Figure 4, the results do not show any trends. To make numerical evaluations, Mann-Kendall trend statistics were applied to test the null hypothesis and the result was statistically insignificant ($p>0.05$). Since there are very few previous records of data and insignificant trends of available datasets, an estimate of the likely disease burden of NDD cases is not possible.

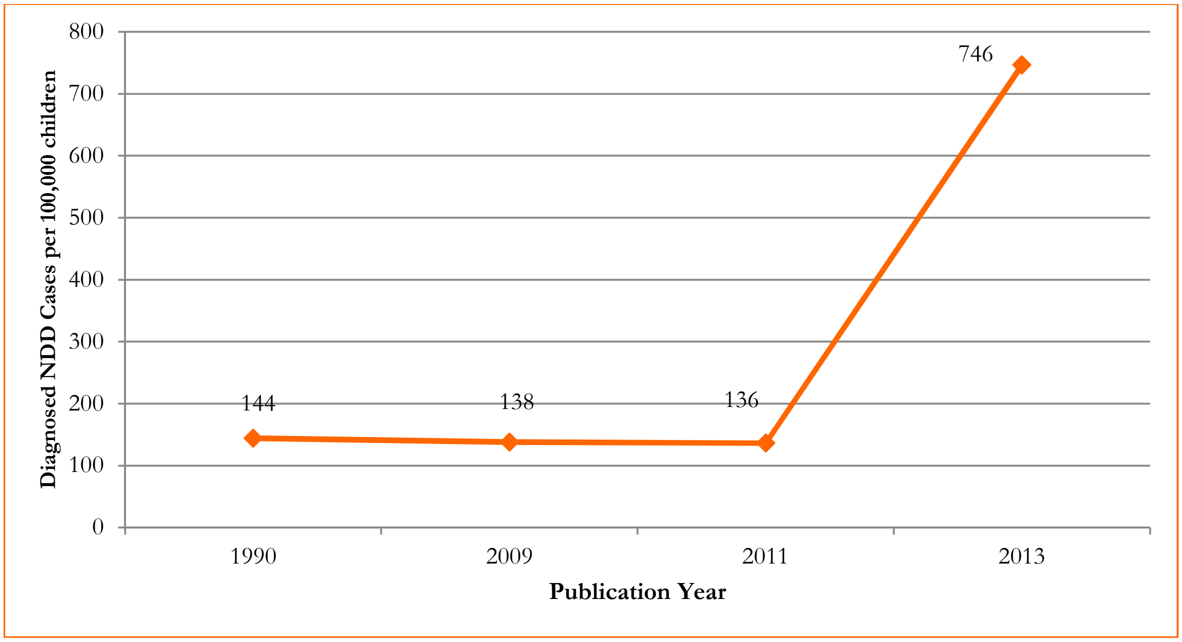

Figure 4: Number of estimated neurodevelopmental disorder cases per 100,000 children from 1990-2013

2 CONTEXT

2.1 Background

A situation analysis is a key foundation for any sound intervention. It helps to ensure a program's relevance and to find out the best course of action by learning about community attitudes and practices regarding NDD, and identifying what has already been done to address NDD and what results and lessons were obtained, as well as who the main actors have been and who might be key to engage. In addition to ensuring the appropriateness of the intervention to the local context, carrying out a situational analysis will help avoid duplication of efforts, something that is needed in Bangladesh.

With the above-mentioned aim, the Institute for Community Inclusion (ICI) will work closely with the Ministry of Health and Family Welfare (MOHFW) in coordination with the National Steering Committee on Autism and Neurodevelopmental Disorders (NSCAND). This present situation assessment would serve as a supplement to update and expand upon the previous situation analysis report completed by the MOHFW and will guide the policy makers in developing a national-level strategy and action plan.

The objective of the Situation Analysis in 2012 was to promote, protect and ensure the sustainable inclusion of persons with NDDs into the mainstream activities of the most relevant Ministries of GoB, using a multi-sectoral, multi-level and multi-disciplinary "life-cycle" approach as represented in the figure below. A review of the existing government programs and services for health, education and employment was conducted. It was clear that the Ministry of Social Welfare (MoSW) is the nodal ministry for issues involving the rights of people with disabilities (PWDs). Figure 5 below depicts the life-cycle needs of all persons (particularly those with disabilities) and the Ministries involved in providing those services. It becomes obvious therefore that several Ministries are inadvertently responsible for meeting the needs of PWDs, which necessitates that they support or partner with the MoSW to implement necessary programs and services.

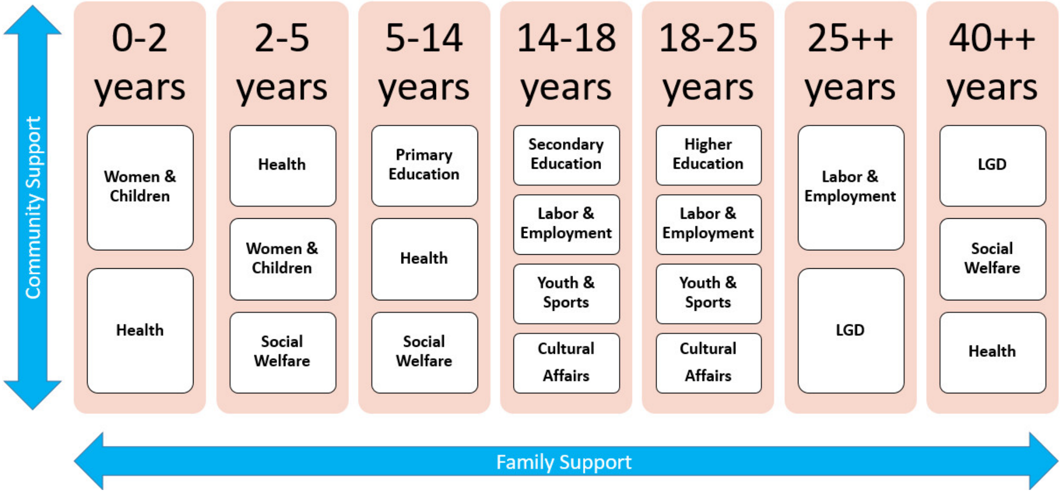

Figure 5 – Priority-based intervention of relevant ministries throughout the life cycle of persons with NDDs

In order to ensure that PWDs receive opportunities to succeed and are included in society, it is imperative that support services are dovetailed into existing government systems. The 2012 Situation Analysis recommended that children with disabilities (CWDs) be served by government mainstream systems where all other, non-disabled children are being served. As is the case with segregated systems for women, school students, or adolescents, parallel and segregated systems for PWDs are against all the human rights paradigms that the GoB has signed and ratified. Segregation excludes PWDs further and reinforces stigma and discrimination. Inclusion, therefore, at all levels of government action, is what was conceptualized through systemic changes within government.

The UNCRPD,[28] which is the only international treaty on disability in the world, emphasizes the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development. This has been the foundation of all autism-related efforts in Bangladesh. The nation has moved from strength to strength in its quest for improving the lives of persons with autism and NDDs.

A strategy adopted

It was thought that a horizontal approach to inclusion of persons with autism and NDDs would be the most cost-effective as well as the most reach-effective. The dual purpose of sustainability would also be best served through dovetailing within and into the everyday routine activities of the government sectors. Very few vertical activities were planned as this would be neither sustainable nor cost-effective in a low-resource country like Bangladesh.

Step-by-step approach

Between March and June 2012, an action plan was developed by an Inter-Ministerial Coordination Committee (IMCC) comprising of eight ministries, namely Health & Family Welfare, Social Welfare, Women & Children Affairs, Primary & Mass Education, Education, Labor & Employment, Local Government Division, and Finance.

The IMCC met over a four-month period and was truly participative. After the first month, its form shifted, starting with five ministries and ending with eight. The resulting plan was called the Strategic and Convergent Action Plan on Autism and Neurodevelopmental Disabilities (SCAPAND), and was subsequently submitted to the Honorable Late President Zillur Rahman.

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[28] United Nations Convention on the Rights of Persons with Disabilities

Late President Zillur Rahman speaking at the release of the SCAPAND

After much discussion and debate, it was decided by the group that the SCAPAND would be embedded in the MoHFW, who would have co-ownership with MoSW and MoE.

Establishment of national committees

The **National Steering Committee** was officially formed in July 2012 with eight Ministries and later expanded to include six more ministries:

- **Health & Family Welfare**[29]
- **Social Welfare**[30]
- **Education**
- **Women & Children Affairs**
- **Primary & Mass Education**
- Finance[31]
- Labor & Employment
- Local Government Division (LGRD)
- ICT Division (Posts, Telecommunications & Information Technology) *(coopted in 2014)*
- Information *(coopted in 2014)*
- Cultural Affairs *(coopted in 2014)*
- Youth & Sports *(coopted in 2014)*
- NGO Affairs Bureau (PMO) *(coopted in 2014)*
- Socio-Economic Infrastructure Division (Planning Commission) *(coopted in 2014)*

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[29] MoHFW is represented in NSCAND by two members: one from the Ministry and one from DGHS

[30] MoSW is represented in NSCAND by three members: one from the Ministry, one from DSS and one from JPUF

[31] Ministry of Finance is represented in NSCAND by two members: Finance Division and Economic Relations Division

Table 3 Ministries involved in persons with NDDs

Five of the 14 Ministries above are highlighted in bold to indicate what are generally considered to be the five key ministries that are most significant for addressing the major needs of persons with NDDs, particularly in the first third of their lives.

The **National Advisory Committee** is headed by Saima Wazed Hossain, who attends the meetings in person or via telepresence.

The **Technical Guidance Committee** consists of well-known experts from across the country, including those with diverse backgrounds such as medicine, education and psychology.

Each committee has its own set of unique Terms of Reference and functions in complete harmony with the objectives and decisions NSCAND.

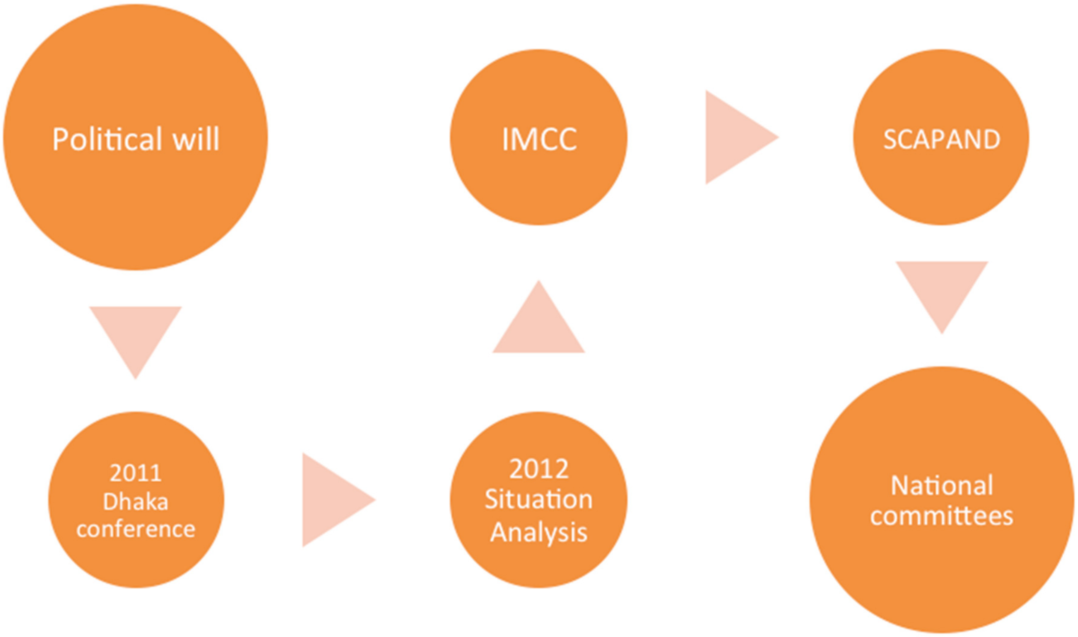

Figure 6 – The journey taken towards achieving multi-sectoral horizontal linkages

Currently, the ongoing activities of NSCAND include mapping the resources available to the 14 ministries, which include financial, human and material resources that can be tapped into collaboratively for the benefit of persons with NDDs. Coordination of activities (and avoiding duplication), convergence of services and supports, and collaborative use of existing infrastructure continue to be the main challenges faced by NSCAND. This document gives an overview of the recent past in order to contextualize the recommendations for the immediate future.

As mentioned earlier, almost all NDD-related activities under SCAPAND were embedded/dovetailed within existing government facilities and services as a horizontal model of inclusion. However, a few vertical structures were felt to be necessary, at a national level, particularly for practicing evidence-based services, for specific research, and for the development of specialized human and material resources that would meet international standards and scrutiny. Three such noteworthy vertical actions are:

I. Institute for Pediatric Neurodisorder & Autism (under MoHFW)

Originally called the "The Centre for Neurodevelopment & Autism in Children", it is the first government initiative to establish a specialist institute for all management, training and research related to pediatric neurodevelopment in Bangladesh. It was established in 2009 at the premises of Bangabandhu Sheikh Mujib Medical University with a multi-disciplinary and multi-agency team to provide comprehensive and tertiary level services to children with NDDs and their families under one roof. It was renamed "IPNA" in January 2015.

II. Autism Cell (under MoHFW)

This was set up in 2014 to serve as the *de facto* secretariat of the NSCAND

and coordinate and integrate speedy and effective accomplishment of its NDD-related activities. It consists of one additional-secretary-level Director General, one joint-secretary level Director and two deputy-secretary-level Deputy Directors plus two supporting staff.

Entrance to the Autism Cell's office at the Bangladesh Secretariat

Staff meeting of the Autism Cell, with the current DG Mr. Subhash Sarkar seated at the right

III. National Academy for Autism & Neurodevelopmental Disorders (under MoE)

This project has been approved and BDT 720 million has thus far been allocated towards it. It has also received approval to begin construction on the three acres of land allotted for the Academy. Meanwhile, the project team is conducting training and advocacy drives while the construction takes place, which is expected to be completed by the end of 2016.

3 GOVERNMENT AND POLICY FRAMEWORK

3.1 Obligations under global and regional treaties

Human rights are a driving force in the global development arena. They are guiding practices and approaches to many marginalized populations, including those with disabilities. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is the founding treaty that changes our understanding of how persons with disabilities should be treated. It gives a voice and rights to those that had a limited influence in the past. The United Nations Human Rights office of the High Commissioner asserts, “The Convention adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptation have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced.”

Bangladesh signed the CRPD on September 5, 2007. Soon after, on November 30th, 2007 Bangladesh ratified the convention. On May 12, 2008, Bangladesh took the last step of ratification of the CRPD protocol.

The United Nations Human Rights office of the High Commissioner states, “All States parties are obliged to submit regular reports to the Committee [a body of 18 independent experts] on how the rights are being implemented. States must report initially within two years of accepting the Convention and thereafter every four years. The Committee examines each report and shall make such suggestions and general recommendations on the report as it may consider appropriate and shall forward these to the State Party concerned.” Thus far, Bangladesh has not submitted any reports to the Committee.[32]

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[32] See United Nations Human Rights office of the High Commissioner, Human Rights Bodies, CRPD country specific information. Retrieved from: United Nations Office of the High Commissioner for Human Rights. Available from: tbinternet.ohchr.org/_layouts/TreatyBodyExternal/Countries.aspx?CountryCode=BGD&Lang=EN

A few years later, on September 7, 2012, the World Health Organization (WHO) South East Asia Regional Office (SEARO) held the fifth meeting of the regional committee at Dhaka, Bangladesh, during which the committee passed **WHO/SEARO Resolution No. SEA/RC65/R8** ***"Comprehensive and coordinated efforts for the management of autism spectrum disorders (ASD) and developmental disabilities"***. In that meeting, the committee requested the regional director to support the activities of autism-related networks, including the South-East Asia Autism Network (SAAN).

Three months later, following lobbying by GoB, **UN Resolution No. 67/82** ***"Addressing the socio-economic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities"*** was adopted on December 12, 2012 at the 53rd Plenary Meeting of the General Assembly.

Soon after that, at the 67th World Health Assembly (WHA), based on Bangladesh's proposal, **WHO Resolution No. WHA67.8** ***"Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders"*** was adopted on May 24, 2014, co-sponsored by more than 50 countries and endorsed by all.

Finally, on September 11, 2014, the ***Global Initiative on Autism*** was launched during a side event titled **"Addressing Autism through Partnerships: A Round-table Discussion for the Development of a Multifaceted Action Plan"** that was held at the 67th Session of the WHO Regional Committee for South-East Asia in Dhaka, Bangladesh.

The Sustainable Development Goals are also a platform for change to which GoB is committed:

- **Goal #4** is on inclusive and equitable quality of education and promotion of life-long learning opportunities for all including PWDs;
- **Goal #8** is on achieving full and productive employment and decent work, for all women and men including for PWDs as well as equal pay for work of equal value;

- **Goal #11** makes provision for safe, affordable, accessible and sustainable transport systems for all persons including PWDs;
- **Goal #17** aims to increase the availability of high-quality, timely and reliable data that is also disaggregated by disability in terms of the collection of data and monitoring and accountability.

GoB is known to take its international commitments very seriously as evidenced by its track record with the MDGs.

The World Report on Disability makes nine recommendations[33] for governments to address the disability issue with seriousness:

1) Enable access to all mainstream policies
2) Invest in specific programs and services for people with disabilities
3) Adopt a national disability strategy and plan of action
4) Involve people with disabilities
5) Improve human resource capacity
6) Provide adequate funding and improve affordability
7) Increase public awareness and understanding of disability
8) Improve disability data collection
9) Strengthen and support research on disability

The Global Campaign for Education suggests seven inter-dependent strategies/areas of action, all of which are necessary to complement each other in tackling exclusion across multiple levels: from the family, local communities, national governments, through to the international community. These seven strategies[34] – all of which will require political will – are:

- **Strategy #1**: Create appropriate legislative frameworks, and set out ambitious national plans for inclusion.
- **Strategy #2**: Provide the capacity, resources and leadership to implement ambitions national plans on inclusion.

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[33] World Health Organization and World Bank Group, *World Report on Disability¸* 261 (2011).

[34] Global Campaign for Education, *Equal Right Equal Opportunity: Inclusive Education for Children with Disabilities* (2013). Available from: www.campaignforeducation.org/en/campaigns/education-and-disability

- **Strategy #3**: Improve data on disability and education, and build accountability for action.
- **Strategy #4**: Make schools and classrooms accessible and relevant for all.
- **Strategy #5**: Ensure enough appropriately trained teachers for all.
- **Strategy #6**: Challenge attitudes which reinforce and sustain discrimination.
- **Strategy #7**: Create an enabling environment to support inclusive education, including through cross-sectoral policies and strategies that reduce exclusion.

It is vital that governments, supported by development partners and the international community, start to take concrete policy action in these areas.

3.2 National legislation and policies

Two new laws have been enacted in the last two years alone; one of which was in the pipeline as a result of GoB signing and ratifying the UNCRPD in 2007. The other was directly inspired by the NDD-related initiative led by Saima Wazed Hossain.

- ***Persons with Disabilities' Rights & Protection Act 2013***

Passed on October 9, 2013, this law replaced the ***Persons with Disability Welfare Act 2001*** because that was not in harmony with UNCRPD. The new law recognizes the following disabilities:

1) Autism spectrum disorders
2) Physical disability
3) Mental illness leading to disability
4) Visual disability
5) Speech disability
6) Intellectual disability
7) Hearing disability
8) Deaf-blindness
9) Cerebral palsy
10) Down Syndrome
11) Multiple disabilities

The official rules for this Act have not yet been issued.

- ***Neurodevelopmental Disability Protection Trust Act 2013***

Passed on November 10, 2013, the official rules for this Act was released on September 2015 and recognizes the following NDDs:

1) Autism spectrum disorders
2) Intellectual disability
3) Cerebral palsy
4) Down Syndrome

It should be highlighted that the chairperson of the NDD Protection Trust is a renowned psychiatrist of Bangladesh and the former head of the National Institute of Mental Health & Research (NIMH&R).[35] The Board of Trustees includes seven parents of persons with NDDs. Moreover, the Trust is supported by an Advisory Council that is chaired by the Prime Minister and convenes twice a year.

But changes in the field of disability, particularly NDDs, are not just about constitutional and legal frameworks of rights. Professional practice and standards and the design and delivery of services now tend to reflect a greater recognition of abilities than disabilities. The understanding of quality of life has shifted from a focus on adaptive behaviors and skills development to recognition of the complexity of people's lives and the profound impact of social, economic and environmental factors on people's lives.[36]

There is also a recognition, now, that people with disabilities can enjoy a quality of life equal to that of others. It is worth noting that parents of persons with NDDs have been nominated to the board.

3.3 Role of Civil Society within Government Structures

Background

Prior to the 2011 Dhaka Conference that triggered nationwide awareness, there was limited understanding about NDDs in Bangladesh, particularly ASD, as it was

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[35] One of three national institutes specializing in neuroscience, the others being IPNA and NINS.

[36] McGinnis, B. (1998). Disability, Community and Society: Exploring the Links. *Tizard Learning Disability Review,* 3(2), 35-35.

not a part of the local medical training curriculum, and therefore was rarely diagnosed the way cerebral palsy, epilepsy and, perhaps, Down syndrome were by most pediatricians and neurologists. The word “autism” does not exist in the Bengali language nor does any other word indicating this syndrome. The vast majority of medical professionals in Bangladesh had limited understanding of ASD; most families would regrettably be given the diagnosis of mental retardation, which was inevitably understood by the public to mean *“pagol”* (i.e., crazy).

Awareness of ASD first seeped into Bangladesh when some parents of children with ASD went abroad to places such as USA, the UK, and Singapore to have their children diagnosed. This was of course only possible for the privileged few. Some of those parents, after having learned about autism and its devastating nature, came back to Bangladesh to raise awareness about this disorder. These were the pioneers of autism and NDDs in Bangladesh who laid the first stones for building what has now become a national priority.

The first NGO dedicated to the rehabilitation of persons with ASD was established in 2000. In the following decade, more such NGOs were established but nearly all were in just two cities: Dhaka and Chittagong. The hardworking, noble men and women who work at these NGOs form the bulk of the pool of experts that Bangladesh has on all matters pertaining to the betterment of the lives of persons with NDDs. An assessment of this sector is prudent because the experiences these NGOs have in working with persons with NDDs far exceed the government’s experience at this time, and therefore these NGOs are indispensable to the development of public services and supports for persons with NDDs. However, the limitations of this project allows for this report to present only a brief overview of the status of these NGOs.

Role and preparedness of civil society organizations

As mentioned earlier, the civil society organizations (CSOs) were the pioneers of services for persons with NDDs in Bangladesh. These organizations began at a time when there was no legislation to empower them or the persons with NDDs, nor was there any government mechanism to give them any kind of material support. From those precarious beginnings, these organizations have developed effective and sustainable ways to rehabilitate and empower children with NDDs – all of which was achieved through sincerity and perseverance, as well as with the financial support from unsung heroes, both local and foreign.

However, some of these organizations, despite doing great work on the field, have reached institutional stagnancy in that they are unable to grow further due to lack of funding. Some of them are even at risk of being forced to either cut back on certain services and activities, or worse, to shut down their operations altogether due to the rising costs of rent, utilities, employee compensation, etc. Losing such organizations would be a great loss to the country because of the wealth of knowledge that they can share with the government, which they have accumulated over the years from their work and interaction with persons with NDDs. Specifically, these organizations can help the government in the following ways:

- The nationwide awareness initiative can and should still be spearheaded by civil society. The parents of persons with NDDs are the ideal people to ignite concern for these conditions among the general public, especially in the rural areas where many misconceptions still linger. Such parents could also train government field workers on how to reach out to rural people and combat these misconceptions so that persons with NDDs and their caregivers are no longer ostracized for these conditions. Parents of children with NDDs need to hear from other parents that there is hope for improvement in their children's lives, provided they ignore social stigma and misconceptions and apply the necessary interventions in a timely manner.
- Civil society can help the government develop a national parent-training program (with associated materials) to help caregivers of children with NDDs deliver home-based early interventions. Many of the NGOs have already been doing this for quite a while, and the government would be wise to collate the best practices, tools and materials developed by these organizations.
- While it is never easy to run an organization on tight resources, a major positive though is that nearly all of these organizations have learned how to operate a special school with minimalist resources. This is particularly pertinent for low-resource settings, where it would be unsustainable to setup a

high-tech special school, which the government couldn't afford to operate and maintain year after year. A low-cost model, similar to most of these NGO special schools, would allow the government to realistically establish a public special school in each Upazila – maybe even in each Union.

- A key component of special education is careful, scientific development of an IEP for each child with an NDD. This is a technique that the special schools have mastered and can easily teach to MoPME's master trainers.
- The NGO special schools can also assist the NCTB in its development of a "National Special Education Curriculum" using their extensive experience teaching children with NDDs and their insight into the learning capacities of such children. This is particularly important because sub-standard education could in fact worsen their cognitive condition.
- The NGOs can assist the government in providing evidence-based research for studies on NDDs being conducted in Bangladesh in order to build up national data on NDDs.
- The NGOs can assist the government in developing standards and operating procedures for local services and supports for persons with NDDs.

Recommendations involving civil society organizations

1) A regulatory body or "watchdog" comprised of parents of persons with NDDs, other key representatives from NDD-centric CSOs, and maybe even self-advocates with NDDs is necessary to monitor and evaluate government services and supports (e..g, therapeutic services, education services, employment services, trainings, etc.)

2) A national-level parents' forum needs to be established in Bangladesh in order to champion the rights of persons with NDDs. This is particularly important for maintaining continuity of services during and after political transitions. PFDA is currently the only such parents' organization in Bangladesh. While they have done remarkable work during their short existence, their visibility is limited to Dhaka, and the group is yet to achieve the kind of national-level prominence that is needed for such an entity to be politically relevant. It is recommended that PFDA work towards vastly expanding its membership and

engaging parents of children with NDDs from all over the country in PFDA's activities.

3) There is an element of competitive attitude between various CSOs and between their officials with regards to who can provide better services to persons with NDDs. While such an attitude is theoretically beneficial, in Bangladesh it is more of a hindrance to progress. It is therefore recommended that CSOs working on NDDs network more with each other, collaborate on projects, share best practices, build up each other's capacities, and present a united voice for awareness and policy lobbying activities. This is particularly vital for smaller organizations as it will make them more relevant in the national agenda and make them more effective (smaller organizations also tend to work more in rural areas and would therefore benefit greatly from the technical guidance of the larger, well-established organizations).

Resource mapping of public sector

MINISTRY	NATIONAL-LEVEL	DISTRICT-LEVEL	UPAZILA-LEVEL	UNION-LEVEL AND BELOW
Women & Children Affairs	• Bangladesh Shishu Academy • 6 skill development training centers	• 64 daycare centers	• ~500 early learning centers	• ~1,600 pre-primary centers • ~900 field workers
Health & Family Welfare	• 14 medical college hospitals • 7 postgraduate institute hospitals • 4 public health institutes • 3 specialized neurosciences institutes: IPNA, NINS and NIMH&R	• 61 district-level hospitals • 87 Health & Family Welfare Centers • 23 school health clinics	• 421 Upazila Health Complexes • ~900 health inspectors	• 1,312 Union sub-centers • 13,500 community clinics • ~40,000 field workers
Social Welfare	• Disability Complex (coming soon) • Autism Resource Center	• 20 Mobile Therapy Vans (12 more coming soon) • 489 upazila officers • 2 technical training centers	• 103 Integrated Disability Service Centers	• 4,500 field workers
Primary & Mass Education	• National Academy for Primary Education	• 55 Primary Training Institutes (12 more coming soon) • 64 district primary education officers	• 120 community schools • 133 Child Welfare Trust PS • 506 upazila primary education officers	• 38,033 government PS • 25,008 newly-nationalized PS • 1,937 non-government PS • 3,818 ROSC schools • ~2,500 assistant primary education officers
Education	• National Academy for Education Management • National Curriculum and Textbook Board • Madrasha Teachers' Training Institute • National Academy for Computer Training & Research	• 1,219 colleges (226 of which offer Honors-level degrees, 102 of which offer Master's-level degrees) • 49 polytechnic centers • 64 district secondary education officers • 64 district facilitators	• 942 private school-and-colleges • 11 public school-and-colleges • 65 technical school-and-colleges • Upazila junior secondary education officers	• 2,412 private junior SS • 16,003 private SS • 316 public SS
Miscellaneous	• 4 Industrial Relations Institutes (MoLE) • Bangladesh Shilpakala Academy (MoCA) • BTV (MoI) • Bangladesh Betar (MoI) • Bangladesh Sangbad Sangstha (MoI)	• 29 Labor Welfare Centers (MoLE) • 37 Technical Training Centers (run by Ministry of Expatriates' Welfare & Overseas Employment) • 64 Deputy Commissioners • 53 Youth Training Centers (run by MoYS, 11 more coming soon)	• 489 Upazila Nirbahi Officers (LGD)	• In-house factory health centers

4 STRATEGIC DEVELOPMENT AND CAPACITY BUILDING

4.1 Systems-change

Over the past several years, Bangladesh has undertaken significant efforts in addressing the needs of individuals with NDD, and there is a good basis to build from. However, creating a highly impactful and sustainable effort that results in realizing the vision of the Bangladesh policy and legislative framework and UNCRPD requires investment in a systematic and comprehensive approach across a full range of domains, with careful consideration of the overall goals and objectives, and the most effective ways to reach them. Such an effort requires a clear vision based on a social and human rights model of disability, fully understanding the wide range of arenas and issues that need to be addressed, strategically determining how to address them, and maintaining a sustained effort over time. The following section discusses a framework and mechanisms for undertaking the type of systems building efforts needed to address NDD in Bangladesh, and provides three different examples.

Collective Impact Framework

Collective Impact is an inventive, creative, and structured approach to tackle deeply complex social problems through making activities collaborative across government, business, philanthropy, non-profit organizations, and citizens to achieve significant and lasting social change. This process is best used when there is no single policy, government department, organization or program that can tackle or solve the increasingly complex social problem. There are five conditions to make meaningful and sustainable progress on social issues: a common agenda, shared measurement systems, mutually reinforcing activities, continuous communication, and backbone support organizations[37].

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[37] Kania, J., & Kramer, M. (2016, 1 20). *The Collective Impac Framework*. Retrieved from Collabration for Impact: http://www.collaborationforimpact.com/collective-impact/

The Five Conditions of Collective Impact[1]

1. Common Agenda
    a. Common understanding of the problem
    b. Shared vision for change
2. Shared Measurement
    a. Collecting data and measuring results
    b. Focus on performance management
    c. Share accountability
3. Mutually Reinforcing Activities
    a. Differentiated approaches
    b. Coordinated through joint plan of action
4. Continuous Communication
    a. Consistent and open communication
    b. Focus on building trust
5. Backbone Support
    a. Separate organization(s) with staff
    b. Resources and skills to convene and coordinate participating organizations

The following are successful examples applying collective impact method:

Example 1: African Health Markets for Equity (AHME) Collaborative[38]

The AHME partnership—launched in Nigeria, Kenya, and Ghana in 2012 and funded through a $60 million, five-year joint investment by the Gates Foundation and the UK's Department for Ineternational Development—includes six backbone organizations supporting a collaboration to address priority health issues affecting the poor.

1. **A common agenda:** Each partner is committed to a common goal: increase coverage of quality care within the private provider system and address priority health issues that most affect the poor, such as reproductive health, malaria, acute respiratory infections, diarrhea, nutrition, maternal care, HIV, and tuberculosis.

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[38] Peterson, K., Mahmud, A., & Weissburg, R. (2014). *Ahead of the Curve: Insights for the International NGO of the Future.* FSG.

2. **Shared measurement systems:** The partnership has agreed to a shared measurement system, including a single logical framework and accompanying set of metrics to track program outcomes.
3. **Mutually reinforcing activities:** A leadership team comprised of two representatives from each organization sets strategic direction and overseas progress on outcomes. A steering committee, made up of senior leaders from the partner organizations as well as the two donors, meets three times a year. The committee oversees the AHME's progress and steps in if work is not progressing appropriately.
4. **Continuous communication:** A coordinating committee in each country, made up of members of the partner organizations and national governments, communicates on a regular basis and meets, at least, quarterly.
5. **Backbone support organizations:** The Gates Foundation identified a handful of organizations, including MSI, PSI, Society for Family Health, Grameen Foundation, International Finance Corporation, and PharmAccess, each with a specific niche in the health delivery and policy arena, and approached them directly.

Example 2: National Coalition for Suicide Prevention[39]

The National Coalition for Suicide Prevention (NCSP) in Australia has agreed to adopt the principles of collective impact, gathering a number of organizations within the diverse suicide prevention and mental health sectors, as well as business and government.

1. **A common agenda and shared measures:** The Coalition commits to a common agenda and shared goal which is a 50% reduction in suicides in Australia by 2023, including halving the number of suicide attempts. Participating organizations align their programs to this agenda resulting in a greater voice and ensuring accelerated progress towards the agreed goals and resolutions.

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[39] *Suicide Prevention Australia*. (2016, January 20). Retrieved from Suicide Prevention Australia Website: http://suicidepreventionaust.org/project/national-coalition-for-suicide-prevention/

2. **Mutually reinforcing activities:** The National Research Action Plan is being developed under the auspices of the NCSP, using the greater collaboration of both funders and researchers to make decisions that are well grounded in addressing the needs of our communities.
3. **Continuous communication:** Bringing together all three sectors of community, business, and government is achieved by working with like-minded community members, partnering with small, medium and large businesses, engaging in the local, state and federal government in a consistent and coordinated approach.
4. **Backbone organization support:** The coalition members identified SPA as the appropriate organization to take on the role of the backbone organization.

Example 3: National Collective Commitment to Solving the Problem of People with Autism

With the ratification of the Convention on the Rights of People with Disabilities (CRPD) in Iran in 2009, governmental sectors, as well as community and private sectors, have worked together to achieve most of the neglected rights for persons with disabilities[40]. These efforts recently resulted in a comprehensive program for people with autism that was first envisioned at the sixth national development plan. This comprehensive plan is recognized as a collective national commitment[41].

1. **A common agenda:** The different participants in the autism arena have a shared vision to fulfill the rights mentioned in the CRPD through agreed upon actions in rehabilitation, education, medical, and social areas.
2. **Shared Measurement:** Deciding to select one of the provinces as a pilot to empower the community and private sector, the government measured how much the massive bureaucratic process would be cut and the quality improved. As the results show, quality of health and education services as well as screening to

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[40] Kamali, M. (2011). An Overview of the Situation of the Disabled in Iran. In A. Moore, & S. Kornblet, *Advancing the Rights of Persons with Disabilities: A US–Iran Dialogue on Law, Policy, and Advocacy* (pp. 15-20). Washington DC: Stimson.

[41] *Iran Online Newspaper*. (2015, December 5). Retrieved from http://www.ion.ir/News/48112.html

collect the incidence and prevalence data strikingly improved. The organization has made it generalizable throughout the whole country.

3. **Mutually reinforcing activities:** Promoting the situation of NGOs and private organizations delivering services to children with NDD, the government provides them some incentives and subsidies. Likewise, these nongovernmental institutions play an important role as specialists and consultants for the government[42].
4. **Backbone support organizations & continuous communication**: The State Welfare Organization (SWO) has been the arm of government providing welfare benefits to those who qualify, acting as an incipient backbone organization for the collaboration[43]. In addition, there are two other ministries that support the plan. While the Ministry of Health and Medical Education have a collaborative relation with the SWO in the research area as well as the increasing of awareness, the Ministry of Education and Office of Rehabilitation Affairs from the SWO are involved in support for the education of the children with autism base on life skills, specifically communication skills[44].

One-Stop-Shops and the Coordination of Intergovernmental Relations

"Coordination in the context of intergovernmental relations can be defined as the arrangement of mutually dependent parts in a way that supports the pursuit of quality, efficiency or other goals."[45] Currently, providing supports and services to persons with NDD is a complex and fragmented process. There are many barriers in meeting the needs of persons with NDD, such as physical, transportation, communication, information, and coordination.[46] A critical aspect of providing appropriate services to persons with NDD is the cooperation and coordination between the government and relevant agencies. Placing services, social benefits, and healthcare in one place minimizes government bureaucracy, increases services delivery to persons with

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[42] *Iran Online Newspaper*. (2015, December 5). Retrieved from http://www.ion.ir/News/48112.html

[43] Moore, A., & Kornblet, S. (2011). Project Introduction-Iran and America: A Dialogue on Disability. In A. Moore, & S. Kornblet, *Advancing the Rights of Persons with Disabilities: A US–Iran Dialogue on Law, Policy, and Advocacy* (pp. 7-14). Washington DC: The Henry L. Stimson Center.

[44] *Iran Online Newspaper*. (2015, December 5). Retrieved from http://www.ion.ir/News/48112.html

[45] Askin J., Fimreite A. L., Moseley A., Pederson L. H. (2011) One-stop shops for social welfare: The adaptation of an organizational form in three countries. *Public Administration.* 89(4): Pg. 1453.

[46] World Health Organization, *World Report on Disability*, 70 (2011).

NDD, and minimizes barriers. This concept, a one-stop shop,[47] would serve as a backbone organization which provides a central location for families and persons with NDD to locate necessary information and services and also provides the government with a central agency to track and hold accountable inter-ministerial efforts related to those with NDD.

One-stop-shops provide an avenue for increased accountability and opportunities for achieving greater efficiency in public administration. Accountability spans citizens, central government, and partner organizations. Upwards accountability (to central government) includes both political accountability to ministers and other parts of the government system, and accountability to regulators, auditors and inspectors (Hood et al., 1999). Greater efficiency in public administration is achieved by making public services accessible within one setting, which may reduce transaction costs and duplication from citizen, provider and government perspectives. In theory, one-stop shops reduce the time and effort that citizens must expend to access the services they need; from a government or provider perspective they reduce the costs of establishing separate services and reduce duplication of activity across agencies (Halligan, 2004).

Previously used in the arenas of social welfare and employment[48] for persons with disabilities,[49] the one-stop shop integrates the public and private sectors in a coordinated approach. This approach corrects the poor coordination between interdependent agencies, and becomes a path to increase quality and efficiency of the provision of services and government management. To assist with coordinating the mutually dependent parts, semi-autonomous agencies are created to operate at an arm's length from the government. This single access point is where policy meets the citizens to maximize convenience through service integration. The one-stop shop has

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[47] Organisation for Economic Co-operation and Development. (2010). Chapter 6: Getting the Right Services to the Right People at the Right Time. In *Sickness, Disability and Work: Breaking the Barriers: A Synthesis of Findings across OECD Countries*, Paris: OECD Publishing. doi: http://dx.doi.org/10.1787/9789264088856-en

[48] Askin J., Fimreite A. L., Moseley A., Pederson L. H. (2011). One-stop shops for social welfare: The adaptation of an organizational form in three countries. *Public Administration.* 89(4): 1451–1468.

[49] Holcomb, P. A., Barnow, B. S. (2004). *Serving people with disabilities through the workforce investment act's one-stop career centers*. Washington D.C: The Urban Institute.

vertical and horizontal accountability to the government, citizens, and partners (Figure 7).

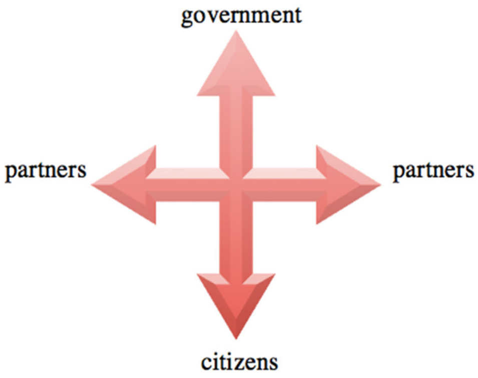

Figure 7 Horizontal and vertical accountability

The breadth and width of a one-stop shop can very on several factors: a) task portfolio, b) participant structure, c) autonomy, d) proximity to citizens, and e) instruments. This depends on how many sectors will be covered through the services, the depth of the information provided, the complexities of dealing with agencies, the level of participation, where the service centers are located, and the level of integration (Figure 8).

Figure 8: Dimensions of variation in one-stop shops[50]

Task portfolio

One-stop shops vary in breadth and depth. Breadth refers to policy areas covered (e.g., all or select disability services, such as education, health and rehabilitation, welfare benefits, employment, etc.) and depth refers to work processes (e.g., does the shop provide information only or coordinate the provision of service and benefit to the client through merged partner organizations and case coordination).

Participant structure

This may be simple or complex, including few or many partners. This is dependent on

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[50] Askin J., Fimreite A. L., Moseley A., Pederson L. H. (2011) One-stop shops for social welfare: The adaptation of an organizational form in three countries. *Public Administration.* 89(4): 1451–1468.

the number of tasks involved and the geographical area covered. Partners may include one or more levels of government (national, regional, and local) and collaborative structures (public-private partnerships).

Autonomy

The degree of control varies with some shops more autonomously run than others. One autonomy versus control issue is whether or not partners are free to participate in the one-stop shop arrangement (mandated from voluntary collaborations). This can be accomplished through legal mandates or incentive-based programs. Further control versus autonomy issues include the extent to which one-stop shops decide on issues such as their own revenues, internal organization, which clients to target, what types of services and products to offer and at what price, quantity and quality.

Proximity to citizens

A general principle of one-stop shops is that they are coordinated around the person and bring the coordination of policy down to the level of the citizen. Virtual one-stop shops are possibly the closest to the citizen of any type of one-stop shop, since they can be present in the citizen's own home via their computer's Internet connection. One-stop shops which operate as physical premises with co-located services are one degree further away from citizens, and are located in citizens' own neighborhoods and localities, often only a few streets away from their home. Regionally based one-stop shops are one degree further still, serving several municipalities.

Instruments

How do one-stop shops facilitate agency coordination and collaboration? This depends on the tasks performed. In cases where pooled information is the task to be performed, co-location, either physical or virtual, may be sufficient. In cases where the one-stop shop involves shared casework between partner agencies, further instruments are needed to complete the tasks. Instruments with deeper integration in one-stop shops include joint leadership, budgets, planning and reporting procedures, recruitment processes, and employment and case coordinators.

The organization of the one-stop shop is that of a generic government entity free from ministerial rules and interference. This is accomplished by the attainment of executive agencies to run service centers. The agencies are responsible for responsiveness and effectiveness. Essentially, a corporate unit, separate from the government, is responsible for the center and has distinct tasks and resources. This will allow the center to deliver a competitive provision of goods and services.

The following are examples from developed or developing countries that are successfully employing the one-stop shop scheme:

Example 1: Askim, Fimreite, Moseley and Pedersen (2011) reported that in 2005, the Norwegian government merged the three main welfare administrations – national insurance, employment, and municipal social services – to create a user-friendly, holistic, and efficient system for its citizens. Thus, in each municipality, a one-stop shop was created that (1) had mandatory participation for the municipalities, (2) that social benefits must be offered through the shops, and (3) that a unitary management model would be recommended but not required. The model was quite successful and created partnerships that focused on the services instead of the sectors that provide them.

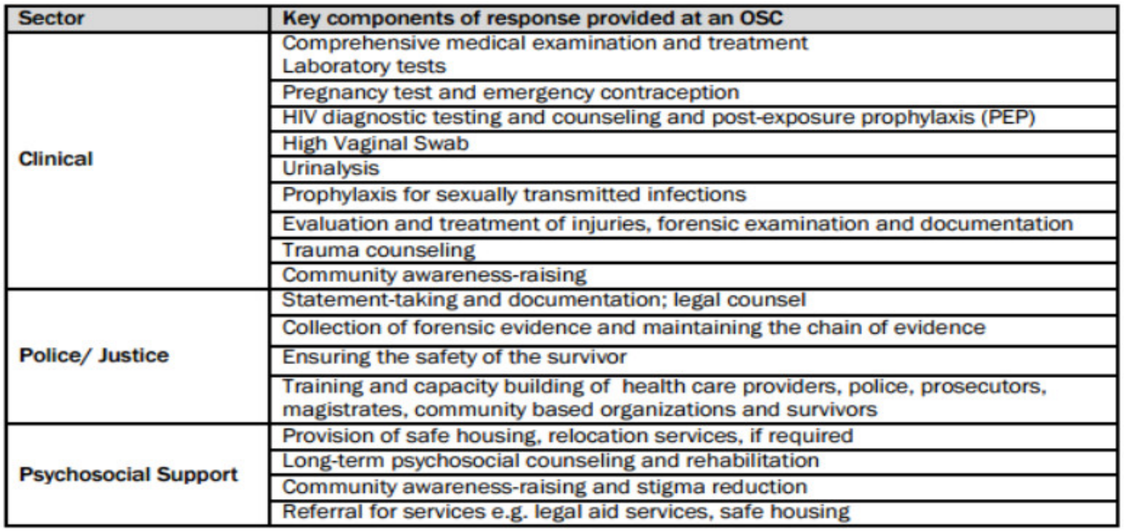
Developing Country Examples

Example 2: Multi-sectoral Response Services for Gender-Based Violence (SGBV) in Kenya and Zambia

Kenya and Zambia are among the countries at the forefront of responding to SGBV in Africa through the establishment of one-stop centers (OSCs), which provide integrated, multi-disciplinary services in a single physical location. Kenya‘s first OSC, offering free medical and psychosocial services, was established in 2001 by Nairobi Women’s Hospital, a private for-profit health facility. With the support of various stakeholders, over 20 more OSCs have been established since, primarily in government health facilities, across the country. Five stand-alone NGO and legal service providers also offers limited OSC services.

From 2005 to 2007, CARE Zambia and its partners implemented a pilot project geared toward developing a successful model for one-stop centers in Zambia. The first two pilot one-stop centers were stand-alone sites (not located in a health facility) and driven by NGOs, but with a referral system to the nearby health facility for secondary medical management.

The basic services forming the core of the OSC model implemented in East and Southern Africa and summarized in Figure 9, encompass health care, police and justice sector responses, and on-going social support.[51]



Sector	Key components of response provided at an OSC
Clinical	Comprehensive medical examination and treatment Laboratory tests
	Pregnancy test and emergency contraception
	HIV diagnostic testing and counseling and post-exposure prophylaxis (PEP)
	High Vaginal Swab
	Urinalysis
	Prophylaxis for sexually transmitted infections
	Evaluation and treatment of injuries, forensic examination and documentation
	Trauma counseling
	Community awareness-raising
Police/ Justice	Statement-taking and documentation; legal counsel
	Collection of forensic evidence and maintaining the chain of evidence
	Ensuring the safety of the survivor
	Training and capacity building of health care providers, police, prosecutors, magistrates, community based organizations and survivors
Psychosocial Support	Provision of safe housing, relocation services, if required
	Long-term psychosocial counseling and rehabilitation
	Community awareness-raising and stigma reduction
	Referral for services e.g. legal aid services, safe housing

Figure 9: Key components of a multi-sectoral response at an OSC

Example 3: UNDP in Ukraine: Administrative Services through One-Stop Shops to European Standards

The one-stop shop Centers for Administrative Service Provision (CASPs) were introduced in 2012 in Ukraine as a model to enhance transparency,

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[51] See http://www.popcouncil.org/uploads/pdfs/2012RH_SGBV_OSCRevEval.pdf

reduce bureaucracy and minimize corruption risks in administrative services.[52] The analytical report to compare two models of administrative service provision, the one-stop-shop centers for administrative service provision versus their provision by the offices of various central bodies of state authorities, was issued in a framework of the UNDP/EU project “Smart Practices for Oversight by Non-State Actors on Administrative Service Provision.”

The analysis shows the obvious benefits of integrated service provision. For service users (citizens and business) it is their responsibility to apply for different services in relation to their life events or facts at a time (e.g., birth of a child, change of residence, etc.). In the case of the second model of service provision (through institutional offices) more time and effort is required of a person. From the point of view of public resources, integrated service provision is more cost-effective, since more resources are needed to create multiple separate institutional offices rather than for one integrated office

According to the expert assessment, about 1/3 were of the centers, primarily those created in the cities which are the regional capitals, became really citizen-oriented offices offering a wide spectrum of administrative services in a convenient way. At the same time, development of the CASPs’ capacities was uneven across the country, with some well-known champions like the centers in big cities, and many less efficient centers at the district level where the technical and resource maintenance is inferior

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[52] See http://www.ua.undp.org/content/ukraine/en/home/presscenter/articles/2015/12/09/administrative-services-through-one-stop-shops-to-european-standards.html

compared to those cities. One major problem for CASPs' creation occurred since various state institutions resist to transferring their services to the one-stop-shop centers as they don't want to lose their source of income.[53]

Building Capacity through a Professional Workforce

Among the critical components of systems building is ensuring the competency of the professional workforce that assists individuals with NDD and their families. Other components of systems building will go for naught, if there is not a professional, well-trained and competent front line workforce to provide services. Preparing individuals to provide critical services to children and adults with autism will require designing a framework for professional development. A capacity-building framework in terms of professional staff encompasses an extensive array of resources including technological, organizational, institutional, and financial. Capacity-building is much more than training; it includes equipping individuals with the awareness, knowledge, and skills to deliver quality services through formal and informal approaches. Capacity-building can be addressed by a neighborhood, city or country and requires a distinct set of actions to plan, fund, deliver and evaluate the results.

The value that guides any capacity-building effort is based on the importance of having a trained workforce who will interact with adults and children with NDD throughout their lifespan. These will include teachers, paraprofessionals, and occupational, speech, and behavioral therapists. Capacity-building includes training but also in-depth pre-service education, continuing education, and processes for observing and documenting that individuals possess required competencies for their professions.

Normally there are three routes used to recognize competency:

1. **Certification**: attesting to the education, skills and training of an individual. Recognition is achieved by successful completion of an exam.

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[53] See http://www.ua.undp.org/content/ukraine/en/home/presscenter/articles/2015/06/09/is-the-centre-for-administrative-services-really-more-effective-and-convenient-for-citizens-0.html

2. **Licensing**: granted to an individual by a government entity such as a district, province or state that establishes its own requirements for practice.
3. **Credentialing**: process by which a provider, such as an NGO, is authorized to practice.

Capacity-building and ensuring competency requires development of and investment in oversight bodies (typically an NGO) that will ensure that education and training curriculum is developed and updated according to evidence-based practices, and that certification, licensing, and credentialing meet industry standards and have integrity. A certification entity also measures the continuation of the competence through a recertification or renewal process.

Development of a systematic approach to workforce development requires recognition that education is a life-long process for support professionals. Education and training curriculum are discipline-specific with the goal of improving the lives and opportunities of those receiving services. If a country is going to invest in sustaining the quality of professional and paraprofessionals and their education and service delivery, efforts should be made to ensure that there are entities in place to deliver education for individuals to prepare them for providing a service while also offering education and training for ongoing career development.

Distinguishing Between Certificates of Completion of Training vs. Certification of Competency

In development of a system for development of a professional workforce, it is important to understand the proper processes for ensuring competency and in particular to recognize that attendance at a training or education program is not equivalent to demonstrating competency. The term “certification” is often discussed regarding assuring a competent workforce without necessarily understanding that certification can mean different things in terms of whether a “certificate” truly indicates professional competency. Simply attending a training or education course for which a certificate is granted upon completion does not necessarily indicate competency. It is therefore critically important to distinguish between a certificate that indicates completion of a training or education program, vs. certification of competency. Certification of competency is a voluntary process by which individuals are evaluated against predetermined standards for knowledge, skills, or competencies. Participants who demonstrate that they meet the standards by successfully completing the assessment process are granted a time-limited credential by a non-governmental organization.[54]

The assessment of competency is independent of a specific class, course or other education/training program and also independent of any provider of classes, courses, or programs. The assessment of competency is NOT designed to evaluate mastery of the intended learning outcomes of a specific class, course or education/training program. Additionally, a certification program provider that is certifying professional competency (and not completion of training or education) is NOT the sole provider of any education or training that may be required for certification.[55]

To retain the credential, "certificants must maintain continued competence. The credential awarded by the certification program provider denotes that the participant possesses particular knowledge, skills, or competencies."[56] The remainder of this section focuses specifically on the development and management of certification of competency that results in an industry recognized credential.

Quality Certification Programs

An entity pursuing certification (non-degree) begins by identifying a set of competencies for each profession. The entity must be separated from the educational institution or other training program that provides the actual personnel preparation (Institute for Credentialing Excellence, 2010). Assessment may take the form of an examination, completion of assignments, portfolios, presentations or other tasks that

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[54] Institute for Credentialing Excellence, *Defining Features of Quality Certification and Assessment-Based Certificate Programs*, 2-3 (2010).

[55] (2010). *Defining Features of Quality Certification and Assessment-Based Certificate Programs.* (Washington, D.C.: Institute for Credentialing Excellence, 2010), 2-3

[56] Ibid, 3

provide evidence of proficiency. The focus of this discussion is on use of an examination to earn a credential.

Competency Development

A certification entity must first establish itself by adhering to standards authored by a state, national or international association. Knowledge, skill and competencies are determined by a Role Delineation/Practice analysis. The analysis validates the relevance to practice for the content areas that will be covered in curriculum and the tasks that will be performed on the job. Subject matter experts are assigned to complete the analysis and develop competencies for each task, which is done through a review of the professional literature and interviews with individuals and their supervisors who are actually performing the work. The analysis also establishes the frequency and relevance of each task such as, "How often is this knowledge or skill applied or used in employment situations?"; "How does application or use of this knowledge or skill affect attainment of a successful situation or outcome?". The more frequently specific knowledge and skills are applied and the more critical specific knowledge and skills are needed, the greater the emphasis of these tasks on the examination. Greater emphasis is defined as greater number of test items (Role Delineation Study, National APSE Certification Institute, Seacrest, April 2011).

A second group of subject matter experts prepare the test questions to be used in the examination to earn the credential. To determine validity, the questions are distributed to a sample of professionals in the field either by electronic or in-person surveys. A final examination is prepared once the surveys are reviewed and the examination questions are revised based on the survey results.

Test administration

The entity (NGO) responsible for administration of the credential manages the examination process. The credentialing administration entity is responsible for arranging for recruiting and registering individuals for the test, arranging for space, etc. Taking of the test and applying for the credential usual requires a fee to be paid by the test taker or the organization they work for.

Maintaining the integrity of the test is critically important in order to ensure the quality and recognition for the credential. The test is typically a paper document, although a computer-based version is also an option. An examination can also be administered verbally as an accommodation for these with reading or writing challenges. However, an on-line test is typical not feasible, due to the need to proctor/monitor the exam administration to ensure its integrity.

Proctors are used as part of maintaining the test and credential integrity. The proctors are trained on administering the test. Their specific duties include: distributing copies of the test to each individual when the test period begins, and collecting the tests at the end of the test period; monitoring the time of test taking to ensure the individual's taking the test do not go over the time limit; ensuring that the individuals taking the test are not sharing information during the test taking; maintaining the security of the test documents prior to and after the taking of the test.

To both help ensure the integrity of the test is maintained, and to incorporate changes as a result of developments in the field, the test questions are changed periodically, typically every year to two years, with new versions of the test created. New versions of the test also allow those who initially did not pass the exam to retake it.

Awarding and Maintaining the Credential

Upon passing the test, the individual is awarded the credential. To maintain the credential, an individual must undertake a specific number of hours of continuing education activities, through in-person and on-line trainings and seminars. Continuing education credits are often earned via attendance at professional conferences. The credentialing administrative body develops the requirements and criteria for continuing education, and approves activities for continuing education. For example, if an organization is holding a professional conference, they will submit information regarding the presentations to be held at the conference (topics, learning objectives, qualifications of speakers), and the credentialing body will approve the conference presentations if they meet the criteria that have been developed.

Credentials must be renewed after a specific period of time (for example, three years). Renewal of the credential requires completing a required number of continuing education hours, completing an application for renewal, and paying a fee.

Using Professional Expertise in Development of Credential

To ensure the quality and integrity of the credentialing program, it is critical to enlist professional expertise on credentialing. In the United States, the services of a psychometrician are used. (Psychometrics "is the science and technology of mental measurement, including psychology, behavioral science, education, statistics, and information technology."[57]). A professional psychometrician:

- Designs and analyzes results of a job analysis or role delineation to define knowledge and/or skill associated with performance domains and tasks associated with the identified profession.
- Establishes examination specifications based on a job analysis or role delineation.
- Facilitates examination development based on examination specifications and item writing principles.
- Analyzes examination results using appropriate statistical methods.
- Ensures that the reported scores are sufficiently reliable for the intended purpose(s) of the examination.
- Ensures that different forms of an examination assess equivalent content.[58]

Oversight

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[57] Cynthia Durley (2005). *The ICE Guide to Understanding Credentialing Concepts.* (Washington, D.C.: Institute for Credentialing Excellence, 2005), 6

[58] Ibid, 6-7

A voluntary governing board provides oversight of the certification program. Its members are stakeholder representatives of the practice area. This is an independent body that has no fiscal or programmatic interests that could conflict with its neutrality. Board member terms are time limited.

The board maintains control over the financial budget, decides the processes used to certify individuals and makes corrections when necessary as determined by examination rates, for example, whether the pass rate is too low, which can indicate that the examination questions are too difficult or not relevant. It determines the protocols for taking the examination, such as monitoring requirements, training of monitors, time allotments and locations. The certification board also decides eligibility for those who can take the examination. Examples of eligibility requirements are minimum years of experience, licenses, education, and/or degrees earned. Additionally, the board will decide the passing score while also determining how the score links to the expected performance of the individual. The board also reviews any test questions that are in dispute.

Routinely the board will assess the adequacy of the examination questions and the tactics it uses to measure competencies and skills. Test questions should be rewritten on a board-determined schedule to ensure that the questions reflect current practice. The board also establishes policies for recertification or continuing education requirements, and hires and manages the staff member that directs the certification entity.

The governing board will develop standards for how it will conduct its business. It must be explicit within these standards that educational or training programs be independent of the certification process. An educational or training entity cannot be part of the certification entity. The certification program should not promote a specific educational or training organization. Also, the certification entity should not provide training that may be required for certification.

Certification entities should communicate the purpose and value of the certification. This is particularly important to individuals and families and ministries who are either funding a service or receiving a service.

Examples of Professional Development and Accreditation

As Bangladesh considers options for ensuring highly competent professionals to assist and support individuals with NDD and their families, the following can be used as examples from countries dealing with similar socio-economic challenges.

Curacao – Medical Training

Busari and Duits (2015) reviewed the competency-based medical training that occurred in Curaçao, a Dutch island in the Caribbean. Curaçao has recently undergone a reform in the healthcare system but has struggled to implement the change due to their limited resources. The researchers assisted in implementing a competency-based training program in the main hospital to ensure levels of training and competent practices by all healthcare professionals in Curaçao. The basic framework for this process was taken from a medical school in the Netherlands. Then, through qualitative processes, the researchers received local stakeholder input on the framework being implemented. The training focused on four main areas: professional standards, distributions of responsibilities, accountability, and quality assurance and improvement. Through training hospital leaders and implementing the framework, the researchers found that this method effectively increased the outcomes in the healthcare setting. The researchers acknowledge that there is more work to be done but that this method was effective in this low-resource community.

South Africa – Technology Field

Similarly, Bonnet (2009) writes about how competency-based training was effective in the technology field in South Africa.[59] The author focuses on the current competencies required to acquire a degree in technology engineering in South Africa.

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[59] Bonnet, P. (2009). Development of A Competency□Based Work□Integrated Learning Program. Asia□ Pacific Journal of Cooperative Education., 10(2), 65-74

The country previously set up standards that followed the competency-based framework, such as: national standards, a registration system, a reporting system, and accredited university programs. These structures have created a robust and competent workforce in South Africa. While the author admits there are still improvements to be made, the overall effectiveness is undeniable.

The UCEDD Model

The University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs), in the United States, are a potential model for building an infrastructure for professional training and research on NDD in Bangladesh.

In the early 1960s, U.S. President John F. Kennedy called attention to the appalling conditions under which many individuals with intellectual and developmental disabilities (then referred to as mental retardation) lived. As a result, the President's Panel on Mental Retardation was formed. Among the recommendations of this panel was creation of university-based facilities on developmental disabilities to conduct training, research, information dissemination, and direct service. The rationale for placing these centers within universities was that it would allow for a venue for cross-disciplinary training among professionals, and availability of federal funds for campus facilities to conduct research and provide training and clinical services. Federal legislation was passed in 1963 to create what are now known as UCEDDs.

As a result of President Kennedy's vision, there are now a total of 68 UCEDDs located throughout the United States, with at least one in every state and territory. Each UCEDD is affiliated with a university, and UCEDDs are expected to serve as liaisons between academia and the community. The Institute for Community Inclusion, in the School for Global Inclusion and Social Development at the University of Massachusetts Boston, is one such center. Each UCEDD is an independent entity but is part of the UCEDD network, and must conform to certain standards. Core funding for each UCEDD is provided by the Federal Government. This funding is used to support the basic organizational structure of these centers, and

UCEDDs pursue other sources of support through federal, state and local grants and contracts, private foundations, donations, and fee-for-service earnings. There are four core functions of the UCEDDs:

- Interdisciplinary pre-service (prior to graduation) preparation and continuing education of professionals in the field.
- Research, including basic or applied research, evaluation, and public policy analysis.
- Information dissemination.
- Community services, including direct services, training, technical assistance, and model demonstrations.

The centers work with people with disabilities, members of their families, state and local government agencies, and community providers on projects that provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to sustain all their citizens. Some UCEDDs are broad based in their focus, while others are focused on specific areas. Among the areas of focus are prevention, early intervention, supported employment, transition from school to adult life, etc. UCEDDs may also focus in part on specific disabilities (e.g., autism).

The development of the UCEDDs has resulted in an infrastructure throughout the United States for ongoing training of professionals both within and outside the disability field on developmental disability issues, resulting in greater understanding, responsiveness, and sensitivity to the needs of individuals with developmental disabilities and their families. The development of the UCEDD network has also created a mechanism for information dissemination to professionals, families, and individuals, to guide and assist them. Just as critically, it has created avenues for ongoing research focused on ensuring that individuals with developmental disabilities are able to enjoy lives similar to their fellow citizens without disabilities.

Other international models for inclusion of NDDs into public sector work

It is always prudent for a country, when addressing any matter, to study the experiences of other countries trying to deal with a complex issue like NDD. It not only gives policy makers and government officials a tangible example, but if the challenges and infrastructure are somewhat similar it obviates the need to re-invent the wheel. This section will briefly share examples that have been gathered through our international network. It should be noted that a thorough detailed review has not been done, and therefore no attempt has been made to assess the effectiveness of the programs.

One good regional model for addressing ASD through the health system is that of the program in Thailand, where autism is embedded within their Mental Health Program. Due to the patronage of the Thai royal family, there has been significant awareness and financial support for the program. They have developed an autism self-tracking pictorial – known as the *Pink Book* – that is given to every parent, thus facilitating self-referrals and reduced need for awareness campaigns. Although Thai law mandates inclusion of children with disabilities in regular schools, there is also a strong network of special schools. It is easy, therefore, for principals to resist inclusion and refer children to special schools. In many cases it is the attitude of the principal toward inclusive education that determines whether or not children with disabilities are accepted and fully included in schools. Therefore, although children are being regularly screened and their progress monitored, education and social inclusion is not discernible.

The front cover of Thailand's "Pink Book"

In India, a Delhi High Court has recently ordered that every school in Delhi must have a full-time special Educator on its payroll. Moreover, the

Sarva Shiksha Abhiyan,[60] a flagship primary education program of their Ministry of Human Resource Development, employs over 20,000 full-time special educators on its payroll, on a contractual basis, to facilitate its multi-option model of inclusive education in the government sector. Similarly, in their health sector, the government has recruited over 800,000 accredited social health activists – *a.k.a.* ASHA – whose purpose is to create awareness on health issues and their social determinants, and to mobilize the community towards local health planning and increased utilization and accountability of the existing health services.

In Vietnam, the government mandates free education for children with disabilities. Since salary structure and other benefits of the teachers is a great concern for them, teachers are paid only for the number of non-disabled students in their classes, thereby ensuring inclusion and zero cost for the education system.

5 ASSESSMENT OF SOCIAL RESPONSE

It is important to consider culture and social response to NDDs when developing strategic capacity related to intergovernmental coordination and service delivery. Social response is defined as the perception of individuals, community and society towards individuals with NDD. This summary of social response is based on review of available literature regarding social response in Bangladesh to NDD and disability in general, combined with information gathered in-country during site visits by the Institute for Community Inclusion.

5.1 Models of Disability

The context for the ranges of social responses is based on and exemplifies various models of disability. While the literature discusses a wide range of models and variations within, the most predominant models are the medical model and social

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[60] A programme aimed at the universalization of elementary education "in a time bound manner", making free and compulsory education to children between the ages of 6 to 14. For more information, visit: www.ssa.nic.in

model. The charity model and human rights model are two additional primary models.

The Medical Model

In the medical model, the limitations of individuals are viewed primarily as a result of their impairments. People with disabilities are seen as individuals with problems that need to be cured and taken care of by professionals. The intent of such care is to make people with disabilities as "normal" as possible, so that they fit into society. Under the medical model, social exclusion is a result of the individual's disability, with the presumption is that it is up to the individual to change in order to fit into society as it exists. The medical model also presumes that individuals often need "special" services specifically for people with disabilities, which often are provided separate from mainstream society. Too often, the result of the medical model is that individuals see themselves as damaged and abnormal.

The Charity Model

The charity model is an outgrowth of the medical model of disability, and has its roots in England's Elizabethan Poor Laws of 1601. The charity model views people with disabilities as victims of circumstance deserving of pity, resulting in a culture of caretaking. Under the charity model, individuals with disabilities are reliant on society and the help, sympathy, and charity of others to meet their basic needs, as they are viewed as incapable of doing so themselves. They need special services such as special schools and special homes because they are viewed as different. As a result of the charity model, people with disabilities will often view themselves as unable to take care of their own needs, resulting in low self-esteem and a limited sense of self-worth.

The Social Model

The social model of disability emerged in the 1970s, as a radical alternative to the medical and charity models. The core tenants of the social model are that the disadvantages of individuals with disabilities are not primarily a result of the individual’s impairments, but instead a result of the social, economic, cultural, and environmental barriers and limitations imposed on them by society. The problems faced by people with disabilities arise primarily from social and societal forces rather than the individual’s disability. Under the social model, access to full society resources, rather than individual “repair,” are key to success. As a result, it is not up to individuals with disabilities to fit into the conditions that have been created within society or otherwise be excluded, but rather it is up to society to create conditions that allow individuals with disabilities to be fully included. One of the most obvious examples of the social model is the building of ramps for wheelchair users – i.e., the condition of a building has been changed so that individuals who use wheelchairs can be fully included, rather than requiring that the individual be able to walk in order to have access to the building. The social model also views disability as part of the overall diversity of society. While not rejecting medical intervention, the social model implicitly acknowledges the normality of an individual having an impairment. As a result of the emergence of the social model, disability has come to be viewed as a socio-political issue leading in many countries to fundamentally different policy priorities and choices, mainly around the removal of barriers, as well as a strong emphasis on human and civil rights.

The Human Rights Model

The human rights model is closely related to the social model, and echoes many of the same principles. This model focuses on the fulfillment of human rights – for example the right to equal opportunities and participation in society – and places disability within overall human rights efforts for individuals and populations that have been too often marginalized. Under the human rights model, society has to change to ensure that all people, including those with disabilities, have equal possibilities for participation. This model stipulates that people with disabilities are entitled to the same basic human rights as all other members of society, including education, employment, and health. Individuals with disabilities should not be reliant on the charity and humanity of others in order to receive these items – they are instead basic human right that any person is entitled to. The two main elements of the human rights model are empowerment and accountability. Empowerment "refers to the participation of people with disabilities as active stakeholders, while accountability relates to the duty of public institutions and structures to implement these rights and to justify the quality and quantity of their implementation." [61]

Other Models of Disability

Although the four models above are the primary models of disability, there are numerous other models that exist within the literature (social adaptive model, economic model, etc.).[62] Of these other models, it is important to note the religious or moral model, which views disability as a punishment inflicted upon an individual or family by an external force, due to misdemeanors or moral failing committed by the individual or a family member. The presence of evil spirits is sometimes used to explain behavior. In some cases, application of the religious or moral model results in shunning and social exclusion of the individual and family by the community.[63]

Evolution of Models of Disability

It is important to recognize that the charity model and medical model of disability are long-standing, with antecedents in the Elizabethan Poor Laws passed in England in 1601. These laws were enacted to aid the "deserving poor, orphaned, and crippled," with persons with disability labeled as "helpless poor" entitled to money and food from society, paid for through a tax on land owners.[64] The social model and human rights model have only emerged in the past few decades. As a result, many services and supports for individuals with disabilities are still based on the core concepts of the long-stranding medical and charity models.

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[61] Handicap International, *Making PRSP Inclusive*. Available from: www.making-prsp-inclusive.org/en/home.html

[62] See "Definitions of the Models of Disability", Disabled World, October 26, 2015 - www.disabled-world.com/definitions/disability-models.php

[63] Alaska Mental Health Consumer Web, "Models of Disability – Keys to Perspective", Alsaka Mental Helath Consumer Web, 2001 - www.akmhcweb.org/ncarticles/models_of_disability.htm

[64] Hansan, J.E. (2011). English poor laws: Historical precedents of tax-supported relief for the poor. Retrieved from www.socialwelfarehistory.com/programs/poor-laws/

Consideration of Models in the Context of Service Design for Individuals with NDD in Bangladesh

As services and supports are designed and delivered, it is critically important to consider which model of disability is being utilized as the basis. This is important as the model will form the foundation for the presumptions about the needs of individuals with NDD and how they should be provided for. Without consideration of whether a model is being used and which specific model is being used, services and supports can be designed in a way that is either inconsistent or not aligned with more modern and progressive approaches. While the medical and charity models of disability are well-meaning, the more progressive social and human rights models will best meet the needs of individuals with disabilities and society as a whole and the design and delivery of services for individuals with NDD in Bangladesh should reflect these models. The world is moving away from the medical and charity models of disability which focuses on the impairment towards the social/rights based model that focuses on the person and the barriers they face, also known as the person-centered approach. This modern approach to disability implies that all people with disabilities have a major say in their decision-making and day-to-day activities, at the same level as their non-disabled peers. The rights-based approach to disability provides three core human rights principles to strive towards as a country makes gains towards inclusion of persons with disabilities:

- Equality and non-discrimination
- Participation and empowerment
- Transparency and accountability[65].

5.2 Status of Social Response

In examining the social response to NDD in Bangladesh via a literature review, it is clear that the current responses encompass the full range of disability models. Autism

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is still often considered to be a curse and people have negative attitudes towards autistic children and their mothers.[66] Parents and families that have a child with a disability may be reluctant to come forward out of shame, lack of knowledge or fear of discrimination. Knowledge about NDD may be limited or nonexistent, and local languages and culture might lack appropriate terms for discussing problems and solutions with families. There also continues to exist a common false belief that that autism and other mental disabilities are caused by ill spirits and require something other than medication (Rabbani et al.).[67] There is also widespread belief in the use of traditional healers, rather than relying on medical staff and other professionals. A study conducted by the NIMH&R revealed that more than 50% of rural residents have faith in traditional healers. These rural residents also considered autism and other mental disorders to be caused by ill spirits, requiring some measure other than medication.[68]

While the social perceptions of NDD are too often based on misunderstandings about the nature of NDD, and on stigma, Bangladesh also has the basis of moving in the direction of a social model and human rights perspective, epitomized by the Dhaka Declaration of 2011 stating that according to the constitution, everyone is equal in the eyes of the law. Religious and cultural beliefs can also serve as positive force for social response. In particular, Ecker (2010) noted research studies regarding the attitudes and perceptions of Bangladeshi Muslims, including:

- Emphasis on the importance of full inclusion into the extended family and community with parents working to immerse their child into every aspect of life, from huge family weddings to individual daily prayers.
- Fathers taking a great interest in teaching their child to mimic prayer behaviors so

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[66] Kalim, T. (2012). *Autism: A Public Health Issue;* Bangladesh Education Article. Retrieved from www.bdeduarticle.com/inclusive-education/27-autism-a-public-health-issue?highlight=WyJhdXRpc20iXQ==.

[67] Rabbani, M., Ahmed, H., Mannan, M., Chowdhury, W., Alam, M., Hossain, T. (2014). (2014) *Autism in Bangladesh: Window for Stigma Removal.* International Meeting for Autism Research. Retrieved from https://www.researchgate.net/publication/268143329_Autism_in_Bangladesh_Window_for_Stigma_Removal

[68] Soron TR (2015) Autism, Stigma and Achievements of Bangladesh. J Psychiatry 18:320 doi: 10.4172/2378-5756.1000320

that the child can be incorporated in the spiritual aspects of their religion, and fathers bringing their children to mosque to pray. The study found that if a child misbehaves in the mosque, it is not seen as offensive to the community, as the community is obligated to assess, assist, respect and give equal opportunity to people with intellectual disabilities

- Viewing the child as a gift from Allah and therefore feeling that they have been blessed with such a child, creating a positive outlook on autism.[69]

Interestingly, given that Islamic society believes that the best therapy is one that enhances the health, psyche and soul of an individual, in seeking services based on Western societies, families in Islamic society believe that the best therapy is one that enhances the health, psyche and soul of an individual (Morad et al., 2001).[70] As a result, in seeking services from Western therapies, Morad found that families were angered by the focus of Western medicine on the limitations of their child with autism. In turn, fathers refused to work with professionals who focused on the weaknesses of their child instead of their child's potential.

5.3 Report on town-hall meetings of parents

To gain a further understanding of social response, a series of workshops and meetings were held at the Dhaka and Sylhet divisions to assess the social response of the individual and families to NDD in Bangladesh, including perception and attitude of individuals, families, community and society towards the disorders and their response towards people with the disorders. Details regarding each of these meetings including the information gathering at each meeting are in Appendix 15. The following summarizes the issues identified, challenges, and recommendations across all three events.

Findings and Issues:

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[69] Ecker, J., (2010). Cultural Belief Systems in Autism and the Effects on Families. 8-11. Retrieved from www.academiccommons.columbia.edu/.../Cultural_Psych_ECKER.pdf

[70] Morad, M., Nasri, Y., & Merrick, J. (2001). Islam and the person with intellectual disability. Journal of Religion, Disability and Health, 5, 65-71.

Diagnosis: A primary issue identified is diagnosis of NDDs. Although the majority of the population lacks knowledge regarding autism, parents may identify the manifestations of NDD in their children and consult a physician. However, families report that there is lack of consistent and reliable screening tools. Doctors also cannot consistently diagnose NDDs properly and distinctly as the symptoms can lead to consideration of a variety of other disorders. In addition, there is often a delay in detection as children do not display behavior indicative of autism or NDDs until 2 1/2 to 3 years old. There is also an absence of suitable diagnostic instruments in schools and healthcare settings

Lack of a referral system: When diagnosis does occur, there is a lack of an appropriate, clear, and definitive referral system.

Impact on family dynamics: The impact on family dynamics and structure is a major issue. There is a lack of knowledge about NDDs among parents and family members, resulting in a lack of understanding of how to best assist and support their child, and manage the overall family dynamics. Impact on the family dynamics includes the need for mothers who are educated and employed to give up their jobs to become the child's caregiver, blaming by the father of the maternal side of the family, significant levels of depression in mothers, exclusion by siblings, and both positive and negative attitudes from relatives. In addition, many parents lack knowledge about NDD, and have limited means to gain information or support.

Community stigma: The reaction from the larger community also poses challenges. Lack of knowledge by the general community is a major gap, resulting in stigma, and a lack of social acceptance by society. Children with NDD are often excluded by their peers. In addition, parents, especially mothers, may experience being blamed for their child's NDD. School teachers may also have a negative attitude towards children with NDDs.

Poor quality of services: Support and care from existing organizations is not of sufficient quality to meet the needs of individuals and families. Services are not based on an individual plan, and not based on the child's level. Both the service providers and families are not aware of services specific to NDD. Referrals for medical care take place, but referrals for therapeutic care are not working. There is also a lack of treatment availability in remote areas.

Lack of qualified personnel: There is a dearth of qualified healthcare providers, therapists, as well as teachers and caregivers, who have the knowledge and training to support families and children with NDD. This results in services being provided by untrained/unqualified individuals.

Cost of services: Costs associated with treatment, doctor visits, medication, and transportation for children with NDDs are a major challenge for families, as these are very expensive, which is made more challenging by the socio-economic circumstances in which many of these families live. In addition a lack of government provision of speech and occupational therapy, the high costs of attending school for children with NDD, and the limited availability and high cost of parent training programs contribute to the financial challenges.

Education issues: Some families noted that special schools are currently providing speech and occupational therapy along with conventional education programming. However, there are many challenges in terms of education, including a lack of coordination between parents and teachers, a lack of flexibility in school curriculums to respond to the needs of students with NDD, and a lack of the three essential supports in many schools (medical, therapeutic, and special education). Dissatisfaction was expressed regarding the lack of experience of many teachers being recruited into schools, and the lack of retention of trained teachers in special schools There is a lack of appropriate teacher training, and no training courses are available to receive appropriate training. In addition, the education system in Bangladesh has no standardized rules and regulations regarding mainstreaming children with NDDs, or parents are unaware of them. Furthermore, because children with NDDs have a lack of basic education for the Primary School Certification, and Junior School Certification, their attainment of higher education is often limited; this is exacerbated in the rural areas because of limited schools and rehabilitation centers.

Employment: The lack of post-school work opportunities for children with NDD is a major issue. There is a need for assistance with employment as individuals with NDD enter adulthood.

Existing infrastructures and policies are of benefit: On a positive note, existing infrastructure, such as the current training centers, were see by some families as a benefit to children with NDD. In addition, the Neurodevelopmental Disability Protection Trust Policy is seen as of value to parents.

Recommendations

The following is a summary of the recommendation from the series of meeting with parent and family groups.

Development of screening tools followed by early intervention: The groups recommended the development of a universal screening tool for early detection of NDDs in every hospital, accompanied by early intervention after early detection. In addition screening and diagnostic tools should be available in schools and community health centers. This would not only assist on an individual basis, but would allow for accurate collection of data so that there is full understanding of the extent of NDD among the population.

Clear and accurate information from doctors: If autism or another NDD is diagnosed, it is critical that the doctor be explicit without hesitating with parents regarding the diagnosis, so that parents understand the specifics of the situation and how to best manage, and how to ensure their child’s needs are taken care of.

Establishment of strong referral systems: An improved referral system was highly recommended, that would include a call center to answer questions about services and disabilities.

Establishment of service centers for NDDs: The groups recommended the establishment of service centers throughout the country with core standards, the availability of early screening and detection services, and where children with NDDs can get services for less cost. This would include access both financially and logistically to therapy services.

Services based on individual treatment plans: Services should be based on the specific needs of individuals and families, not on general blanket assumptions.

Use of ID cards to enhance access to services: One of the groups recommended the use of a system, such as ID cards, to enable children with NDD to more efficiently access services.

Professional training: There is a need for extensive training of staff providing supports, including medical staff, community services staff, and educators, to ensure consistent quality. This also includes training to improve both teacher knowledge and attitudes towards students with NDD.

Training centers: A group recommended the creation of NDD training centers, for professional development, and where knowledge is developed, and information can be accessed.

Parental awareness: It was recommended that all couples be informed about the signals and symptoms of NDD during pregnancy, so that they look for potential signs of NDD after the child is born.

Parental and family support: Training for parents, siblings, and relatives of individuals with NDD was recommended, to ensure they have the necessary information to provide care for their family member and manage the various challenges involved within the home and community. Parental support recommendations also included establishment of parent-to-parent peer groups, which may help to socialize a baby and child with autism or other NDD, and reduce the potential psychological effects on families, such as depression, of parents. Counseling, training, and guidance to parents on an ongoing basis using a common platform was also recommended.

Education: Creating and expanding opportunities for children with NDD to attend mainstream schools was recommended, as well as establishing additional specialized schools offering services such as 1:1 education. Specialized schools must also ensure they are using qualified trained personnel, and that students are able to access and use the services provided. Improving monitoring and quality assurance of existing schools was also recommended.

General awareness and media campaigns: In order to combat the issues of lack of community acceptance and stigma, awareness campaigns for the general public via television, billboards, and other media were recommended, as well as campaigns to raise awareness within the medical community. In addition, awareness of NDDs should be integrated within school curriculums.

Day care for children with autism: There is a need for a day care system for children with autism whose mothers are employed.

Preparing individuals for employment: The establishment of supports focused on preparing individuals for employment (pre-vocational) as well as actual vocational supports was recommended, in support of the notion that every child has a right to work and use their talents.

Facilities at parent workplaces: The establishment of policies that ensure parent workplaces provide facilities that accommodate children with NDD was recommended.

6 SERVICE DELIVERY AND IMPLEMENTATION

6.1 NDD Best Practice Models

It is important to capitalize on the best practice models of other developing countries and to use those models to promote effective change in Bangladesh. The following sections provide information and best practices from similar developing countries to provide fluidity in replicating these models. This process allows limited resources to be used efficiently and effectively. The criteria used for best practices includes:

- Demonstrable change
- Replicability
- Sustainability
- Person-centered[71]

6.2 WHO Guidelines and Logical Framework

The World Health Organization (WHO) created guidelines for community-based inclusive development based on community-based rehabilitation (CBR) for persons with disabilities (2010). The WHO conducted multiple CBR studies in developing countries to create the guidelines. The purpose of the guidelines is to strengthen CBR programs, increase inclusive development in developing countries, support stakeholders to enhance the quality of life for persons with disabilities, and encourage empowerment of persons with disabilities. The guidelines follow a twin-track approach that ensures (i) "disability issues are actively considered in mainstream development work, and (ii) more focused or targeted activities for people with disabilities are implemented where necessary."[72] This approach ensures that the poor and marginalized populations are also reached. The CBR guidelines, outlined by the matrix in Figure 9, show five components and five elements within each component.

Figure 9 CBR matrix.

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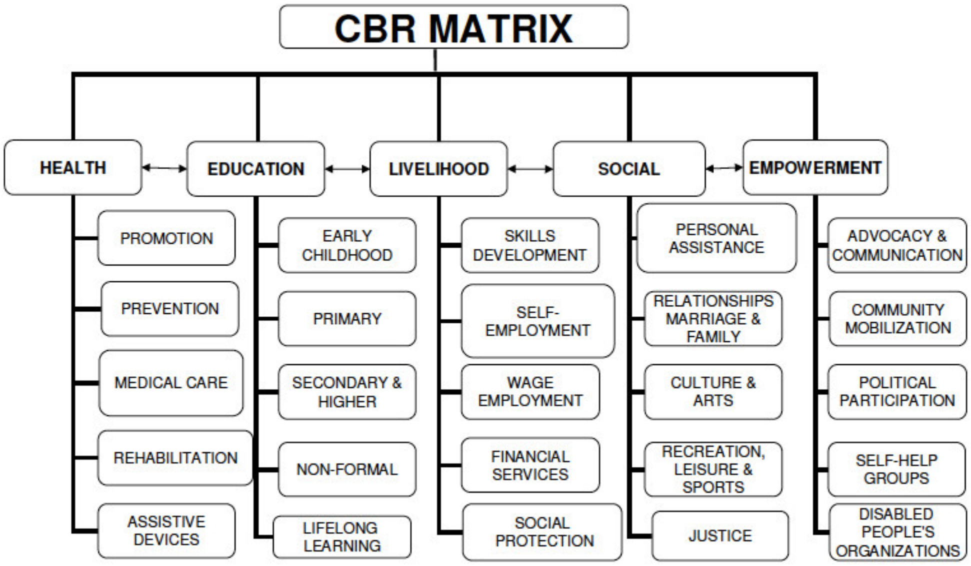
[71] Handicap International, *Making it Work: Good practices for disability inclusive development and humanitarian action*, 45 (2015)

[72] World Health Organization, *CBR Guidelines: Introductory Booklet*, 20 (2010). Available from: www.who.int/disabilities/cbr/guidelines/en/



The matrix was created to ensure that minimal services are provide in each area that is essential to human rights for persons with disabilities. The benefits of CBR include: advocacy for persons with disabilities, coordination between local and national government, creating and monitoring local action plans, and implementing program activities.

To effectively assess services, the WHO recommends using a logical framework to ensure that the services have the components that are required to be successful (see figure 2). The framework aims at looking at what each program does and how it achieves its purpose. The framework also looks at the potential issues or risks that the program may have.[73]

Figure 11 CBR logical framework

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[73] World Health Organization, *CBR Guidelines: Introductory Booklet*, 48 (2010). Available from: www.who.int/disabilities/cbr/guidelines/en/

	Summary	Indicators	Sources of verification	Assumptions
Goal				
Purpose				
Outcomes				
Activities		Resources needed	Cost	

Using this framework, a monitoring body will be able to assess if the organization or program is able to carry out their responsibilities or if their personnel need further training, if all or some aspects of the program should continue, if the program is very impactful could and should it be implemented elsewhere, and if resources have been well spent. Ultimately, the monitor is looking at the five following areas:

1. Relevance
2. Efficiency
3. Effectiveness
4. Impact
5. Sustainability

6.3 International Service Provision Recommendations

When looking at the services in Bangladesh, there are overarching concepts that need to be kept in mind. First, the services should be well coordinated between the ministries and local NGOs. Second, the services should be reflected in the action plan. Third, services should be sustainable; thus, one-time trainings are not encouraged.

The World Report on Disability lists these types of services to consider in developing countries:

- Health services
- Welfare services
- Counseling for parent or family
- Assistive device services
- Medical rehabilitation
- Counseling for disabled person
- Educational services
- Vocational training
- Traditional healer

Also, the World Report on Disability lists alternatives to mainstream service provision.[74] This information can assist Bangladesh in thinking outside the box to find alternative service provision solutions.

- Structural modifications to facilities.
- Using equipment with universal design features, such as adjustable chairs.
- Communicating information in appropriate formats, such as pamphlets with pictures and words.
- Making adjustments to appointment systems, such as clustering appointments for persons with disabilities.
- Using alternative models of service delivery, such as mobile clinics and house calls.

Some examples of these services from other developing countries are as follows:

In South Africa, screenings and mental health support are integrated into holistic medical care, and in Iran mental health responsibilities have been clearly defined and

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[74] World Health Organization and World Bank Group, *World Report on Disability*, 74 (2011).

included within general health care settings.[75] Another intervention has been training professionals (medical, educational, social services) to screen, diagnose, and offer interventions for NDD, and to network with each other.[76] In China, public (state-owned and run) hospitals, as well as private and public rehabilitation centers, provide children with NDD training courses such as sensory integration, fine and gross motor skills, and speech therapy.[77]

India has piloted an intervention using innovative technologies such as telepsychiatry, a mobile health technology, and distributing technological aides (mobile devices, laptops, etc.) to families to access intervention programs, and to enable access to support, networking, resources, and information.[78]

Other countries, such as Jamaica, have implemented low-cost, school-based intervention to support the needs of students with autism. In Chile and Uruguay additional resources are allocated to support educational services for students with disabilities.[79]

Numerous countries offer private early intervention and education centers for children with autism. In Vietnam, in addition to private early intervention centers, services are provided through some public hospitals in Hanoi. Two public universities have established private early intervention centers that offer full day programs, as well as a

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[75] Funk, M., & World Health Organization. (2010). *Mental health and development : Targeting people with mental health conditions as a vulnerable group*

[76] *Autism initiave in Tajikistan* (2015). World Health Organization, Retrieved from: http://www.euro.who.int/en/countries/tajikistan/news/news/2015/04/autism-initiative-in-tajikistan.

[77] Sun, Xiang, Allison, Carrie, Auyeung, Bonnie, Matthews, Fiona E., Murray, Stuart, Baron-Cohen, Simon, & Brayne, Carol. (2012). Service provision for autism in mainland China: A service providers' perspective. *Research in Developmental Disabilities, 34*(1), 440-451.

[78] Malhotra, & Padhy. (2015). Challenges In Providing Child And Adolescent Psychiatric Services in Low Resource Countries. *Child and Adolescent Psychiatric Clinics of North America,* Child and Adolescent Psychiatric Clinics of North America.

[79] World Health Organization, and World Bank. 2011. *World Report on Disability*. Geneva, Switzerland: World Health Organization, p. 39.

part time supplemental program for students with NDD who attend a mainstream kindergarten.[80]

In some locations, such as China, language and life skills trainings are provided to children with NDD through public hospitals.[81] State-run rehabilitation centers also offer classes and life skills training sessions

6.4 Service Inventory

The research team mapped the existing services and supports addressing NDD in the country. Service provision may be informal in nature and known more through word of mouth. Mapping will include the service provider's name, type of services provided, population served, and region of country served. This mapping process will be iterative as additional providers are identified. A long-term goal is to create a more complete resource guide for families and providers. This complete guide is beyond the scope of this project, but will begin and can continue to develop over time.

Icddr,b will collect checklists from the different government organizations like the ministry of social welfare, ministry of health, and other public-private service providers in Bangladesh, and make an inventory after compiling all of the lists.

Methodology

In order to find out the organizations providing services for NDD care across the country, the research team has started searching data bases, Google, different organizations' websites, and social media, as well as contacting personnel through snowballing to obtain the organization lists. A spreadsheet is being made for making an inventory by compiling all the organizational lists that we have collected.

Findings

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[80] Ha, Vu, Whittaker, Andrea, Whittaker, Maxine, & Rodger, Sylvia. (2014). Living with autism spectrum disorder in Hanoi, Vietnam. *Social Science & Medicine, 120*, 278.

[81] Sun, Xiang, Allison, Carrie, Auyeung, Bonnie, Baron-Cohen, Simon, & Brayne, Carol. (2012). A review of healthcare service and education provision of Autism Spectrum Condition in mainland China. *Research in Developmental Disabilities, 34*(1), 469-479.

Seventy organizations have been listed from Dhaka, Chittagong, and Sylhet and ten organizations were found through snowballing methods. In the lists, there are 18 government organizations and 28 non-governmental organizations. Two organizations were not interested in being included and three were out of services. Twelve organizations were found through the registry of patient records. Inventory collected through e-mail, via phone call, and by visiting organizations were four, 19 and 23, respectively. After completing the collection of inventory, the number of organizations was up to 46 (government and non-governmental organizations were both included).

Three organizations – IPNA, child development centers (CDCs) and the Jatiyo Protibondhi Unnayan Foundation (JPUF i.e. the National Foundation for the Development of Disabled Persons) – are already established under the government, and many special schools and service centers have been established to provide the services under non-governmental or private sector. According to services listed at the government level, the disabilities that are most commonly represented are: Autism Spectrum Disorder, cerebral palsy, Down syndrome (18), and Attention Deficit Hyperactivity Disorder (17). All of the organizations offer speech and language therapy, occupational therapy, and physical therapy. In addition, early intervention programs, assessment, medical support and counseling are also provided by all these organizations. Seventeen of the organizations were using psychological support, sensory integration therapy, play therapy and behavior therapy. All of these organizations also maintain referral systems.

On the other hand, there was a concern that well-baby clinics are not available. No organizations were using telemedicine and vocational training, which is very important for autism and other NDDs. Dental and eye check-ups, residential facilities, transportation, parents' training, and ADL (activities of daily living) training are scarce and need to be increased. There are no home visit services.

According to 28 non-governmental organizations, 27 of 28 institutions work on autism, 21 institutions work on cerebral palsy and Down syndrome, 18 focus on speech delay, 11 on ADHD and sensory processing disorders, 17 on learning disability, 3 on child stroke and hearing disabilities, five on multiple disabilities, and one organization works with other disabilities. There are 23 institutions giving special and inclusive education, 24 institutions giving early intervention, 26 offering parental and family counseling, 27 individual counseling, 4 other counseling, and 17 giving psychological supports. There are 24 institutions doing assessment, 25 offering individual educational plans and goals, and one giving ambulant teacher service. Nine institutions are giving medical support, 21 are doing physical assessment, 14 have employment and pre-vocational opportunities, 15 provide vocational training, and 18 offer social and educational rehabilitation services.

Twenty-six institutions create activities of daily living plans, 26 give teachers/administrative training and work development skills, 28 give parents training, 23 give siblings and caregivers training, six offer telemedicine, 11 have individualized programs for children with NDD, and 24 have social integration programs. There are 25 institutions giving occupational therapy, as well as those giving physiotherapy (19), speech and language therapy (26), behavior therapy (22), cognitive therapy (16), sensory integration and music therapy (14), play therapy (21), dance therapy (16), group therapy for socialization (20), home visit services (23), and 19 have referral services. There are 18 institutions giving parents support and 11 institutions work on providing services for low-income children with disabilities. 20 institutions coordinate with other organizations, 17 are intensive learning enhancement programs, only seven institutes have focus groups and peer groups, 20 are arranging or conducting countrywide seminars and workshops, 18 are focused on mass awareness, nine give dental and eye check-ups, four give free clinics (outdoor), two offer day care, only one institution has residential facilities, and two give financial support for autism and neuro-developmental disorder in Bangladesh.

Discussion

In summary, most of the organizations evaluated are using multiple types of therapy, but mainly speech & language therapy comparative to other types of therapy.

Rehabilitation and vocational training centers should be creating more therapies and creating job postings for NDD professionals. Telemedicine and well-baby clinics at clinics or hospitals, as well as their referral systems, should be maintained properly. Home visit services should be included. Teacher/parent training and counseling/psychological support must be offered and implemented properly. Residential facilities should be included for children with NDDs in special schools.

Organization Categories

Organization Category	Dhaka	Chittagong	Sylhet	Total
Government	16	1	1	18
Non-government	23	2	3	28
Total	39	3	4	46

Table 5 Type of organization by category

Organization provides services by type of disability

Icddr,b has collected an inventory of 46 entities, both government and non-governmental organizations. Among them, 45 organizations provide autism services. When looking at organizations at the government level, mainly services for ASD, CP, Down syndrome and ADHD were found.

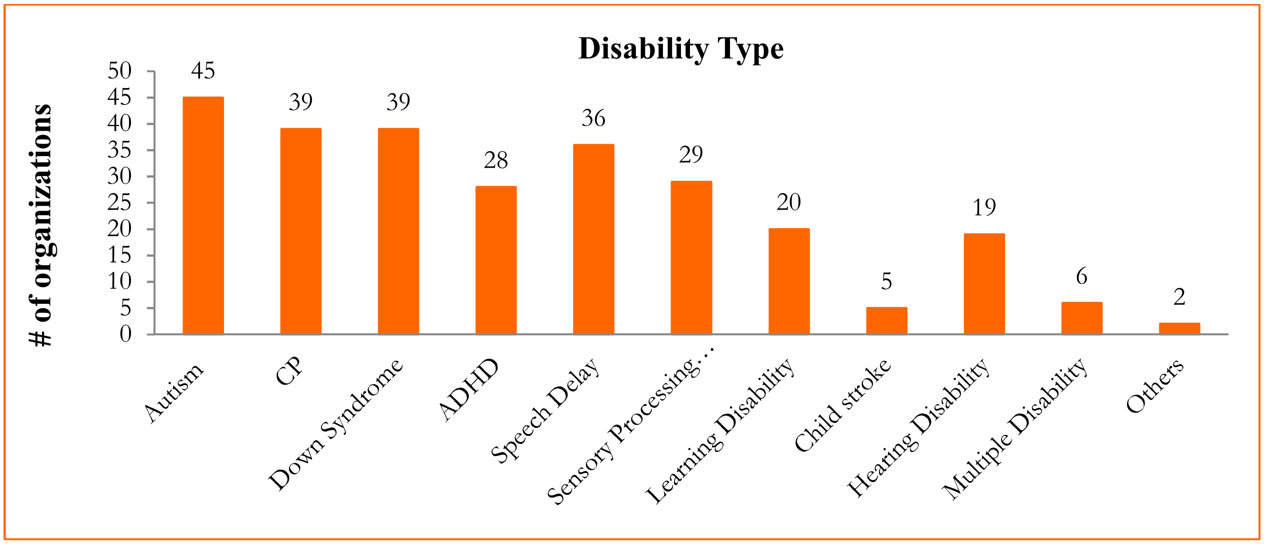


Figure 12 Number of Organizations by disability type

Current Services

The graph below shows that, among the 46 organizations in Bangladesh that provide services for autism and NDDs, 28 organizations provide special education, 25 provide inclusive education, but only 31 organizations provide training for capacity building.

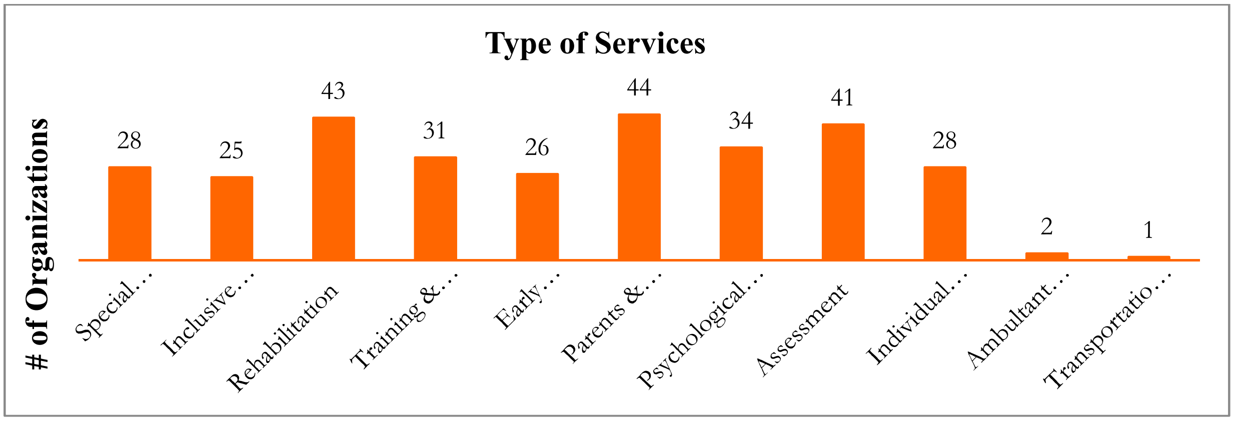


Figure 13 Number of organizations by type of services

Number of organizations that provide different types of rehabilitations

Of the 46 organizations, three (all in Sylhet) don’t offer any type of rehabilitation services. Among the 43 organizations that support rehabilitation, 16 organizations provide vocational services, which are very important for people on the autism spectrum and those with NDDs.

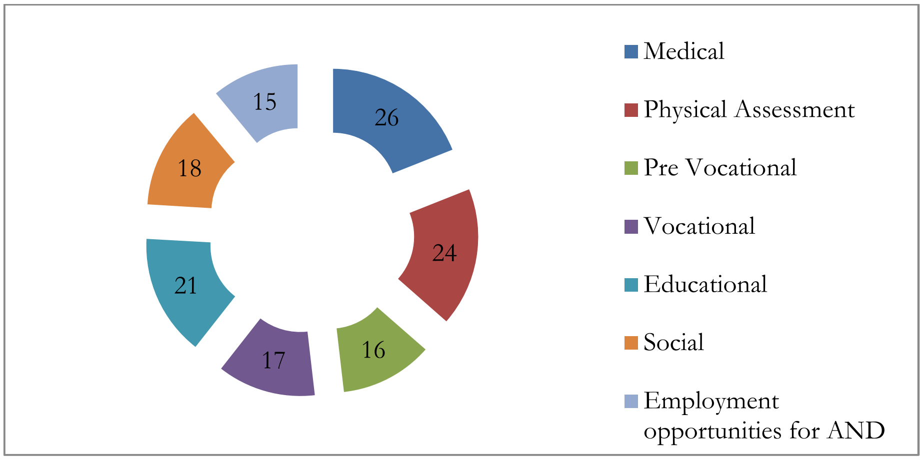


Figure 14 *Number of organizations by type of rehabilitation*

Training and Capacity Building

Among the 46 organizations in Bangladesh, only 31 provide different types of training for capacity building of parents, teachers, family members, or school staff. As the chart below shows, 31 organizations provide parents' training, but only six provide telemedicine, which is very important for people on the autism spectrum and those with NDDs.

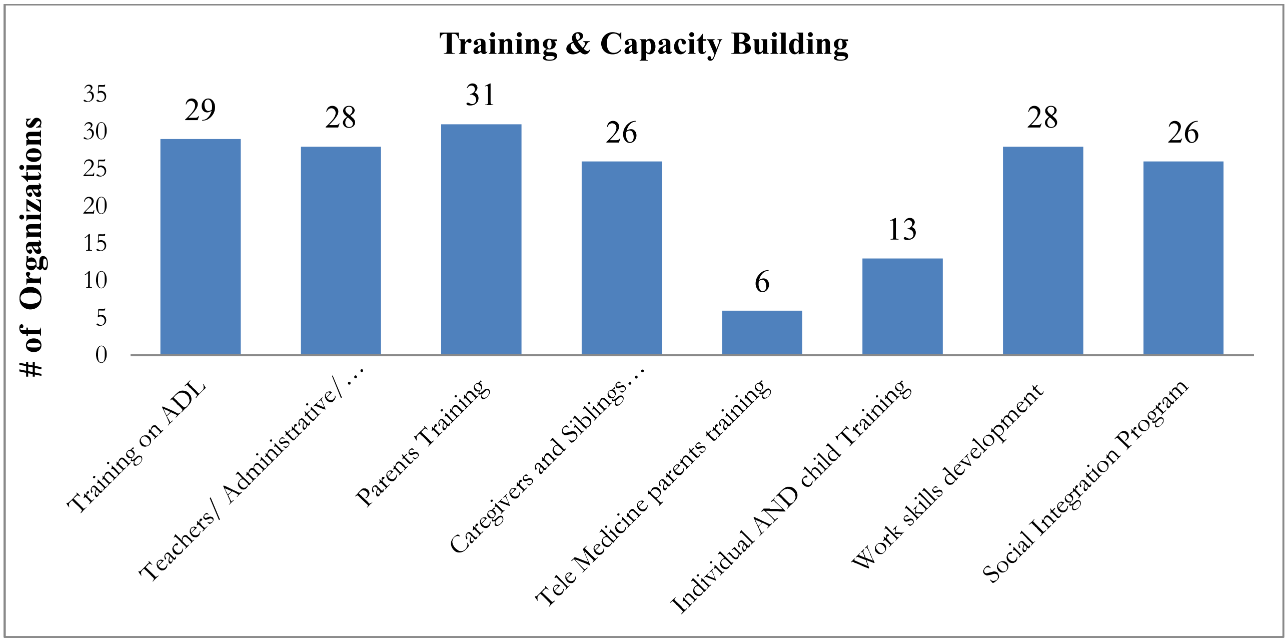


Figure 15 *Number of organizations by type of training*

Number of organizations that provide different types of therapeutic services

As the chart below shows, most of the organizations (44) provide speech and language therapy.

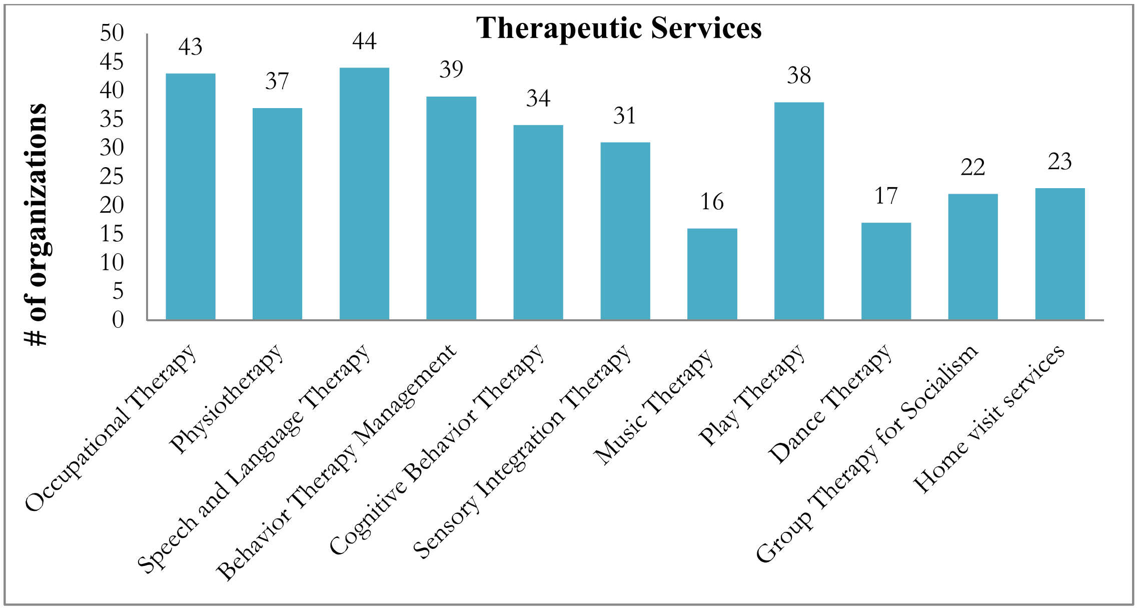


Figure 16 *Number of organizations by therapeutic services*

Discussion

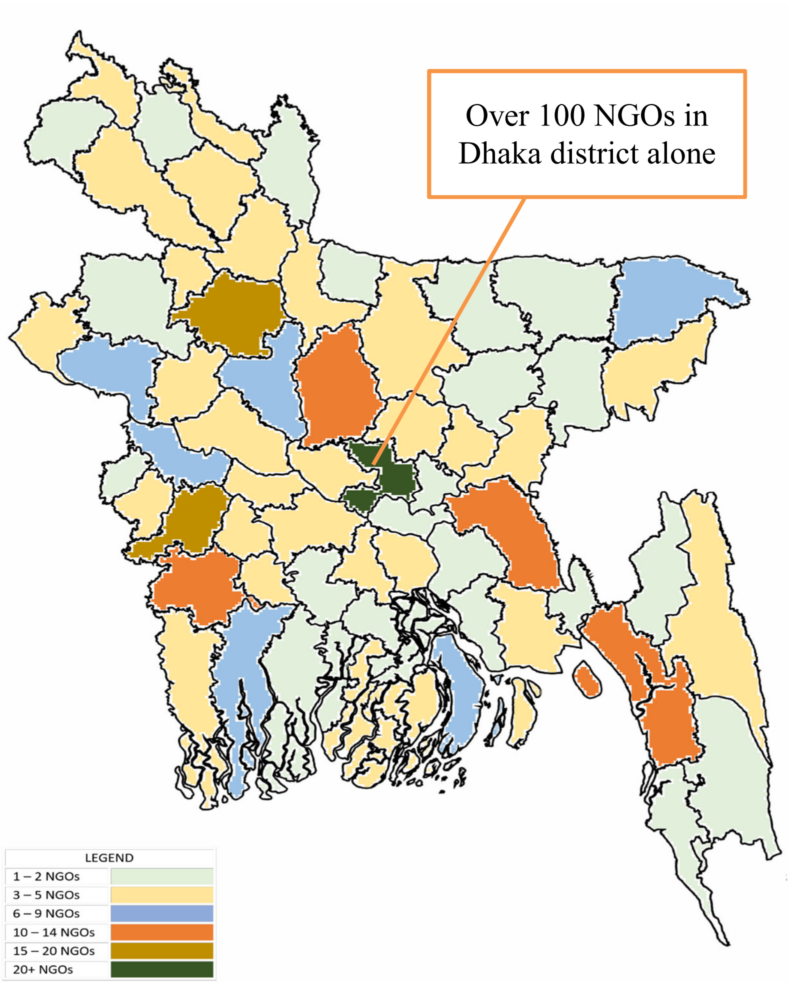
From the literature review, it was found that most of the literature was on disability in general, but very little of it focused on autism and NDDs in Bangladesh. The literature reviewed showed different disability populations and within multiple contexts in Bangladeshwhich lead inconsistent results. Some studies were conducted in solely in specific areas due to lack of resources which does not represent the entire population of Bangladesh. There were methodological differences represented in the diffrent findings. ;Limited articles were foundin addition ,most of the literature was comprised of review articles, none of which addressed prevalence of NDDs. So it is difficult to analyze the trend of prevalence of autism and NDD in Bangladesh. For the third objective, the most common challenges came out from parents' meetings in Dhaka , Sylhet, and Chittagong. Barriers mentioned at these meetings included inefficient tools to screen autistic and NDD children; lack of knowledge among parents, family members, relatives, social communities, and even clinicians, as well as unskilled care givers. Also, meeting attendees agreed that treatment, medication, transport, and education are too expensive, so that it is difficult for parents to bear all these costs. Another issue was duplication in services provision due to lack of coordination among different government and nongovernment sectors.

Inventory of civil society service providers and their services for persons with NDDs

At this time, there isn’t a complete database of all private service providers in Bangladesh. Various entities such as MoSW and the National Forum of Organizations Working with the Disabled (NFOWD – a local NGO) possess lists of only those NGOs registered with them. Nearly all of the major NGOs can be found in at least one of these two lists, but the smaller NGOs will almost certainly not be registered with either of them. A complete inventory of service providers therefore cannot be provided without a thorough nationwide census of organizations working with persons with NDDs.

Figure 17 below illustrates the distribution throughout the country of NGOs currently registered with NFOWD that work with PWDs. Although this is by no means indicative of the exact number and distribution of such organizations, it is presented here to show the unevenness of service provision from civil society throughout the country. Registration with NFOWD is fee-based; therefore, the kind of NGOs that register with it are mostly those that are well-established and have the resources to operate year after year. Given that autism is a politically favorable topic in Bangladesh, many of the NGOs that work with PWDs in general also claim to offer services for persons with NDDs, but in reality most do not. Some, however, do try to reach out to persons with NDDs to offer help, but most of those NGOs don’t have the setup or the qualified personnel to properly address NDD-specific needs.

Figure 17 – Nationwide distribution of NGOs that work for PWDs[82]



The lack of a complete national database will not, however, prevent the investigators from presenting a useful overview of services for persons with NDDs from civil society. That is because the investigators have had nearly five years of experience working directly with the major NGOs of Dhaka and Chittagong on a variety of awareness initiatives and policy development workshops. The investigators have also visited, over the years, a number of these NGOs and seen first-hand the scope of their services, their strengths and their weaknesses. From that experience, it can be reported that the major NGOs all share the following aspects:

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[82] List of registered NGOs by district acquired from NFOWD.

- They all work almost exclusively with children with NDDs (predominantly those with autism, cerebral palsy, Down syndrome, and intellectual disabilities);
- They are all essentially special schools/skill development centers;
- They are mostly run by parents/caregivers of children with NDDs;
- They are largely funded by a combination of donations from their members, donations from local philanthropists, and tuition fees;
- Most are based on rented premises;
- Most of their staff come from a variety of backgrounds (e.g., school teachers, physiotherapists, occupational therapists, etc.) that received on-the-job training so that they would be able to work with children with NDDs;
- Most of their efforts are focused on:
    - Raising awareness
    - Advocacy and lobbying
    - Parent and professional training
    - Sensory integration
    - Life skills training
    - Social skills training
    - Primary and secondary education
    - Vocational training and skill development

Below is a list of the typical services that a child with an NDD would receive at any of these established NGO special schools:

1) General Development Assessment (GDA) is performed (using tools such M-CHAT, ADOS, etc.) by a multidisciplinary team of psychologists, pediatricians, neurologists, physiotherapists, occupational therapists and special educators. However, no special school in Dhaka has all of these professionals together.
2) Based on the result from the GDA, an Individualized Education Program (IEP) is then developed by observing and interacting with the child for over a month and partially exposing him/her to different activities.
3) The child is paired up with a special teacher who conducts the child’s IEP as charted, carefully recording his/her progress in detail. The IEP is reviewed periodically in

order to measure the child's developmental progress. The IEP is then adjusted according to that progress.

4) Part of the IEP incudes a customized version of the National Curriculum for primary and secondary education. Children are taught at the rate that they are comfortable with and emphasis is placed on subjects that either intrigue them or wherein they display a unique aptitude.
5) Most of the special schools employ some basic to advanced sensory integration and other rehabilitation techniques and equipment to improve the children's senses and motor skills.
6) The children are engaged in a wide variety of activities ranging from art, handicrafts, music, gentle sports and games, drama, field trips, life skills exercises and socialization exercises.
7) Upon achieving a certain level of development, children are then given some rudimentary vocational training and skill development.
8) Finally, upon reaching their mid-to-late teens, the school either tries to mainstream the children into regular schools or tries to place them in jobs at companies with favorable, sensitized work environments.

Adequacy of existing services and supports for persons with NDDs

The aforementioned services encompass the bulk of services offered by the major NDD-centric NGOs that have successfully established a reputation for themselves in Bangladesh. The standard of these services vary from school to school depending on the capabilities and competence of the personnel they employ and the financial resources at their disposal. Some schools give emphasis on sensory integration and rehabilitation whilst others focus on vocational training and skill development. Other large NGOs such as the Centre for the Rehabilitation of the Paralysed (CRP), Center for Disability & Development (CDD) and BRAC have NDD-focused projects among the myriad of work that they do, some in large scale and others in small scale.

On November 3, 2015, Shuchona invited 22 prominent NGOs from Dhaka and Chittagong to a consultative workshop during which Shuchona solicited their opinions about potential NDD-focused projects in Bangladesh based on their own experience in working for children with NDDs. Another meeting was held on December 14, 2015 this time specifically with eight special schools based in Dhaka. The purpose of that meeting was to ascertain the current gaps they have in service delivery and the challenges they face in addressing those gaps. The feedback acquired from those two meetings plus the experience that Shuchona has in working with such organizations over the past few years have altogether allowed the investigators to present a list of issues pertaining to service delivery from civil society:

- The greatest strength of all of these NGOs is that they are nearly entirely parents-based organizations who have done tremendous work in creating awareness of NDDs in society.
- Funding is a perennial concern for nearly all of these NGOs, which greatly inhibits their ability to expand the scope of their services, to hire capable personnel and to acquire better equipment.
- Most of these special schools are set up on rented premises, which means that all the facilities are cramped and there is very little playing space for the children. Moreover, there is always the lingering fear that they would have to relocate to another premise if they cannot make rent. However, a few of the special schools such as SWAC and AWF are taking steps to move to their own facilities in a couple of years' time.
- It is very difficult for them to find qualified personnel to work at these schools as there aren't that many good professional courses available in Bangladesh that are capable of producing quality, job-ready special educators and therapists. It is their experience that most of the graduates from local special education programs lack the necessary tools and sensitivity for working with children with ASD and other NDDs. Therefore, all of these schools invariably have to train their own staff to be able to work with such children.

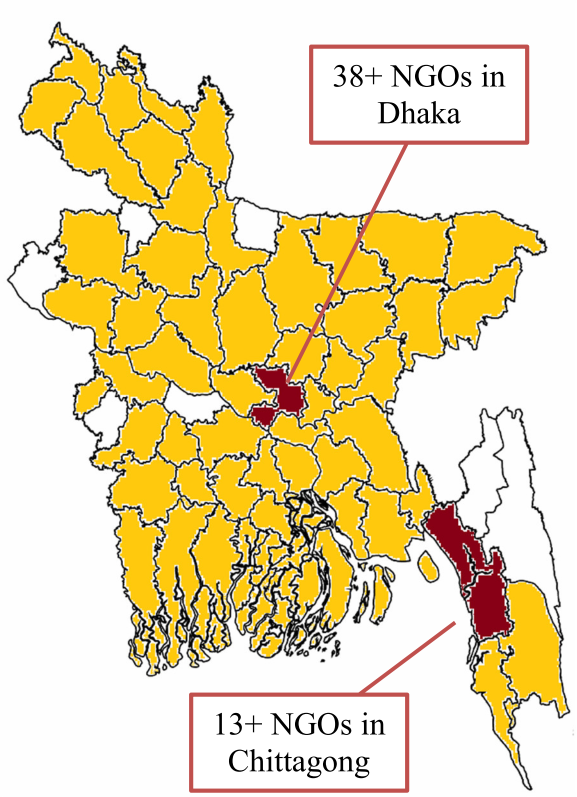

Figure 18 – Presence of NGOs specializing in NDDs in Bangladesh

- The vocational training and skill development activities at most of these schools are limited to some rudimentary activities such as handicraft work, needle work, block printing, some basic computer skills, etc. None of these skills would help youth with NDDs hold respectable jobs to sustain themselves when they get older.
- Despite having limited resources, these special schools have indeed been able to generate significant development within the children they work with. This shows that these organizations know what they are doing but are unable to expand on the scope of their services due to the aforementioned limitations in resources.
- Because most of these NGO special schools are dependent on tuition fees, most of the children they attend to come from middle and upper class families. While many of them have done activities to aid children with NDDs from poorer families, the underprivileged remain largely without service.

Figure 18 illustrates that 55 out of the 64 districts of Bangladesh each have anywhere between one and five well-established NGO special schools that cater specifically to children with NDDs. While this distribution is impressive, it should be noted that the Society for the Welfare of the Intellectually Disabled (SWID) – probably the oldest NGO working for persons with NDDs in Bangladesh – operates over 80 special schools alone, thus accounting for more than 60% of the special schools represented by Figure 18. This figure also illustrates, as did Figure 17, the lopsided concentration of NGOs in Dhaka, and to a lesser degree, in Chittagong.

Assessment of Services

The following information defines the support and services holistically from medical, social, rehabilitative, and academic perspectives. Furthermore, supports and services from the Ministry of Health, the Ministry of Social Welfare, the Ministry of Local Government and Rural Development, the Ministry of Education, the Ministry of Primary and Mass Education and the Ministry of Women and Childs Affairs have been included.

Methodology

A workshop was held on 26th January, 2016 in BRAC Centre INN, Dhaka, Bangladesh with the expert working group consists of policy makers (the ministries mentioned above), clinical experts (psychiatrist, pediatricians, neurologists, academics, institutional managers, and social workers) organized by icddr,b. List of stakeholders was recommended by the Director General of Health Services (DGHS). To attend the meeting, selected expert working groups has been invited through e-mail, invitation card, and confirmed by phone call. A total of 25 experts who are well known to their profession participated in the meeting. Four teams were formulated based on five different perspectives: medical, social, rehabilitative, academic and policy. Every team had 5 to 6 members to discuss the selected thematic areas in a brainstorming session. In addition, one moderator and two note takers supported each group. The entire session was recorded through consent of stakeholders. Another meeting was held in Sylhet division. Six clinical experts shared their views guided by selected thematic area. The purpose of this meeting was to identify the existing situation, describe the priority of problem and recommendations on NDDs in Bangladesh. The meeting was organized with different groups of experts sharing same platform, discussing preliminary findings and recommendations in order to achieve the objective.

Supports and Services from the Medical Perspective

The expert working group identified a few current situations that helped support children with NDDs. First, some pediatricians received special training to diagnose and treat autism and NDDs cases. Second, most pediatricians can preliminarily diagnose NDDs.

Finally, the Ministry of Health and Social Welfare conducted a survey on disability through a joint venture which identified persons with disability by census. It has since been discontinued.

There are current challenge and gaps that have been acknowledged by the expert working group. Largely, there are inadequate skilled human resources and logistic supports for care of people with NDDs, including autism. This could be due to a lack of specific curriculum on disability in medical education. There are many kinds of special services; however, most are only available centrally in the city and not easily accessible. In addition, the costs of services are high and unaffordable for many families. Correspondingly, services are not being sought out at the proper time due to lack of awareness and social stigma about NDDs. There is a poor referral system and coordination among all kind of medical services for NDDs is absent. There is a lack of proper maintenance of patients' records in some organizations and facilities, partially because there is no centralized database containing patients' records. The basic health infrastructures are poor.

Based on the above challenges and gaps, some recommendations were identified by the expert working group. Creating community awareness so that parents seek care at an appropriate time is one of the first steps. A basic training for pediatricians should be mandatory to increase the correct identification of NDDs in the preliminary stage; this would include appropriate training for the related disciplines personnel working on the ground level. To ensure quality of services and personnel, a monitoring and evaluation system should be put in place. Furthermore, a standard screening and diagnostic tool should be developed to facilitate the identification of autism and NDDs such as the Rapid Neuro Developmental Assessment (RNDA). This should be incorporated with different EPI schedule starting from 9 months both in urban and periphery. After diagnosis, parental counseling should be offered addressing the co morbid condition and follow up services. An appropriate and strong referral linkage should be introduced through all levels of the health system. Similarly, capacity building of all the medical personnel from every tier of the health system would assist in creating a proper referral system. Once a patient if refereed, there need to be a central data pool for registry of individual patients profiles countrywide. Strengthening of the existing infrastructure needs to ensue to ensure proper functioning of the health system services for NDD services. Relatedly, strengthening the infrastructure and capacity of Shishu Bikash Kendra and establishment of the new branches will assist to cover hard to reach areas.

Supports and Services from the Social and Rehabilitative Perspectives

Existing opportunities:

There is an array of services in country such as community health clinics, schools for children with AND, and training centers. Considerable training is being provided for staff at training centers and some organizations are conducting training for parents. Additionally, private organizations are beginning to offer rehabilitation services for individuals with physical disabilities.

The Ministry of Social Welfare is supporting 103 centers in 64 districts and 39 upazilas. A new community based service delivery model is the use of mobile vans, which are being deployed in 20 districts. Services are given to individuals with a variety of disabilities including autism. A variety of professionals such as physiotherapists, occupational therapists and speech therapists staff the mobile vans. An audiologist and an optometrist were assigned to children with disabilities.

Challenges/ Gaps:

Within the country, there are challenges that hinder service provision and the rehabilitation of those with NDD. Primarily among these are a delay or absence in detecting the disability and providing an accurate diagnosis early in the child’s life. A contributing factor is the lack of awareness and knowledge about NDD by family members and the community at large.

Services exist in some areas but not in others. When they do exist, the services are sporadic and not comprehensive. For example, there may be a community health clinic but the community does not have access to a speech and language therapist and NDD rehabilitation only includes daily activities and does not include providing specific therapies according to what a child or adult actually needs.

Lack of awareness is a contributing factor to services being underutilized. Conversely, when the benefits of services are realized, the demand for them exceeds the capacity to provide them, as there are not enough professionals or para- professionals available to deliver services. Low pay scales are one reason why there is a personnel shortage and if the pay scales are not adjusted for experience and competence, there will be continuing problems in attracting individuals to pursue occupations in the NDD field.

Contributing to the service delivery challenges are funding shortfalls or a comprehensive and coordinated mechanism for establishing costs and funding services across ministries. As identified in other areas of this analysis, establishing a data collection system is a priority. Such a system will identify who needs services, the location where the services are needed, categories of services and projected costs. Once a data collection system is in place, the government will be able to monitor costs and make better decisions about efficiency and effectiveness in service delivery. Currently, many services are very expensive which may be due to the scarcity of service providers and when services are delivered, there is a premium for receiving them.

Disparities exist between services in rural and urban areas, with the urban areas benefitting more from the available services.

Finally, practices for referring individuals for services are not uniform across the country.

Recommendations

The ministries should develop a coordinated plan for screening, diagnosing, and providing services. Included in this plan is to assign priority for services using a triaged approach. The plans should be tailored for rural and urban areas and be respectful of the differences in these including the availability of resources and services. A coordinated plan would define the specific roles of the ministries in identification, treatment and rehabilitation. It would also describe how the individual efforts in each of the ministries (MOHFW, MSW, and MOF) are unique, not duplicative, yet linked to one another. Each ministry will develop a budget for these planned activities and adjust it annually. Ministry policies will be better informed if data drives the design. Developing a centralized data collection system will be essential for quality planning and implementing the plan's goals and objectives and fiscal analysis and budgeting.

Communities can provide support to individuals and families if they are provided with awareness and knowledge about NDD. Information should emphasize how people with NDD should be included within the family and community and the importance of education and rehabilitation in a person's life. Additional information should be provided to families to help them in determining whether their child has an NDD by understanding developmental milestones.

Qualifications should be established for each profession including educational requirements, licensing, and continuing education. There should be policies and procedures developed for managing, training, and evaluating personnel.

The role of the business community should include providing charitable donations to schools and rehabilitation centers, creating jobs for people with NDD, and promoting the inclusion of people with NDD within their local communities.

Poor families should be provided with funds to help them care for their family member. The Jakat fund can be used for this purpose.

Supports and services from academic perspectives

Existing opportunities:

Special schools and training centers are increasing in numbers as teachers and more individuals are becoming aware of the educational and rehabilitation needs of people with NDD.

Challenges/Gaps

There is not uniformity among these in the types of curriculum or services being offered. For example, not all students are receiving an IEP, not all individuals are learning activities for daily living, not all schools are conducting home visits, classrooms are set up differently, and needs assessments vary among the schools and providers. Some schools offer training to staff and parents and others do not. Many teachers are not properly trained about autism and NDD.

The cost of services is high. Private schools rely upon private fund raising in addition to charging a tuition fee. There is a scarcity of professional therapists who can deliver OT, SLT and PT and students may not be able to access comprehensive services as a result.

Other challenges related to services are:

- There are no rehabilitation services for older people with NDDs.
- There is a lack of hostel/residential facilities
- There are no processes in place for monitoring and evaluating the performance of schools and providers
- There are no processes for pricing and financing services.
- There is no data collection system for measuring educational attainment, rehabilitation interventions, and outcomes

Families

Families should be offered awareness, education and services to help them care for and support their child with NDD. Physicians and health clinics should counsel women about pre-natal care and developmental milestones.

To increase the capacity of families to recognize NDD and provide services to their children, the country should train a cadre of parental master trainers who can train other parents as secondary trainers.

- ➢ Continuous support should be given for Autism and NDDs /Sodor hospital counselor/psychologists could be of good help

Institutions

- ➢ Ensuring better education for individuals with autism and NDDs
- ➢ Ensuring better services with a standard infrastructure for individual organization

- Teacher and parental training should be ensured in every institute
- Minimum standard should be set for each type of institutions
- A monitoring cell should review and evaluate the quality of the services and organizations
- Maintaining such referral system where schools will be also considered as part of the system
- Mainstream schools/institutes should be flexible enough to accommodate Autism and NDDs children based on their functional level
- Services should be given from a total lifespan-based approach

Government

Ministries should coordinate their public awareness campaigns to reduce duplication. Media campaigns should use a variety of media including print and electronic media.

Credentials should be established for teachers of students with NDD. Teachers should be taught using a competency-based curriculum, and public and private schools should follow the same curriculum.

Special schools should be accessible to those from all economic classes. Residential and non-residential schools should be expanded in rural and remote areas; these can be part of a government primary or secondary school.

The curriculum in secondary schools should include vocational training, work experiences and internships in trades or professions that exist within their communities. These training opportunities will be effective for preparing individuals for employment once they exit secondary school.

Supports and Services from the Ministry Perspective

Ministry of Health and Family Welfare

The Ministry of Health and Family Welfare（MoHFW）mentioned the wide range of opportunities. In national level, 14 ministries of the government formulated a strategic and convergent action plan for autism and NDD in

Bangladesh. The national steering committee, under the guidance of the chairperson of the national advisory committee, previously sat in once every two months and monitored the activities of the 14 ministries to ensure that the policies are being implemented properly, including on the root level, by the secretary of the MoHFW.

In addition, the MoHFW provides basic training on autism and NDDs to all doctors from multiple tiers of the health system, including doctors of upazila health complexes, nurses, community health workers, and training in community-based clinics. The other benefit is raising community awareness through the celebration of world autism day by joint co-operation with ministry of social welfare. In addition, using IEC behavioral change communication (BCC) materials such as posters and published booklets (thus far, four booklets have been published). To monitor and ensure quality of services, the ministry needs to conduct more studies/research from community level to tertiary level with the Autism Cell. Under the leadership of MoHFW, Institute of Pediatric Neuro disorder & Autism (IPNA), BSMMU and sishu bikash clinic in a tertiary care hospital have developed a database of services and a referral system.

The MoHFW also named current challenges and gaps that they are facing. The policies from the government are not yet being implemented properly. Similarly, there is no monitoring and evaluation system. There is also a lack of screening tools to identify autism and NDDs, as well as lack of early identification and intervention in rural area are of problems that exist in Bangladesh.

Based on necessities and needs in Bangladesh, MoHFW recommended following issues: It is necessary to establish a coordinated integration and evaluation system under the umbrella of the national steering committee by secretary ministry of health system. Furthermore, there is a need to develop the screening tool for identification of children with Autism and NDDs in the grass root level, community level with the integration of five ministries – Ministry of Health and Family Welfare (MoHFW), Ministry of Social Welfare (MoSW), Ministry of Primary and Secondary Education (MPSE), Ministry of Women and Child Affairs (MOWCA), and Ministry of Local Government and Rural Development (MLGRD). Also, early identification and intervention in the rural areas, educating parents in urban and rural areas, linking integration of service delivery, monitoring health and progress of the children with NDDs, and developing abovementioned challenges of government services particularly in community clinic, child development center, women and children affair clinic (sishu bikash clinic) and tertiary hospital. Lastly, developing database system in different tiers of health, education, and training centers would be beneficial.

Ministry of Social Welfare

There are different types of benefits provided by Ministry of Social Welfare (MoSW). The custodian of NDDs Trust Board started functioning in July 2014, by which rules have been formulated. The board holds an orientation to services with the help of director general health service (DGHS) and considers short, medium and long term future plan for services. In addition, the district committees formed in 64 districts in Bangladesh, have been developed. The monitoring system was established including Jatio Unnayan Protibandhi

Foundation (JPUF) for district level and upazila level. MoSW gives the orientation and training to provide one stop medical service to Autism and NDDs people to all the hospital in Bangladesh, providing special care of all kind of health services and considering the needs of these people without any delay as a special prevailed person. Moreover, social protection has been disseminated at Autism and NDDs trust rules and laws and financial stipend is under process in primary, secondary and higher secondary level.

Regarding JPUF, two policies in form of law and rules exist which have been formulated of law 2013 and rules 2015, one in general and another particularly on NDDs. Also, there are a number of services includes: introducing scholarship for student with different disabilities, allowance for poor parents, introducing mobile therapy (i.e., van services) as well as awareness programs (i.e., fairs, workshops, training for capacity building and training for parents of children with autism). There are disability specialists, automatic reporting systems, and a third-party evaluation system in JPUF, as well.

However, additional challenges could be mentioned, such as lack of satisfaction with existing Autism and NDDs services (adequacy/affordability/accessibility is not enough, lack of funding, lack of quality workers, low quality of services), as well as the need for a proper diagnosis system and technical assistance for “seba shahajjo kindra” in terms of logistics and technical support.

The ministry recommends increasing integration and coordination with other ministries without any duplication of the services. Access to more funds also would be beneficial.

Ministry of LGRD

The Ministry of Local Government, Rural Development and Cooperatives (LGRD) reported that they have developed a five year action plan for NDDs and will incorporate autism and NDDs into the sectors of education, health, and family planning at both the Union Parishad level and the Upazila Parishad level. In addition, the Ministry of LGRD has incorporating autism in the health committee in City Corporation and has established a Health Affair Committee. Local representatives also celebrated World Autism Awareness Day on 5 April. Capacity-building activities were also provided within the urban primary health program where training was provided to doctors and local level representatives and officials. Challenges noted by the Ministry of LGRD included no funding allocations and the lack of an awareness-raising program.

The Ministry of LGRD recommended that capacity-building continue for doctors of the sub-district (upazila) health complex, the specialized doctors at the Division level, doctor training programs such as BSMMU, and the establishment of a special NDD cell at each Union Parishad. The Ministry also would be open and recommends more established cooperation between ministries and through an NDD trust board with representatives from the Institute for Pediatric Neurodisorder & Autism **(**IPNA) and MIAH.

Ministry of Education

The Ministry of Education has established a special monitoring cell for NDDs related to schools, provided increased skill development for therapists and teachers, and developed a curriculum for doctors related to NDDs. From a policy perspective, the Ministry of Education has developed a shared ownership and understanding of NDD as a mainstream education issue. They are working diligently to create awareness of persons with NDDs and foster an autism-friendly environment. In addition, the Ministry of Education is strengthening its inclusive education program to provide the necessary education to students with NDDs in alignment with the 2010 National Policy.

Ministry of Women and Child Affairs

The Ministry of Women and Child Affairs has undertaken several initiatives related to NDDs in collaboration with development partners. They have established a monitoring cell and are focusing their efforts on awareness, enabling environments, early screening and intervention, prevention of disability through programs to stop early marriage, and trainings. The Ministry has begun the process of establishing an early screening program in collaboration with the MOHFW (including the integration of early screening issues within the early learning development standards). They are mainstreaming children with autism into Early Childhood Learning Centers to increase enrollment at the preprimary level. They are raising-awareness of NDDs among members and developing a peer leader (Kishoree) club with parents, family members, and society. Lastly, their field-level officials will participate in the training primary care and awareness-building program on autism conducted by Global Autism BD.

7 ASSESSMENT OF PREPAREDNESS

7.1 General impact

When one considers the fact that in this region, disability is a low-priority area, and that all disability-rehabilitation issues are the sole mandate of MoSW; and, that the role of the health sector is confined only to preventive and curative measures (even that is largely with physical, mental and sensory disabilities); compounded further by the complexity and invisibility of ASD and NDDs in the professional and public domain – then one must conclude that this NDD initiative in Bangladesh, with 14 Ministries on board, has achieved substantial success in the last four years. While it is true that much more remains to be done in terms of adequacy, quality and monitoring, it is also critical to document and acknowledge the integrity of the very intent of multi-sectoral convergence, desired by many countries but not achieved by too many. Given below, are the highlights of the action taken so far, by each of the five key Ministries. Reports on the activities of other member-Ministries of NSCAND are also given, but briefly.

1) Each of the 14 Ministries have each been executing a five-year convergent action plan that are based on the SCAPAND but is far more detailed.
2) All 14 member-Ministries have focal points on NDDs at Joint Secretary/Additional Secretary level.
3) To ensure uniformity of public understanding, IEC material on NDDs is being prepared by the Ministries in conjunction with external parties for use by all Ministries. They are also developing a massive celebrity-led awareness campaign, with celebrities selected from various sectors including sports, performing arts (film and television) and fine arts. Following vetting by the TGC, the TV spots will be broadcast by Bangladesh TV channels, and used at grassroots level by field workers of all Ministries for community awareness.
4) To ensure maximization of resource-utilization by the member-Ministries, a resource-mapping exercise of the 14 Ministries is currently being undertaken. This will further strengthen convergence and cross-sharing of available resources, both material and human. Shuchona has prepared its own version of the resource mapping, which is presented in Chapter 11 of this report.
5) To ensure uniformity in screening and identification of NDDs by the field workers of NSCAND members, a common screening and identification tool is being developed by TGC.

Aside from the general impacts, this report will also present the impact of individual Ministries.

7.2 Impact of the Ministry of Health & Family Welfare

Background

The Ministry of Health & Family Welfare has the dual responsibility of delivering health services to the people of Bangladesh as well managing family and population related affairs. Their prime objective is to improve the productivity of the people by reducing health-related burdens and suffering and achieving higher levels of nutrition, early childhood development and immunity to diseases. Because of its massive infrastructure and abundance of human and material resources, GoB decided to embed the national agenda to address autism and NDDs in MoHFW and thus made it the lead Ministry in NSCAND

Service provision for persons with NDDs

1) An Autism Cell was set up to coordinate inter-ministerial activity, which is unique in this region where disability matters are routinely dealt with by MoSW and only the prevention aspects are dealt with by the MoHFW.
2) All 14 government medical college hospitals have wings for disabled children that are staffed by a multidisciplinary team that includes pediatricians, psychologists and physiotherapists.
3) Researchers at Dhaka Shishu Hospital have developed and extensively field-tested a Rapid Neurodevelopmental Assessment tool.
4) Discussions on NDDs are held annually at all 17 government medical colleges during World Autism Awareness Day (WAAD), followed by Q&A sessions.
5) MoHFW hired ICI to update the *Situation Analysis of Autism & NDDs in Bangladesh*.
6) Figure 9 presents the types of key healthcare facilities under MoHFW where screening and detection of NDDs could be done. This setup was planned in 2012 but is yet to be comprehensively implemented.

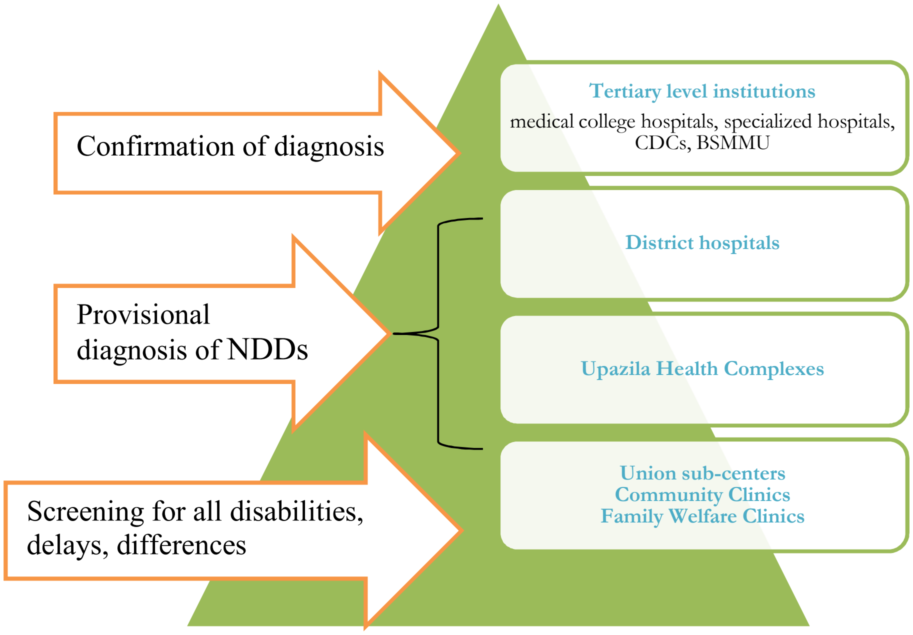

Figure 19 – Pyramid of key health facilities under MoHFW

7) In June 2015, MoHFW in collaboration with WHO's Department of Mental Health and Substance Abuse and several other countries, organized a side-event entitled *"From resolution to action"* during the 68th WHA in Geneva.
8) Table 6 presents a list of the various types of service providers and other stakeholders that IPNA trained during 2010-2015:

Table 6 – List of types of service providers and other stakeholders that have received training on NDDs from IPNA since 2010

Participants	Nos.
Doctors, therapists, psychologists, special educators	1,980
Parents/caregivers, educators, therapists	600
Doctors from various upazilas	400
Psychology students	80
Health workers, field workers, local Leaders	400
Special school teachers with minimum two years of experience	65

Participants	Nos.
Doctors from various district hospitals and UHCs	200
Medical professionals, paramedics, medical students, therapists, special school teachers, regular school teachers, social workers	200
Students of Dhaka University's Dept. of Education & Counseling Psychology	68
Select pediatricians, neurologists, psychologists, psychology students	76
Doctors from various government hospitals and clinics	60
Master Trainers from BRAC Education's Health Department	30
Consultant physiotherapists from JPUF	20
Teachers from various special schools	20
Neurologists, pediatricians, psychiatrists, psychologists, therapists, parents of PWDs	40
Physiotherapist, occupational therapist	25
Physicians from Dhaka South City Corporation	30
Training for medical officers from 472 UHCs for MoSW's Disability Detection Survey	472

9) Figure 20 presents the numbers of cases of NDDs diagnosed at IPNA since 2014:[83]

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[83] No diagnostic data prior to 2014 was supplied to Shuchona by IPNA.

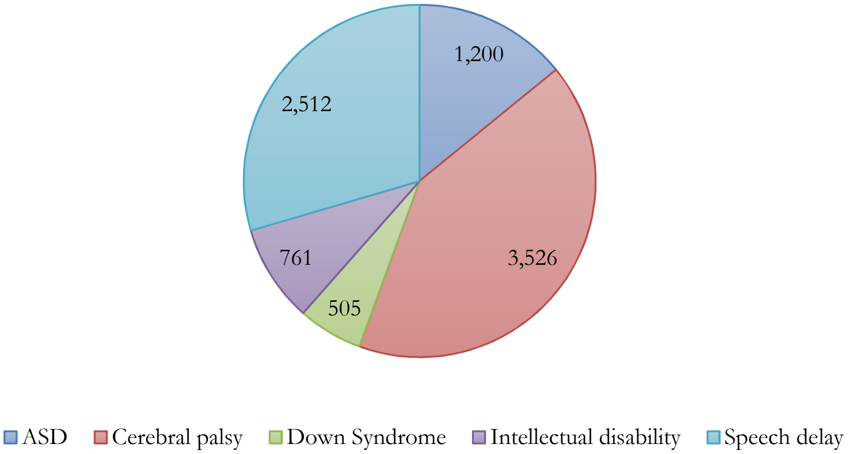

Figure 1 – Cases of NDDs diagnosed at IPNA since 2014

10) Figure 21 presents the age distribution of children with NDDs visiting the CDCs set up at the 15 medical college hospitals:

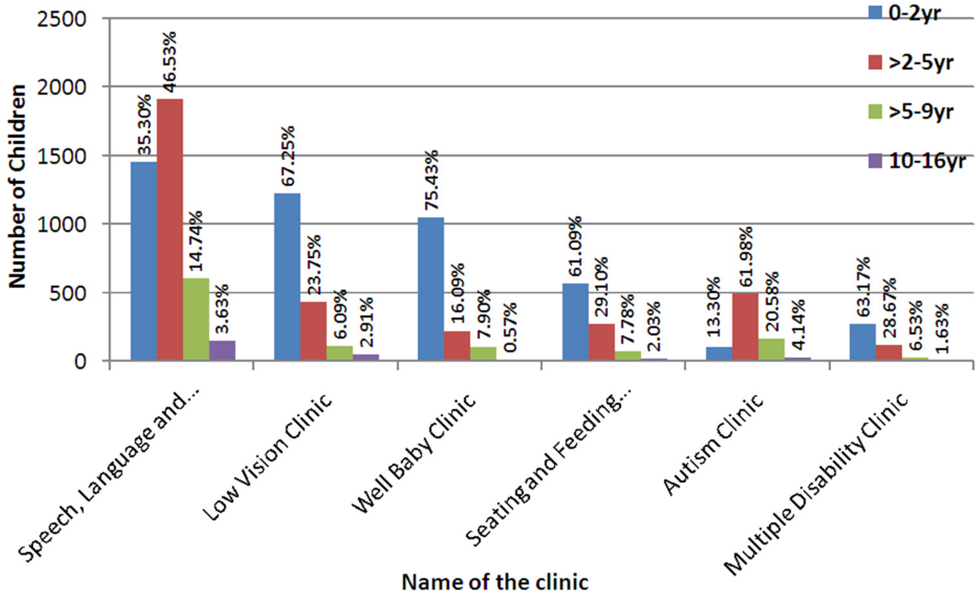

Figure 2 – Age distribution of children with NDDs attending MoHFW's CDCs

11) The National Institute of Mental Health & Research (NIMH&R) hospital specializes in psychiatric care for all ages, including community and social psychiatry. It also provides psychotherapy and some occupational therapy

services. The Child, Adolescent & Family Psychiatry department hosts a "child guidance clinic" twice a week (Mondays and Thursdays), during which the following services are delivered to clients with ASD and NDDs:

- Screening (using tools such as M-CHAT, AQ10, TQP, etc.)
- Outpatient and inpatient care
- Occupational therapy and other rehabilitative care
- Counseling for parents
- Dissemination of free guidebooks

12) The National Institute of Neurosciences (NINS) is the first hospital specializing in neurological care. It is equipped with advanced radiology and imaging equipment. A specialized outdoor department for receiving cases of epilepsy, neurodegenerative and neuro-metabolic disorders of children, as well as for the rehabilitation of children with ASD and counseling services. It also has a world-class neuro-rehabilitation equipped with modern physiotherapy instruments. Although it is equipped to handle cases of ASD and perhaps other NDDs, there hasn't been significant advertisement of this capacity to the general public, not in comparison to the other services it provides. This is illustrated by the fact that since May 2012, NINS has served only 101 clients with ASD, 849 with CP, 460 with ADHD and 1652 with other NDDs and mental health problems.

Table 7 below presents a summary of the activities that MoHFW planned to undertake as per their 2012 action plan and their corresponding implementation status.

Table 7 – Summary of the status of specific activities that MoHFW planned for since 2012

SPECIFIC ACTIVITIES	IMPLEMENTATION STATUS

To enhance the capacity of health service providers at different levels	
Training of doctors, nurses and other health service providers on autism	The following service providers were trained from Jul 2012 – Jun 2015: 7,775 HI, AHI and HA 1,500 SACMO and nurses 138 doctors
Inclusion of SCAPAND in three operational plans (IST, NCDC, and ESD)	Most of the activities expressed in SCAPAND have been incorporated in those three operation plans.
Setup of a sub-committee on capacity building (MoHFW and BSMMU-IPNA)	Sub-committee on capacity building had been formed to prepare strategic plan, training modules and guidelines.
Training of doctors (40 batches), nurses (100 batches) and field workers (3000 batches)	300 doctors trained in 10 batches.
To increase mass awareness among parents, relatives and community volunteers	
Development of mass awareness through health education, advertisements, IEC materials, *uthan boithok* etc.	Mass awareness drives have been conducted through health education, IEC materials, meetings, workshops, seminars etc., but data on these drives are either not available or not provided.
Development of IEC materials, training modules and family guide book	IEC materials were developed in 2014-15: - Autism booklet - Assessment policy booklet - “What are ASD?” booklet - “How to achieve general behavioral development in persons with autism” booklet - posters on autism No family guide book has been developed as of yet.
Celebration of WAAD	WAAD is celebrated each year throughout the country jointly with MoSW. “Light It Up Blue” done throughout the country at Zila and Upazila level.
Sensitization of the whole nation on autism with the help of MoI	Sensitization underway in collaboration with MoI. TV spots and documentary are being produced and will be completed in 2016.
Screening of all children for autism and developmental disabilities and introduction of the autism registry	
Training of Health & Family Planning field workers, paramedics and doctors in screening, assessment, diagnosis and identification of high-risk factors	Primary training for some of these have been given but this will be implemented in larger scale after the final protocol has been developed. Protocol is under finalization.

Inclusion of screening/assessment/diagnosis for autism and NDDs under the regular duties of field workers, nurses and doctors at different levels of MoHFW	DGHS has setup a sub-committee to develop a training module and primary screening tool for the national health care system.
Training of field workers in providing home-based care during routine home visits	Trainings will be given in 2016-2017
Family counseling	Counseling done on a routine basis but it needs strengthening.
Development of a strong bi-directional referral chain between the grassroots-level workers, parents and the secondary and tertiary care providers for proper reporting of the feedback on services.	Process has been initiated.
Setup of surveillance systems for high-risk pregnancies as well as tracking of high-risk babies	Surveillance and tracking systems not yet set up.
Inclusion of children with disabilities in family clinics/child guidance clinics	It will be done in 2016-2017.
To gradually understand the use of low-cost assistive devices	This project is being done by MoSW instead.
Development and use of self- surveillance tools for all first-time parents	Process has been initiated and will be done by DGHS in collaboration with TGC in 2016-17
To train/counsel/support parents of children with autism in home-based management and rudimentary therapeutic interventions through home-plus-hospital based services	TOTs being done followed by training of parents in 2016-17.
Special service development and implement for autism	
Set up of a disability section in each medical college hospital with special focus on NDDS;	Circulars issued to all Government hospitals to establish separate in-house autism units or, if that is not feasible, then to make establish fast-track service for persons with disabilities. One 30-bed specialized ward for persons with NDDs currently being set up at IPNA and will be completed in 2016.
Inclusion of ASD-related services at the telemedicine clinics	Instructions have been issued to the existing 44 telemedicine clinics to include ASD-related services in 2016-2017.
Research and Development	
National-level epidemiological studies of autism and development of NDD registries in hospitals	Survey on autism and NDDs in Bangladesh jointly conducted by DGHS (NCDC), MoHFW (RCHCIB) and BMRC in 2013. Databank on autism and NDD cases

	attended to at the 15 CDCs has been developed, being maintained and is available online.
Incorporation of ASD in MBBS Curriculum	
	Research revealed that the current MBBS curriculum allocates 2 course-hours (under the Psychiatry module) to child psychiatric disorders including autism, wherein the students learn about the causes, early identification management and counseling of persons with ASD.[84]
Collaboration with other Ministries	
	NSCAND began with eight members and later expanded to 22 members (see Appendix 13) to enhance collaboration. Till today 12 meetings of NSCAND have been held.

MoHFW's plans for the immediate future include strengthening of the Autism Cell expanding training of health-related staff and using the TGC-recommended screening tools at the community level.

Adequacy of services

Through its specialized facilities – namely IPNA and the 15 CDCs – good-quality multi-disciplinary services are being provided for children with NDDs, but the intake capacity for multiple interventions is limited as is their coverage throughout the country. These centers do not provide assistive devices either. Referral systems are weak and IPNA is based in Dhaka (without any other branches); therefore, access is limited for parents from rural and remote areas. There aren't enough trained professionals to adequately cover the needs of all CWDs in Bangladesh in the health, education and early childhood sectors.

Role and preparedness of MoHFW

The role of the health sector is crucial in prevention, promotion, medical treatment and rehabilitation of PWDs. The MoHFW has a specific role in screening, early detection, proper diagnosis and evidence-based community-centered early

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[84] Medicine & Allied Subjects. Retrieved from: bmdc.org.bd/mbbs-curriculum-update-2012/

intervention through their various health centers. In terms of preparedness for NDD-inclusion, they have expended time, money and effort in training, developing training materials, and awareness creation. However, training in specific use of tools, and in identification of disabilities at the community level, based on the dovetailing approach, has had limited impact so far. They are now ready to implement this part of their mandate.

Specific recommendations for MoHFW

1) To develop greater clarity of their specific role as coordinators of the Action Plan (a daunting task, to say the least), the staff of the Autism Cell need sensitization on NDDs, including visits to well-established, successful inclusive services and schools in Bangladesh, as well as exposure to international best practices.

2) To successfully bring about inter-ministerial convergence, the Autism Cell may wish to organize an inter-ministry workshop of heads of programs/projects (such as NAAND, RCHCIB, ELCD, etc.) to gain an understanding of resources and activities of the other NSCAND members. Ground-level convergence can also be more effectively organized though regular meetings and sharing of information by the focal points. (The ministries hold administrative responsibilities, whereas the divisions have functional responsibilities. So far, the ministry and division officials participate in NSCAND meetings, whereas the main players are those at mid-level positions. The action plans are developed by ministries in consultation with their Program Heads, but understanding of that planning does not always percolate downwards.)

3) Issues of prevention through surveillance of high-risk pregnancies and high-risk neonates need to be addressed. This is an incomplete task left over from the previous action plan.

4) The issue of embedding early screening, detection and early intervention of childhood disabilities into their Expanded Program on Immunization needs to be taken forward. This could be a critical entry point for children with disabilities,

especially if MoHFW developed and disseminated a booklet on self-tracking by first-time parents.

5) It is recommended that a few union sub-centers as model centers in NDD management be developed, perhaps in collaboration with MoSW

6) A module on NDDs in the nurses' curriculum at pre-service level is recommended.

7) The Guide for Monitoring Child Development[85] is a monitoring tool to gauge the development of children who are at risk for developmental disabilities or delays. This is a simple tool designed for low-and-middle-income countries for use by field-level non-professional workers. It has been field tested in four countries thus far and is an excellent option for MoHFW to consider implementing in Bangladesh. Minimal training would be needed for it to be utilized.

8) The gap in service provision for the 0-2 year age group in the lives of children in Bangladesh, to whom no services are provided by any ministry, needs to be addressed. This is a particularly vulnerable period for CWDs, where both positive impact as well as neglect can have long-term consequences in the person's lifecycle.

9) Despite all the meetings and the trainings, the action on the ground remains invisible in terms of screening, early identification and intervention for children with NDDs, nor is data made available other than data from IPNA. The CC visited by Shuchona found the personnel there to be very enthusiastic, but they had not received any specific training on NDDs. Benefits derived from training of large numbers of health personnel (see Table 3) has not reached children with NDDs. The need for a systematic approach to ensuring training has impacted on the ground should be addressed.

Specific recommendations for MoHFW

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[85] Ertem, I. O., Dogan, D. G., Gok, C. G., Kizilates, S. U., Caliskan, A., Atay, G., ... & Cicchetti, D. V. (2008). A guide for monitoring child development in low-and middle-income countries. Pediatrics, 121(3), e581-e589.

10) To develop greater clarity of their specific role as coordinators of the Action Plan (which is a daunting task, to say the least), the staff of the Autism Cell need sensitization on NDDs, including a possible visit to any of the well-established, successful special schools in the country, as well as exposure to international best practices.

11) To successfully bring about inter-ministerial convergence, the Autism Cell may wish to organize an inter-ministry workshop of heads of programs/projects (such as NAAND, RCHCIB, ELCD, etc.) to gain an understanding of resources and activities of the other NSCAND members. Ground-level convergence can also be more effectively organized though regular meetings and sharing of information by the focal points. (The ministries hold administrative responsibilities, whereas the divisions have functional responsibilities. So far, the ministry and division officials are the ones who participate in Steering Committee meetings, whereas the main players are those at mid-level positions. The action plans are developed by ministries in consultation with their Program Heads, but understanding of that planning does not always percolate downwards.)

12) To address issues of prevention through surveillance of high-risk pregnancies and high-risk neonates. This is an incomplete task left over from the previous action plan.

13) To take forward the issue of embedding early screening, detection and early intervention of childhood disabilities into their Expanded Program on Immunization. This could be a critical entry point for children with disabilities, especially if MoHFW developed and disseminated a booklet on self-tracking by first-time parents.

14) To develop, perhaps in collaboration with MoSW, a few union sub-centers as model centers in NDD management.

15) To include a module on NDDs in the nurses’ curriculum at pre-service level.

16) The Guide for Monitoring Child Development[86] is a monitoring tool to gauge the development of children who are at risk for developmental disabilities or delays. This is a simple tool designed for low-and-middle-income countries for use by field-level non-professional workers, and minimal training would be needed. It has been field tested in four countries thus far and is an excellent option for MoHFW to consider implementing in Bangladesh.

17) There is a gap in service provision for the 0-2 year age group in the lives of children in Bangladesh, to whom no services are provided by any ministry. This is a particularly vulnerable period for CWDs, where both positive impact as well as neglect can have long-term consequences in the person's lifecycle.

18) It needs to be specifically mentioned here that despite all the meetings and the trainings, the action on the ground remains invisible in terms of screening, early identification and intervention for children with NDDs, nor is data made available other than data from IPNA. The CC visited by Shuchona found the personnel there to be very enthusiastic, but they had not received any specific training on NDDs. Benefits derived from training of large numbers of health personnel (see Table 3) has not reached children with NDDs.

19) After three years of executing their action plan, staff at all levels of various ministries are still asking: *"What can I do?"* It is obvious that there is some level of confusion. It is therefore recommended that the Autism Cell develop, with the help of local experts on the field, a booklet on roles and responsibilities of every government functionary at national, divisional, district, upazila and union level in facilitating the realization of rights of persons with NDDs. Since the MoHFW is leading this agenda, it is incumbent on them to undertake this effort.

20) High-risk neonates need to be tracked over a three year period of time. For instance, staff from MoSW's 103 ISDCs could visit nearby hospitals to start non-medical neonatal clinics, on a weekly basis; that would be an excellent example of

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a convergent activity. Interventions made at this stage of life can greatly reduce the severity of disability and vastly improve functional outcomes of many.

21) It is important to ensure that the Autism Cell is funded independently and made permanent, sustainable and included in the ministry organogram.

22) There is a massive shortage of rehabilitation professionals and consequently, there is an urgent demand for expanding and upscaling training courses/centers for physiotherapists, occupational therapists, speech-and-language therapists, orthotics and prosthetics specialists.

23) The Autism Cell should be renamed to "NDD Cell" to better reflect the scope of its mandate.

24) Given below are recommendations from the 2012 Situation Analysis that have not been undertaken yet, but are still relevant today:

Table 8 – Recommendations from the 2012 Situation Analysis that are pending fulfillment

RECOMMENDATIONS	SUGGESTIONS ON HOW TO ACHIEVE THEM
i) Address the NDD situation in the health sector with proper understanding of the nature and scope of these disorders	➢ Establish capacity to conduct first level screening at CCs and maybe even at the Union sub-centers ➢ Set up an efficient referral system between the field workers and the doctors and therapists at secondary and tertiary level healthcare facilities ➢ Establish capacity to perform provisional diagnosis of NDDs at UHCs and district hospitals
ii) Ensure routine usage of the two sets of screening and assessment tools that have already been validated for Bangladesh throughout all	➢ Deliver training on assessment tools to all UHCs and district hospitals.

Government hospitals	
iii) Develop more medical doctors trained on NDDs, as well as more qualified physiotherapists, occupational therapists, speech-and-language therapists, orthotists, prosthetists, developmental therapists, etc.	➢ Include modules on NDDs in undergraduate nursing programs ➢ Enhance the physiotherapy course at NITOR and set up other rehabilitation courses such occupational therapy, speech-and-language therapy, etc. ➢ Establish short and long courses on speech-and-language therapy
iv) Improve preventive efforts	
v) Improve and proliferate early screening, referral, detection, diagnosis and interventions/counseling	
vi) Efficiently manage available resources when in situations of competing and compelling needs	➢ Develop synergies with successful NGOs such as BRAC for both capacity-building as well as improving service-delivery mechanisms
vii) Make better strategic planning for addressing NDD-related issues	➢ Setup a working partnership between GOB and NGOs in order to jointly address the NDD situation as a national public health initiative
viii) Deliver services to the unreached in rural and remote areas	➢ Establish tele-rehab facilities in seven Regions (Regional Centers on ASD, which will be discussed in detail in the development of the Action Plan)
ix) Increase awareness of NDDs among the general public	➢ Address this issue through the Bureau of Health Education: a) Interactive public theatre b) Celebrity-led campaign c) Using radios for generating awareness among rural public d) Incorporating NDD-related discussions in monthly meetings of all upazila councils e) Involving the District Commissioners in awareness and advocacy efforts and setting up information kiosks at their offices f) Meeting periodically with the editors of major print media (through MoI)
x) Better coordination of activities that are currently	

scattered and in some disjointed from the overall nexus of services	
xi) Address the serious lack of convergence in the continuum of service delivery among the various relevant Ministries	➢ Reiterate the fact that inclusion of PWDs is their right and that Bangladesh has ratified UNCRPD and that GOB is obligated to promote, protect and ensure parity rights.
xii) Conduct more research on NDDs	➢ BSMMU, NIMH&R, NINS and NITOR could be empowered and enabled to identify research priorities and conduct research at national and sub-national levels

In conclusion, the MoHFW has undertaken many pertinent activities to prepare itself and others to address the needs of persons with NDDs. Now the action on the ground in terms of direct services, as well as inclusion of screening and identification of NDDs into routine community work needs to happen more visibly, and soon. The dovetailing into existing activities has not happened yet.

7.3 Impact of the Ministry of Social Welfare

Background

The Ministry of Social Welfare has been the nodal Ministry for all disability matters as per the Rules of Business of GOB. They continue to play a key role in a continuum of service-delivery options, legislation, NGO-support, human resource development and advocacy. Their activities are conducted through the Jatiyo Pratibondhi Unnayan Foundation (JPUF), in Dhaka, which offers services, special education training centers (three one-year courses, one each for visual, hearing and intellectual disability), research and publications, in addition to administration and planning.

Service provision for persons with NDDs

1) The NDD Protection Trust, which is currently embedded in MoSW, is the official Government entity mandated to ensure the fulfillment of the rights of persons

with NDDs in Bangladesh. Specifically, it is responsible for ensuring for persons with NDDs the delivery of physical, mental and financial support, proliferation of technical knowledge in order to educate them and to give them social empowerment. It is envisaged that this entity will one day become the apex authority in the Government system to oversee the delivery of services and supports to persons with NDDs throughout their lives and to guarantee their rights.

2) The Department of Social Services (DSS) under MoSW conducted a national level Disability Detection Survey (DDS) which, according to the latest count (which is ongoing), states that there are approximately 1.4 million[87] PWDs in Bangladesh (see Figures 22 and 23 below for disaggregation of this number of PWDs). It should be noted that DSS claims to be still in the process of entering data from DDS as well as of new clients that register through the online process. It is their assertion that they will eventually have similar numbers of PWDs as per other scientific estimates and expert opinions. DSS is also responsible for issuing ID cards to registered PWDs and thus far about 12,000 cards have been issued.

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[87] This corresponds to a disability prevalence of 0.88%, which is significantly lower than the 2010 HIES finding of 9.07%.

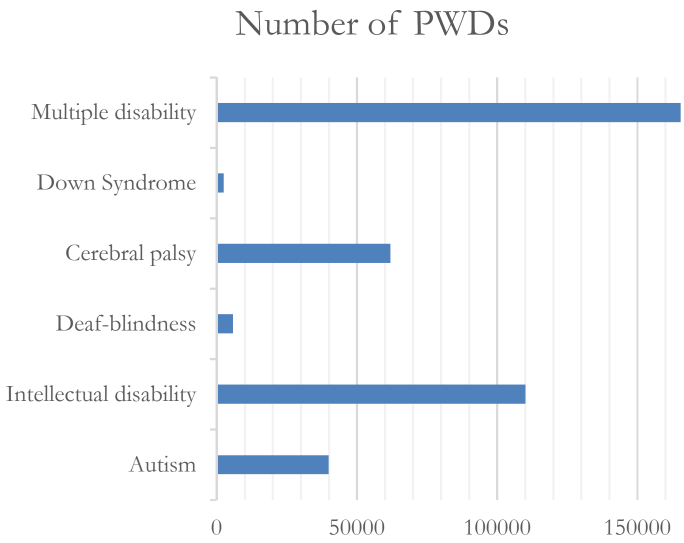

Figure 3 – Number of persons with NDDs determined from the DDS

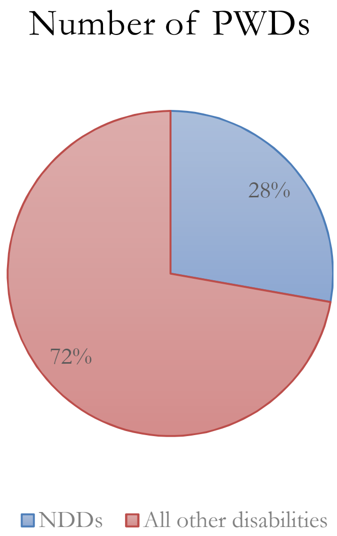

Figure 4 – Ratio between persons with NDDs and other disabilities determined from the DDS

3) JPUF operates 103 Integrated Disability Service Centers (IDSC) – 50 of which are funded by the World Bank – distributed across the country. Their main functional services-delivery areas are through these centers.

Table 9 – Numbers of NDD clients registered at CDCs and the service transactions delivered to them since 2009

TYPE OF DISABILITY	TOTAL NUMBER OF PWDs REGISTERED AT IDSCs	TOTAL NUMBER OF SERVICE TRANSACTIONS AT ALL IDSCs
Autism spectrum disorders	3453	31163
Intellectual disability	2453	25162
Cerebral palsy	25897	233718
Down Syndrome	3200	26500
Multiple disabilities	4706	41825

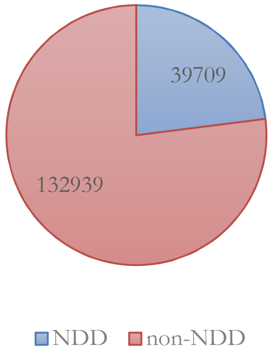

Figure 24 – Number of NDD vs non-NDD clients registered at the IDSCs

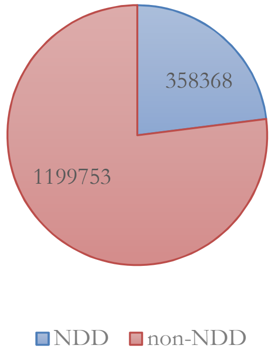

Figure 25 – Number of service transactions at the IDSCs for persons with NDDs vs persons with other disabilities

Figures 24 and 25 both indicate that persons with NDDs account for nearly a quarter of all clients and transactions at all IDSCs combined. This data shows that the average PWD receives nine service transactions at the IDSC. The congruence of the two indicators suggest that either the IDSC sets a specific number of follow-ups per client or that there is another explanation that cannot be proven with the existing data.

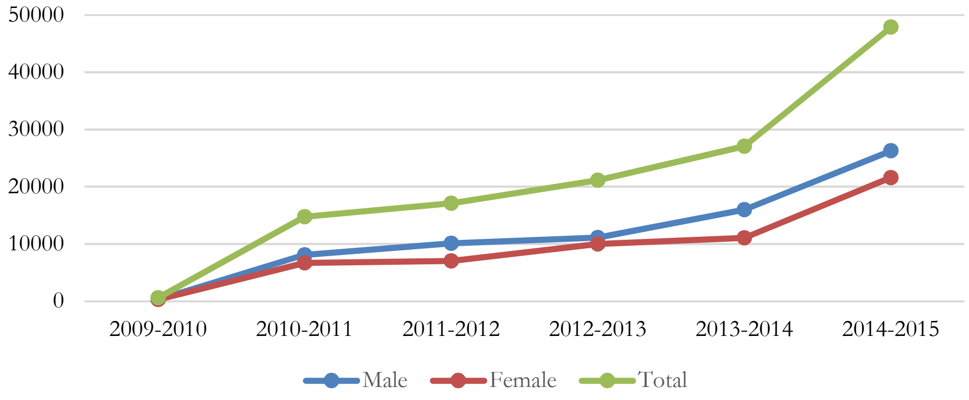

Figure 5 – Number of PWDs newly registered at IDSCs since 2009

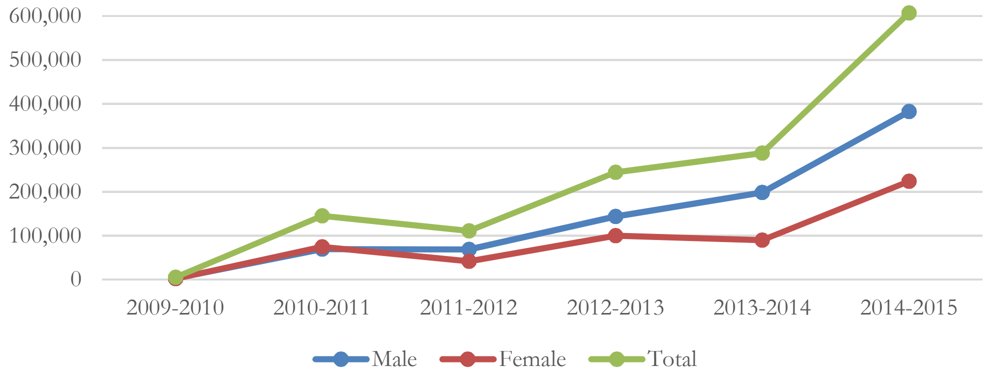

Figure 6 – Number of service transactions per year to PWDs since 2009

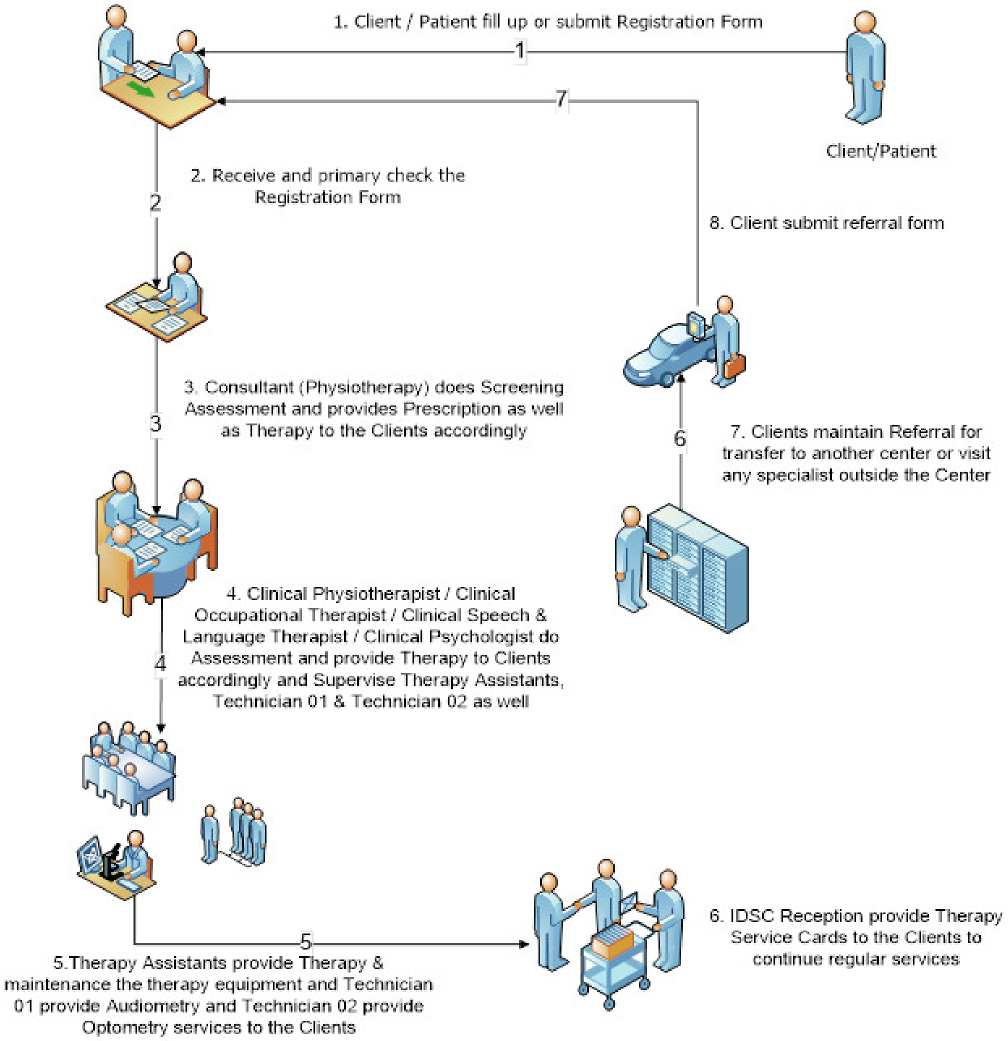

Figure 7 – Workflow at a typical IDSC

4) JPUF is operating 10 special schools[88] for children with NDDs (four in Dhaka district and one each in six other divisions), where altogether 120 children with NDDs are being taught. In addition, MoSW is subsidizing (either partially or fully) the salaries of teachers in 61 private/NGO special schools.
5) All of JPUF's in-house staff have been trained on NDDs, including 4,500 field workers.
6) An Autism Resource Center has been set up in annexure with the IDSC located on JPUF's premise, and so far 2,500 persons with NDDs have been served there.

   The three Special Educator's training courses that they offer now has more content on NDDs.
7) MoSW is the nodal Ministry responsible for the UN World Autism Awareness Day, during which the theme is to light up blue all major buildings in Bangladesh the 2nd of April.
8) A 15-storeyed multipurpose "Disability Complex" – for which the foundation stone was laid in April 2014 – is scheduled to be built in the outskirts of Dhaka. Their aim is to have all disability services under one roof at this complex. The complex will also host trainings of service delivery personnel, conduct research, produce publications, disseminate awareness materials, and will also have training facilities for Paralympics and Special Olympics.
9) JPUF has developed an app for speech therapy that has been disseminated to all IDSCs.
10) Several workshops, seminars, cultural shows are regularly organized by JPUF and these have components of NDDs in all. Individuals with NDDs are routinely included in their cultural shows (the 2015 WAAD was comprised solely of persons with NDD whereas in the past, only those with visual impairments and in wheel chairs would be typically involved).
11) Training of parents has been conducted across the country, details of which are in Table 10 which show that emphasize that these covered even remote areas.

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[88] Shuchona visited one such school in Jatrabari and found that it is in fact a room within the IDSC at Jatrabari, where a few children with NDDs are taught. Another special school is in the JPUF compound, and that one is a free-standing structure.

Table 10 – List of trainings on management of children with ASD, delivered by JPUF

DATE OF TRAINING	DISTRICTS FROM WHICH PARENTS WERE INVITED	NO. OF PARENTS TRAINED	RESOURCE PERSONS
Apr 2014	Dhaka, Munshiganj, Narayanganj, Singair (Manikganj), Autistic School, Special Education Center, Welfare Foundation, Autism Resource Center	32	Prof. Dr. Md. Golam Rabbani Chair person; NDD Trust Dr. Kh. A Mamun Specialist in Autism & Bio-Medical Engineering, AIMS Lab UIU Dhaka Dr. Rawnak Hafiz Chairperson; Autism Welfare Foundation Mr. AHM Noman Khan Executive Director; CDD Dr. Rajib Hasan Disability Specialist; JPUF Sadia Talukder Clinical Occupational Therapist; ISDC Mirpur Tumpa Karmakar Cl. Speech & Lang. Therapist; IDSC Kaniz Nahar Cl. Speech & Lang. Therapist; IDSC Mr. Jahangir Alam Senior Psychologist; JPUF Mst. Nasrin Sultana Consultant (Physiotherapy), JPUF Mrs. Ferdousi Moula Bangladesh Protibondhi Foundation (BPF) Mrs. Romela Morshed Bangladesh Protibondhi Foundation Dr. Mostafa Mahabub Assoc. Prof; Dhaka Shishu Hospital Mrs. Nurjahan Dipa Parents Forum of the
Jun 2014	Dhaka, Jamalpur, Barura (Comilla), Khulna, Rupsha (Khulna), Rajshahi, Cox's Bazar, Natore, Sylhet, Tangail, Bhairob	32	
Jul 2014	Bagerhat, Noakhali, Pirojpur, Netrokona, Jessore, Barisal, Kushtia, Tangail, Jamalpur, Narshingdi, Narayanganj, Laxmipur, Natore, Morrelganj (Bagerhat)	43	
Aug 2014	Sirajganj, Chittagang, Rangunia, Jamalpur, Chandpur, Tangail, Narshingdi, Lalmonihat, Nilphamary, Thakurgaon, Dinajpur	30	
Sep 2014	Jessore, Barisal, Kushtia, Tangail, Natore, Rangunia, Chandpur, Tangail	30	
Oct 2014	Joypurhat, Cox's Bazar, Comilla, Dhaka, Noakhali, Kushtia, Bhaluka	30	
Nov 2014	Sherpur, Barguna, Shariatpur, Gaibandha, Rangunia, Sunamganj, Rangamati	31	
Dec 2014	Lalbag, Jatrabari, Uttara	30	
Jan 2015	Sylhet, Rangpur, Nilphamary, Rajshahi, Chittagang, Barisal, Khulna	30	
Feb 2015	Gaibandha, Shariatpur, Rangunia (Chitttagang), Pabna, Munshiganj, Jhinedah, Moulvibazar	30	
Mar 2015	Bhairob, Barisal, Rajshahi, Jessore, Fulabari (Kurigram), Sirajganj, Rupsha (Khulna)	31	
Apr 2015	Sunamganj, Joypurhat, Magura, Madaripur, Chuadunga, Munshiganj	30	
May 2015	Tungipara (Gopalganj), Narayanganj, Faridpur, Noakhali, Bagura,	30	

	Lalmonirhat, Sathkhira, Kushtia		Differently Able (PFDA) Mrs. Asma Begum Shilpy Developmental Therapist; Dhaka Shishu Hospital Mrs. Sabina Hossain Principle; SWAC
Jun 2015	B.Baria, Chandpur, Bhola, Dinajpur, Panchagar, Kurigram, Nilphamari, Norail, Thakurgaon	33	
Jul 2015	Barura (Comilla), Naogaon, Moulvibazar, Pabna, Bhola, Potuakhali	30	
Aug 2015	Bhairob, Barisal, Rajshahi, Jessore, Fulabari (Kurigram), Sirajganj, Rupsha (Khulna)	32	
Sep 2015	Sunamganj, Joypurhat, Magura, Madaripur, Chuadunga, Munshiganj	43	
Oct 2015	Tungipara (Gopalganj), Narayanganj, Faridpur, Noakhali, Bagura, Lalmonirhat, Sathkhira, Kushtia	30	
Nov 2015	B.Baria, Chandpur, Bhola, Dinajpur, Panchagar, Kurigram, Nilphamari, Norail, Thakurgaon	30	

12) JPUF has procured 20 mobile therapy vans (MTVs), which are basically mobile units of the IDSCs intended to extend disability services and support in the remote areas within the attachment of one IDSC but covering two or three districts. The MTV is 25 feet long, 8 feet wide and 18 feet in height, and is equipped with a set of therapy and other portable equipment. The MTV is also installed with multimedia projector and public address audio system to make announcements during public awareness campaigns. Services provided by these MTVs also include physiotherapy, occupational Therapy, speech-and-language therapy, hearing level test, audio distance test, and distributing assistive devices. As of February 1, 2016, after 38 days of service, the 20 MTVs have registered 43,139 new PWDs, of whom 8,209 are persons with NDDs. Twelve more vans are in the pipeline and are expected to go into service by the end of the year, which would give JPUF a total of 32 vans – enough for each van to cover two districts. Some districts such as Dhaka and Chittagong already have well-established, easily accessible services for PWDs, which would then allow JPUF to assign one van for a single district – thereby achieving larger service coverage.

One of the first MTVs to go into service, pictured here parked inside the JPUF premises

A therapist treating a child with disability inside an MTV

The future plans of MoSW with regard to NDDs include:

- Acquisition of 10 more MTVs;
- Development of a cloud-based self-tracking app for ASD (based on the M-CHAT);
- Development of an online registration system connected to a national database that would automatically refer a newly-registered PWD to the nearest IDSC; home-based training could also be conducted and monitored through such a system

Role and preparedness of MoSW

MoSW is best placed to provide rehabilitation services to children and young adults with NDDs, primarily because they have been mandated to serve PWDs from the time the ministry was established. Since the formation of NSCAND, not only have many of their existing programs been expanded to include the needs of the NDD population, but they have also developed targeted activities like creating an Autism Corner at each of their IDSCs. Although the transition has been easier for this Ministry (compared to others), it should be noted that until 2011 the NDD population was not provided with any of the services they required.

Adequacy of services

The serious shortage of trained professionals/service providers impacts on the adequacy of services available for the large numbers who need them. Poverty further exacerbates the situation making it impossible for daily wage earners to travel frequently for the multiple interventions that are needed for children with NDDs. Since there are no quick-fix solutions to NDDs, parents often get demotivated and drop out. Ministries do not have adequate number of staff to follow up each and every case, especially those from remote areas. Quality of service is good in some places but compromised by the limited number of available professionals in others.

Specific recommendations for MoSW

1) The impressive range of services being proposed and set up by MoSW at national and sub-national levels are not being met by development of the necessary number of service-providers to implement these services. There is a huge dearth of qualified rehabilitation professionals including Special Educators. Currently, JPUF has only three one-year courses for special education, yielding approximately 60 successful graduates per year; this HRD effort needs both upgrading and up-scaling if it is to match the expected demand consequent to implementation of the action plan. It is imperative therefore to match expected demand with supply of service-providers who will ensure quality services from a rights perspective. It is recommended that MoSW take active steps to upscale the number of training institutions/courses who prepare special educators for various disabilities.

2) Customized in-service capacity-building and professional development specifically for each category of rehabilitation professional (not only on subject-expertise but also on rights and entitlements of PWDs) need to be planned on a step-by-step basis with active support from institutes in the region with expertise in NDDs.

3) A "National Directory of Rehabilitation Services, Doctors, Psychologists and Service Centers" needs to be developed and widely disseminated across the country to benefit families as well as field-workers from other Ministries.

4) The aforesaid "National Directory" should lead to the development of a coherent referral system, which does not exist at the moment.

5) In each of the 103 IDSCs, services of visiting doctors are needed to provide a correct diagnosis of NDDs. Currently this is being done by physiotherapists, whose pre-service training includes very limited exposure to NDDs. Incorrect labeling is both morally and practically unethical.

6) A statutory and autonomous body is needed for standardizing, regulating and giving accreditation to rehabilitation and disability-related training courses and

training institutes. For this, a "Rehabilitation Council of Bangladesh" needs to be established through legislation. There is already so much awareness of NDDs in the country that parents have begun to demand services that the Government has not been able to provide fully. This gap between demand and availability of services is currently being filled by under-qualified non-state players who exploit this lack of regulation and demand for services by offering fraudulent services at hefty prices, such as a miracle "cure" for autism. Desperate parents who are not knowledgeable of the nature of NDDs are being duped unscrupulously.

7) It is also time to develop residential and respite care services for adults with NDDs whose parents are senior citizens with progressively reduced abilities and thus cannot manage their wards at home, especially those with mal-adaptive behaviors. This problem is aggravated in the case of nuclear families with 1-2 children and no support systems. Respite care facilities allow parents to leave their NDD-affected children for a few days at a time, while they go away on out-station work.

8) MoSW may also consider developing a home-care "Parenting Guidebook on NDDs" (such as a pictorial) particularly for parents for whom the daily/weekly travel for child-services is not a feasible option.

9) The very young babies with NDDs (even the high-risk ones) are not being catered to fully or appropriately by the current continuum of Government services. In the absence of a cure, it becomes imperative to identify the infant with an NDD very early in life, even within one hour after birth. This is called *2nd generation early intervention*, which, is possible if MoHFW and MoSW converge their efforts, where babies with low Apgar scores at birth or those from the neonatal ICU are referred to by doctors to high risk surveillance clinics (based within the Hospital but staffed by professionals from MoSW, perhaps on a weekly basis). Interventions made at this stage would lead to much better functional outcome for at-risk babies.

10) Another gap in services is in livelihood-related aspects, where more investments are needed in employment-related vocational training programs for adolescents and adults with NDDs.
11) MoSW needs to consider establishing its own “Orthotics & Prosthetics Center” to facilitate the development, measurement, fitting and maintenance of assistive devices and artificial limbs.
12) JPUF’s Autism Resource Center should be renamed to “Autism & NDD Resource Center” and consequently expand the role it plays.

7.4 Impact of the Ministry of Education

Quality education is a critical component of child development and a means of self-empowerment, independence and social integration. CWDs are no exception. They need and deserve educational opportunities as much as other children do. In fact, without educational opportunities, children with disabilities face huge barriers to full social and economic participation in society. Without educational services and opportunities, CWDs will likely grow up to become economically and socially dependent and vulnerable to long-term poverty.[89]

The violation of the right to education is usually the first step in a series of unfortunate violations of human rights. Exclusion of CWDs from the classroom, in fact, *facilitates* their exclusion from mainstream society. That is because a lack of educational preparedness prevents economic emancipation for not only the individual but the entire family. A debilitating and stifling cycle of poverty and exclusion sets in at a young age and continues throughout the rest of their lives. Poverty also leads to poor health, which in turn can lead to other disabilities. Therefore, preventing exclusion from education is a matter of priority for both poverty reduction and

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[89] UNICEF, *Inclusive Education Initiatives for Children with Disabilities: Lessons from the East Asia and Pacific Region* (2003).

development. Having an education gives PWDs better access to jobs, healthcare and other services, thus completing the process of their inclusion in society.[90]

This realization is beginning to percolate through multiple layers of MoE as well as MoPME in Bangladesh. Towards this end, both Ministries are making serious efforts to create an enabling environment for children with disabilities in general and those with NDDs in particular.

Background

MoE is the apex policy-making institution of the government regarding administration and development of post-primary education to higher education including *madrasah*, technical and vocational education. It also formulates laws, rules and regulations for the management and administration of post-primary education and the institutions of the country. There are several attached bodies for supervision and management of formal education in post-primary and secondary schools, colleges, *madrasahs*, technical school-and-colleges, polytechnic institutes, engineering colleges and universities.

Service provision for persons with NDDs

1) An endeavor to set up a "National Academy for Autism and Neurodevelopmental Disabilities" is underway with an initial funding allocation of BDT 720 million. In April 2015, they appointed a parent of a child with ASD as its first Director.
2) Two hundred master trainers have been trained in inclusive education on NDD already by NAAND in collaboration with NAEM, TTC, HSTTI and BMTTI.
3) These master trainers have conducted forward training of 1,450 head teachers across the country including 11,200 teachers and officers. In addition to this, 1,700 *madrasas* teachers and USEOs were also trained by the master trainers. A total of 50 TTC, HSTTI, BMTTI, and NAEM faculty were involved in the training programs.

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[90] Global Campaign for Education, *Equal Right Equal Opportunity: Inclusive Education for Children with Disabilities* (2013). Available from: www.campaignforeducation.org/en/campaigns/education-and-disability

4) All government training institutions at the B.Ed level now have modules on NDDS at pre-service level. This is a major achievement as it will significantly reduce the need for in-service training on NDDs.
5) From Classes III to XI, disability is included in the school curriculum in increasingly complex ways.
6) To date, there are 72,113 CWDs enrolled in secondary schools throughout the country, but NDD-inclusion is very limited. No details were made available other than the fact that they are using the same curriculum, and no other support (other than teacher training) has been provided for them.

Table 11 – Number of CWDs enrolled in all secondary schools as of 2015

TYPE OF DISABILITY	**NUMBER OF PWDs**
Autism spectrum disorders	Not categorized in census
Physical disabilities	25735
Psychosocial disorders	Not categorized in census
Visual impairment	14672
Speech disability	4999
Intellectual disability	7525
Hearing disability	6629
Hearing-visual disability	Not categorized in census
Cerebral palsy	Not categorized in census
Down Syndrome	Not categorized in census
Multiple disabilities	Not categorized in census
Others	12571
Total	72113

7) A component on ASD has been incorporated into MoE's foundation training course for newly recruited teachers which is mandatory for teachers before they start working.
8) MoE has issued a circular to all Technical Education schools to allocate a 5% quota for CWDs to enroll, and a similar circular allocating a 2% quota in all other government secondary schools.
9) DSHE is providing an allowance of BDT 500 to children with ASD in secondary schools.

Future plans of MoE include:

- preparation of 400 master trainers
- creation of better opportunities for inclusion of CWDs in secondary schools
- improved data collection
- tracking of ASD and NDD students in government schools

Role and preparedness

The role of MoE has so far been confined to training as preparation for inclusive education. Several senior staff have travelled to other countries to learn about their models of inclusive education. It is therefore somewhat surprising that details of NDD-inclusion in secondary schools/classrooms were not available. It would be fair to say that some level of preparedness is there, but it has not been transferred to classrooms as yet.

Adequacy of services

In the absence of sufficient data regarding provision of services in secondary schools, it is difficult, and ethically wrong, to comment on the adequacy of services.

Specific recommendations for MoE

1) A new "Right to Education Act," currently under preparation, should have inclusive education for PWDs clearly and cogently factored in. Unlike the Education Policy, it should include within its ambit, all severity levels of

disabilities and not just the mild and moderately affected. Global trends indicate that the education ministry should be the holder of all education-related efforts, including the special schools. It is therefore recommended that the system of special schools currently under MoSW be closely linked to MoE so that there is seamless inclusion of CWDs.

2) MoE should take steps for ensuring inclusion of NDDs in private B.Ed teacher training courses at pre-service level. This will reduce the load on in-service training in the future. There is evidence to prove that if inclusive education is taught at pre-service level, then the teacher is better prepared to educate all children and include CWDs in their classrooms, and the teacher does not think of it as an add-on responsibility.

3) Major reforms are needed in teacher education in order to prepare them for genuine (as opposed to tokenist) inclusive education. This is the new thrust in developed countries and in some neighboring countries as well. There is a need to rethink how we prepare teachers to teach all students in one classroom, as a matter of child’s right rather than a teacher’s choice.

4) Although very large numbers have been trained so far already, a calibrated approach to training of general teachers is highly recommended. There is a need to customize the training. Officials of Ministry departments may need only a three-day sensitization program, whereas general teachers need a planned and systematic professional development program to be able to realistically support the learning of an NDD child in a classroom of 40 children. This cannot be achieved from a one off seven-day effort. A detailed capacity building program needs to be planned in phases with separate skill-building objectives for three main areas: Curriculum Adaptations, Classroom Transactions/Management and Alternative Forms of Evaluation.

5) Universally, there is now greater emphasis on developing culturally appropriate measurements of inclusivity, many of which are based on Mel Ainscow’s **Index of Inclusion** in the UK. One such “Index of Inclusion” for Bangladesh is needed

as it moves forward towards more inclusive schools. This could also be used as a monitoring tool.

6) Accessibility in Bangladesh, as it is understood in the UNCRPD, needs to go in Bangladesh, beyond ramps and accessible toilets. International standards include tactile tiles, signage and communication strategies where material disseminated to students are made in accessible formats.
7) Teaching learning materials form an important component of inclusive education. There is huge shortage of these materials in Bangladesh and therefore investment needs to be made to develop them in Bangladesh.
8) In coordination with NCTB, a committee needs to be established for the purpose of adapting the curriculum at both secondary and primary levels. Developing exemplars of Curriculum Adaptations for every subject and every class on how to teach students with various disabilities in the same class with their non-disabled peers would be an essential aspect in every teacher training course. This may take a year or so, but would immensely facilitate real inclusion for CWDs.

More research on NDD-related issues pertaining to education needs to be done by local academics, which could be funded by MoE.

9) The MoE and MoPME may find it worthwhile to consider employing, perhaps on a contractual basis, some qualified special educators to assist general teachers in the schools. It should be noted here that MoE has already pledged to provide school psychologists to the schools. But due to the lack of a sufficient number of trained and qualified persons, this pledge has not been followed up by concrete steps. In addition, Dhaka University established the Department of Education and Counseling Psychology in 2011 and the Department of Communication Disorders in 2015. If academic preparation provided in these two departments can be enhanced up to internationally competitive standards, it would go a long way to meeting local needs of CWDs in mainstream schools.

7.5 Impact of the Ministry of Primary & Mass Education

Background

Bangladesh is mandated by Article 17 of its Constitution as well as by the Government's priority to achieve quality education for all. Its major function is to formulate and implement policies and programs concerning primary and mass education, including non-formal education. Related to these activities, MoPME also undertakes training and research activities related to primary and mass education and coordinates activities of other Ministries, Government agencies and NGOs in the field of mass literacy and adult education.

The Directorate of Primary Education is the key department under MoPME responsible for managing education services at the nation's 122,176 primary schools. Other major departments include the Bureau of Non-Formal Education and the National Academy for Primary Education.

Bangladesh is one of the few countries where enrollment of girls in primary schools is higher than that of boys, and rural enrollment is higher than in urban areas. This degree of remarkability will hopefully also be achieved in the Government's effort to put more and more CWDs in primary school.

Service provision for persons with NDDs

1) A popular local cartoon called "Meena" features a child with autism named "Anu," who is a friend of the main character. The cartoon airs regularly on BTV, which is free-to-air and most children with access to television in Bangladesh watch it regularly. Meena was developed to be a role model, and the fact that Meena has a friend with autism sends a strong and positive message to children across the country.
2) Their record on training, as with the other ministries, is very good. So far:
    - 100 master trainers have been trained in inclusive education with special focus on NDDs;

- TOTs was done for 270 officials for implementation of inclusive education;
- Training of one teacher from each government primary school on inclusive education has been completed;
- Training on inclusive education has been given to all field officials (2,694 participants) of DPE.
- Training has been given to Assistant Directors of Primary Education of all 64 districts of Bangladesh on inclusive education (they have been designated as District Focal Persons for autism as well);
- Training on inclusive education has also been given to two Instructors/Assistant Superintendents from each Primary Training Institutes.

3) Three manuals for teacher training include small components on NDDs, largely on theory and on advocacy.
4) Data on some NDDs has been included in BANBEIS[91] from 2012 onwards. According to BANBEIS, in 2013, there were 14,398 CWDs enrolled in Class V (7598 boys, 6800 girls), which is the exit point from primary school. In 2014, there were 12,764 CWDs enrolled in Class VI (7259 boys, 5505 girls), which is the entry point for secondary school. Therefore, from this data it is found that 1,634 children (339 boys, 1295 girls) dropped out during the transition from primary school to secondary school is – a dropout of 11.35%. This is comparable to the overall dropout rate of 14.11% during the same period. In 2015, children with NDDs (that includes "intellectual/mental" and "autistics" as far as DPE is concerned) constituted 0.1% of the primary education student population[92].

Table 12 – Class-wise enrollment of CWDs in all primary schools in 2015[93]

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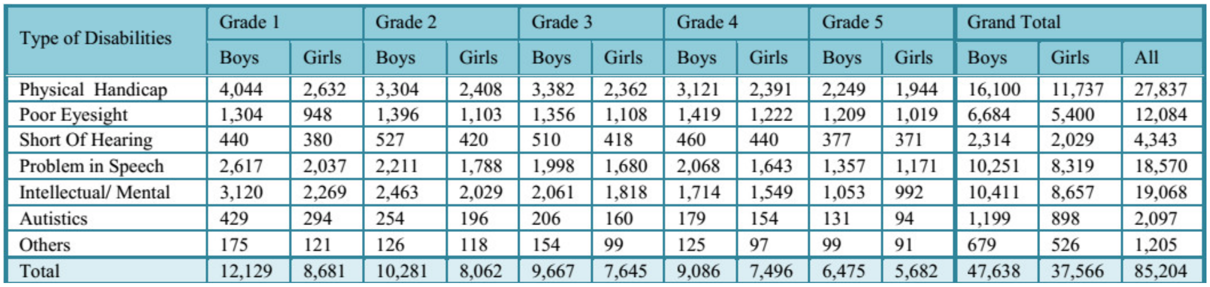
[91] Available at: www.banbeis.gov.bd. Currently hosts data from the censuses of 2009 until 2014 only.

[92] Sourced from the "2015 Annual Primary School Census", which has not yet been officially published. An electronic copy of the pre-publication draft was supplied to Shuchona by DPE.

[93] ibid.



Type of Disabilities	Grade 1		Grade 2		Grade 3		Grade 4		Grade 5		Grand Total		
	Boys	Girls	Boys	Girls	Boys	Girls	Boys	Girls	Boys	Girls	Boys	Girls	All
Physical Handicap	4,044	2,632	3,304	2,408	3,382	2,362	3,121	2,391	2,249	1,944	16,100	11,737	27,837
Poor Eyesight	1,304	948	1,396	1,103	1,356	1,108	1,419	1,222	1,209	1,019	6,684	5,400	12,084
Short Of Hearing	440	380	527	420	510	418	460	440	377	371	2,314	2,029	4,343
Problem in Speech	2,617	2,037	2,211	1,788	1,998	1,680	2,068	1,643	1,357	1,171	10,251	8,319	18,570
Intellectual/ Mental	3,120	2,269	2,463	2,029	2,061	1,818	1,714	1,549	1,053	992	10,411	8,657	19,068
Autistics	429	294	254	196	206	160	179	154	131	94	1,199	898	2,097
Others	175	121	126	118	154	99	125	97	99	91	679	526	1,205
Total	12,129	8,681	10,281	8,062	9,667	7,645	9,086	7,496	6,475	5,682	47,638	37,566	85,204

It should be highlighted that the number of CWDs found in the 2015 APSC is almost 20% less than the number found in the 2014 APSC. DPE explained that they included definitions of disabilities in the 2015 APSC questionnaire, which resulted in more accurate identification of CWDs.

Table 13 – Percentage of CWDs that drop out during primary school years (2012-2014)[94]

Transition	2012 → 2013			2013 → 2014		
	Boys	Girls	Total	Boys	Girls	Total
Class 1 → 2	0.9%	13.0%	5.9%	-16.0%	-15.3%	-15.7%
Class 2 → 3	8.0%	12.7%	10.1%	-11.1%	-7.5%	-9.5%
Class 3 → 4	-1.6%	6.0%	1.8%	-12.6%	-6.9%	-10.0%
Class 4 → 5	-7.4%	-2.6%	-5.2%	-28.4%	-25.4%	-27.0%
Negative percentage indicates drop-out						

Role and preparedness of MoPME

In both ministries related to education, it would appear that training has been done in large numbers. The development of specific competencies for classroom management

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[94] Sourced from APSCs of 2012, 2013 and 2014, available at BANBEIS.

or in curriculum adaptations has not been addressed in the detailed way that this important activity deserves. Before either ministry starts to plan and ensure that learning outcomes for NDD children will be similar to that of other children in the classrooms, a lot more planning and action is necessary in teacher-preparation. To plan for quality inclusion in general schools, more investment is needed in focused capacity-building in a calibrated manner.

Adequacy of services

Due to a lack of data and specific information on services and trainings from the ministry, it is unethical to comment on the adequacy or the quality of inclusion. A questionnaire requesting such details was sent to MoPME and their response to it showed that teacher training and assistive devices were the major focus of supports for inclusive education. Teaching learning materials were not provided to support the teaching learning process. It is evident that more investments are needed in enhancing quality of inclusive education.

Specific recommendations for MoPME

1) As mentioned earlier, currently in use are three good teacher training manuals which are partially inclusive of NDD-teaching, but not from a practical, classroom orientation point of view. It is recommended that a practical “How to Do Inclusive Education” manual in Bengali be prepared, field tested and disseminated to all schools. This may take one to two years to develop but will ultimately benefit many and ensure successful inclusion in classrooms. The emphasis should be on how to teach subjects, rather than on rectifying disabling conditions.

2) Research needs to be conducted on various aspects of inclusive education including, but not limited to, the Impact of transition from special to inclusive schooling on children with disabilities; from primary to secondary and higher education and employment.

3) MoPME may find it worthwhile to consider employing, perhaps on a contractual basis, some qualified special educators to assist general teachers in the schools to take inclusive education forward more meaningfully.

4) Seven recommendations made for MoE earlier are also applicable for MoPME, perhaps even more so, because primary education comes first in the dynamic cycle of life.

5) Use of IT as a learning and/or teaching tool is highly recommended. Tablet computers, for instance, have applications in teaching skills, such as the use of specialized apps for teaching reading, social skills, vocabulary, communication, math, science, etc.

6) Training of school management committees is being done and is a good idea, so perhaps a booklet on such training could be developed to ensure uniformity of messages sent out to them.

7) It is recommended that some model inclusive schools be developed to become examples of good practice for others to visit and learn from. These could be used as teacher-training models in inclusive education, for both undergraduate and postgraduate levels of courses.

8) It is recommended that MoPME incorporate the principles of *Universal Design of Learning*[95] and a cross-disability approach towards education related training and material development.

9) The duration of the Certificate in Education course is too short for conceptualizing the pedagogic subjects and its application to the teaching learning process. This needs to be extended and should include supervised practice teaching.

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[95] A framework developed by CAST (an education research NGO in Boston, USA) to improve and optimize teaching and learning for all people based on scientific insights into how humans learn. For more information, visit: www.cast.org/our-work/about-udl.html

10) To meet the need for training instructors at the PTIs, DPE could coordinate with NGOs and other private training institutes having expertise in teacher training in the field of inclusive education.

11) A strong collaboration between NCTB, NAPE and the PTI is essential for the development and implementation of primary education and Certificate in Education curricula, embracing inclusion.

Both education ministries report that, so far, their efforts have been focused more on creating awareness, promoting the concept and value of inclusive education and conducting workshops and training programs. Clearly, it is time now to take inclusive education beyond the training centers and into the classrooms of government schools.

7.6 Impact of the Ministry of Women & Children Affairs

Background

Bangladesh is committed to the overall development and empowerment of women. The promise of the State is to guarantee the rights of women (Articles 27, 28, 29 and 65 of the Constitution). Especially, Article 28(4) paves the way for enactment of legislation to facilitate women's development. Apart from constitutional obligations, Bangladesh is a signatory of almost all international conventions and documents related to women's development. MoWCA is engaged in the formulation and implementation of policies and programs related to the welfare and development of women and children.

Service provision for persons with NDDs

1) The Department of Women's Affairs has instructed all residential and non-residential training centers to include class/module on ASD in all training courses, which has resulted in a special chapter being incorporated in the life skills training module for the members of adolescent clubs; TOT for this is provided to the peer leaders of these adolescent clubs, who in turn trained other members of the club, who further conducted awareness raising programs for the community people – a cascading effort.

2) Occasional discussions on autism are being conducted in monthly coordination meetings of the Jatiyo Mohila Sangstha (JMS). NDD related topics have been incorporated in the training manual of JMS and sessions are held in every training program of JMS and its projects.
3) Occasional discussions on NDDs are taking place during *uthan boithaks* throughout all 64 districts and at 50 district offices in order to promote public awareness.
4) *Kishore-kishori* clubs are discussing high risk factors in disability in their regular meetings.
5) 30 officers from the Ministry, district offices, project offices and partner organizations like BRAC, Phulki and Grameen Shikkha have been trained as master trainers on NDD-inclusion. Additionally 520 master trainers have been trained to disseminate information to the training of facilitators.
6) A circular has been issued mandating the inclusion of two CWDs in every Early Learning Center and daycare/pre-primary center (see Appendix 16). According to MoWCA, They are reporting that a total of 1,995 CWDs are enrolled at Early Learning Centers, which is approximately 3% of their total student population.
7) Orientation is being given regularly to parents/caregivers of CWDs at the daycare centers. Furthermore, CWDs are being referred to appropriate institutions for proper therapy.

Children at the daycare/pre-primary center having breakfast

8) 30 master trainers of the ELCD project have been trained and ELDS content validation is ongoing.
9) The 12-hour daycare centers for working mothers attached to industrial bases are inclusive of CWDs. One such center visited did have CWDs who were well integrated into the set-up.
10) A really creative, well-designed, self-tracking pictorial for parents has been developed and distributed with the help of UNESCO.
11) A mass campaign against child marriage is going on under two projects supported by GIZ.

Children at a daycare/pre-primary center in Mirpur, Dhaka that was visited by Shuchona

Role and preparedness of MoWCA

MoWCA is a critical entry point for children with disabilities because their mandate includes the youngest years of life (0 – 3 years), which is when NDDs need to be detected. Disability itself is a new concept to this ministry, and NDDs are even more unfamiliar territory. However, the new Secretary, transferred here from MoSW, is a highly motivated individual, and is keen to include NDDs in the routine work of the Ministry. There appears to be renewed energy in taking the NDD initiative forward.

They now have clarity about their role but need much more preparation in terms of skills and knowledge-building.

Adequacy of services

In the absence of data, it is impossible to measure adequacy of services. Some pre-school teachers mentioned that they will start receiving practical training from this year onwards. The BRAC-operated Early Learning Centers that Shuchona visited appeared to be better placed to integrate CWDs (some children with visual impairments, intellectual disabilities, and hearing loss were there), but children with ASD were not seen. But overall, the investigators were impressed with the quality of services provided at these facilities, as well as with the cleanliness and neatness.

Specific recommendations for MoWCA

1) The importance of early child care and education can never be over-emphasized. In the case of NDDs, this is the critical entry point in the process of inclusion into mainstream society. Where there is no cure as is the case with NDDs, early identification itself becomes a form of intervention. Therefore, the role of MoWCA is a critical one for achieving three types of prevention:
    a. primary prevention through awareness about risks for disability, health promotion and micro-nutrient fortification;
    b. early screening/identification of disability, which is a secondary form of prevention;
    c. early intervention, which is a form of tertiary prevention.
2) It is recommended that some model inclusive child development centers be developed from amongst the existing daycare/pre-primary and Early Learning Centers.
3) The first two recommendations would necessitate development of specific skill-sets for early interventions of NDDs for some staff.

4) Some of the more spacious ELCD centers could be used additionally (during the afternoon perhaps) as "Disability Care Centers" in the communities, with some special equipment, personnel and approach, where mothers could be trained in simple NDD-management skills, use of multisensory low-cost teaching learning materials made from waste material, with organization of peer-group trainings. This would be an invaluable opportunity for convergence between MoSW and MoWCA.
5) In order to make them more sustainable, it is recommended that MoWCA fully take over the financing and management of all ELCD centers.
6) Data collection on NDDs and other disabilities from the ELCD centers is needed.
7) MoWCA's 10921 helpline should be made NDD-inclusive.
8) A parent-training book on inclusive learning for CWDs is recommended.
9) MoWCA, directly or through its partners, should employ special educators to help them to set up their inclusive ELCD centers.
10) MoWCA should address issues of women with disabilities and include them in the policies and planning of JMS settings.

7.7 Impact of the Ministry of Labor & Employment

Background

The Ministry of Labor & Employment aims to reduce poverty by creating employment opportunities and expanding the workforce by developing both skilled and semi-skilled manpower. It is also mandated with the responsibility of ensuring that the rights of workers are respected in all factories and offices and that due process is adhered to when dealing with grievances and violations through labor courts. Finally, MoLE also strives to establish minimum wages for various industries, enhance productivity of factories by nurturing employer-worker relations and ensure the welfare of workers in the workplace.

MoLE oversees the activities of six entities to achieve the aforementioned objectives:

- The Department of Labor is the key agency within MoLE that is tasked with implementing the statutes of the Bangladesh Labor Act 2006 and other relevant laws and policies;
- The Department of Factory Inspection is responsible for ensuring that the factories in the various industries are operating according to national laws and international standards;
- The Labor Appellate Tribunal is the final court (after the local Labor Courts) for resolving disputes arising at workplaces;
- The Minimum Wages Board negotiates with industrial unions to institute minimum wages for their respective workers;
- The National Skill Development Council is a body of multi-spectrum senior government officials chaired by the Honorable Prime Minister and the architect of the National Skill Development Policy; and
- The Bangladesh Labor Welfare Foundation is a forum for voicing the needs and concerns of industrial workers.

Service provision for persons with NDDs

At present, neither MoLE nor any of the departments under it have any established, recurring services for persons with NDDs. However, the NSDC has kept a clause in the soon-to-be-ratified National Skill Development Policy that mandates all employers to recruit 5% of their employees from among disabled persons. Furthermore, the NSDC also plans to set up a center of excellence for persons with disabilities.

Adequacy of existing services and supports for persons with NDDs

The 10% allocation that NSDC has stipulated in the upcoming National Skill Development Policy is indeed a step in the right direction; however, there is a concern that without a sub-allocation for persons with NDDs, they would find it difficult to compete with those with less complicated disabilities (such as physical disabilities) for the spots in the 10% allocation.

Role and preparedness of MoLE

Bangladesh has 65 technical school-and-colleges and 49 polytechnic colleges (both administered by MoE), as well as 37 technical training centers (administered by Ministry of Expatriates' Welfare & Overseas Employment). Even though these are run by other ministries, the NSDC is in a position to ask such institutes to offer vocational and skill development opportunities to persons with disabilities.

MoLE also operates four Industrial Relations Institutes that are responsible for training employers and mid-to-high level managers on how to nurture employer-worker relations through evidence-based human resource management.

MoLE has established 29 labor welfare centers across 20 districts that provide services to workers in industrial areas, such as primary healthcare, family planning, counseling, awareness training, dispensing welfare and some recreational activities. Finally, according to MoLE, all factories of the 42 formal industrial sectors of Bangladesh are required by law to set up and maintain a small health center or clinic within their respective premises. However, nearly all of the small factories and most of the mid-range factories do not fulfill this obligation.

Recommendations

It is recommended that the NSDC specify within the disability employment allocation a small sub-allocation for persons with NDDs so that they get sufficient opportunities to work. In order for this to be realized, the Department of Factory Inspection needs to monitor the employers to ensure that such quotas are being fulfilled. This sub-allocation could be repealed once a trend of hiring persons with NDDs becomes established throughout the country.

It is recommended that the NSDC encourage the existing government training institutes to offer specialized courses for persons with NDDs and/or include persons with NDDs in their existing courses, provided that the instructors of those courses get the necessary sensitization and training on classroom transactions when dealing with such a type of students.

The labor welfare centers are frequently visited by workers who see it as a convenient place to get basic medication, some advice on their rights and to meet their peers. Therefore, these centers are a viable entry point for delivering awareness initiatives to a significant number of people. Thus, it is recommended that key info-materials on NDDs (such as red flags and what to do when these are found in a child) be delivered to these centers to be included as part of their family planning and counseling topics.

7.8 Impact of the Local Government Division

Background

The Local Government Division is a constitutionally mandated vital part of governance in Bangladesh. It comprises of five major levels: Union Parishad, Upazila Parishad, Zila Parishad, Municipalities and City Corporations. Bangladesh is divided into 64 Zilas (districts), each of which is further divided into seven to eight Upazilas (sub-districts), each of which are in turn divided into nine to ten Unions – the smallest demographic in LGD. The eleven largest cities in Bangladesh are run by City Corporations while the remaining 323 cities and towns are run by Municipalities.

Each of these governing bodies in LGD are run by elected and/or non-elected officials:

Governing	Major members of the governing body

Unit	
Union Parishad	Chairman*, 9 general members*, 3 women members*
Upazila Parishad	Chairman*, Vice Chairman*, Women Vice Chairperson*, Upazila Nirbahi Officer
Zila Parishad	Deputy Commissioner
Municipality	Pouroshava Mayor/Chairman*
City Corporation	Mayor*
	**elected officials*

Table 15 LGD Officals

LGD is responsible for, among other things, local governance, financing and regulating governing officers, maintenance of public parks and the construction of public facilities. In addition, the Union Parishads are responsible for maintenance of law and order, providing welfare services and managing agricultural, industrial and community development schemes within the union.

Service provision for persons with NDDs

LGD issued a circular to City Corporations, Municipalities and Union Parishads instructing them to periodically include in their regular council meetings discussion of issues pertaining to ASD. In addition to that, the Union Parishads have all been supplied brochures on ASD to educate the council members on the nature of ASD and the challenges faced by those with these disorders. Finally, LGD reported that they have primary education officers under whom are assistants who are responsible for going from village to village to collect data on children with disabilities.

Adequacy of existing services and supports for persons with NDDs

The research for this report has revealed that the officials at LGD are uncertain of their role in the NSCAND and what is expected of them to do in service of persons with NDDs. Their knowledge of NDDs is limited to a superficial understanding of ASD.

Role and preparedness of LGD

Despite their lack of understanding of the subject of NDDs, there exists great scope of work that could be done by LGD to address the needs of those with these disorders. For instance, the Union Parishads are ideal forums to combat the myths and stigma surrounding NDDs that still exist within rural communities. That is because the governing officials of the Union Parishads are elected from the immediate community of villages and therefore have very intimate relationships with the locals and are thus highly effective in changing mindsets and asserting policy. In addition, LGD operates the “National Institute for Local Government (NILG)” where future non-elected administrators are trained and is thus a useful pre-service entry point for awareness and sensitization initiatives.

Recommendations

The five governing levels of LGD occupy, in their respective domains, the apex positions of governance and administration of government services. They are the proper entities to ensure oversight of service delivery over the life cycle of persons with NDDs. Therefore, it is recommended that LGD issue detailed circulars to all governing units in the country informing them of the complete nexus of government services (i.e. prenatal and antenatal care, early detection, early intervention, welfare support, therapy, education, livelihood development, etc.). Administrators should be aware of these services and ensure that their constituents are aware of the needs of the local community. They can partner with local NGOs for PWDs and disabled persons’ organizations (DPOs) by giving them an adequate platform for enhancing awareness and social inclusion. Although direct service delivery may not be undertaken by this ministry, participating in the national and international awareness campaigns would go a long way to reduce discrimination and stigma and enhance health seeking behavior and access to appropriate treatments and interventions.

An additional necessary function is the implementation of one of the goals of the NDD Protection Trust: the formation of district-level sub-committees. These sub-committees could act as channels for caregivers of PWDs to directly access elected officials (first to Union chairpersons and then to Members of Parliament) if any of the rights of PWDs are violated by any party. Such complaints should be officially documented by the local governing unit and made available to bodies such as the NDD Protection Trust for their attention.

The Union Parishad halls are important places frequently visited by the locals to get information from their representatives and administrators as well as to voice their concerns. Therefore, it is recommended that LGD allow for awareness and sensitization info-materials to be channeled by the various government service providers (e.g. DGHS, DPE, DSHE, etc.) through the local government units.

It is also recommended that topics of study on NDDs and other disabilities are included in the coursework at NILG so that future non-elected administrators are duly sensitized about the difficulties, needs and rights of this generally forgotten segment of the population.

Finally, it is recommended that LGD include PWDs in their economic development schemes, with particular attention to persons with NDDs as they are least likely to be able to access economic opportunities due to the relatively more difficult nature of their disorders in comparison to the difficulties faced by persons with physical disabilities.

7.9 Impact of the ICT Division

Background

The ICT Division was split from the Ministry of Science & ICT in December 2011 in order to give more thrust to the country's IT sector. Thereafter, it was merged with the Ministry of Posts & Telecommunication in 2014. The Government of Bangladesh has placed great importance of ICT at the highest policy level and is keen to keep pace with the modern changing world. ICTD is responsible for sub-ordinate organizations such as the Bangladesh Computer Council (BCC), the Controller of Certifying Authorities (CCA, overseer of digital signature projects under the Digital Bangladesh program) and the Bangladesh Hi-Tech Park Authority (BHTPA).

Service provision for persons with NDDs

In October 2014, ICTD reported that they had trained 20 children with ASD on computer skills through video tutorials. However, other than that one-off activity, ICTD has not reported any established, recurring services specifically for persons with NDDs.

Adequacy of existing services and supports for persons with NDDs

There are no services for which an assessment of adequacy is required, but it should be noted that there are other activities that ICTD is currently engaged in where there is significant scope for persons with NDDs. However, to assess the technical and programmatic attributes of those activities are beyond the scope of this report. This report will only present possible entry points for the inclusion of persons with NDDs in the planning and implementation of those activities.

Role and preparedness of ICTD

Current research indicates that PWDs have significantly lower rates of ICT use than non-disabled people; in some cases, they may be unable to access even basic products and services such as telephones, television and the Internet.[96] Yet it is also well established that the IT sector is an area in which persons with NDDs could thrive, provided they have the opportunity to participate and the necessary environment to flourish. ICTD has already demonstrated its willingness to create such opportunities, as evidenced by the aforementioned training program done for children with ASD. Computer-related work is often appealing to persons with NDDs due to the minimal demand on social interaction (which can be a particular challenge for them), the intricate details of computing language, and the very structured and repetitive nature of computer programming.

ICTD is currently working on establishing computer labs in 2,000 educational institutions across the country. It is also actively involved in creating new jobs in the

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[96] World Health Organization and World Bank Group, *World Report on Disability* (2011).

IT sector as well as enhancing the nation’s capacity to attract outsourced IT work from abroad. Finally, ICTD is also investing heavily in the establishment of two technology parks: one in Kaliakoir (Gazipur District) and the other in Jessore District. These major initiatives demonstrate ICTD’s enthusiasm to develop the nation’s IT sector, and also suggest that it has tremendous sway with local employers in the IT sector who are hugely benefiting from such initiatives. One of the barriers to employment training opportunities for persons with NDDs is that most training programs are intended for customer relations work (e.g., call centers); a misunderstanding exists that those with NDDs (particularly ASD) are ill-equipped to do well in this kind of work.

Recommendations

The National ICT Policy 2015 is a guideline for the sector to ensure comprehensive and effective use of ICT to materialize the government's vision to make Bangladesh a middle-income country by 2021. The policy has been developed such that it will be less regulatory and more focused on development and promotion. Therefore, it is in ICTD’s interest to include persons with NDDs in their planning because this segment of the population is almost entirely unemployed and possesses untapped potential. For instance, the German software giant SAP is employing persons with autism to do coding and software debugging. Similarly, ICTD could tap into individuals’ potential by:

- promoting the development of training modules and courses that persons with NDDs all over the country could take, either online or at one of the numerous public and private training centers;
- encouraging software developers to produce programs and apps for persons with NDDs to help them learn and communicate (many such programs have already been created in other parts of the world, but they are not culturally suited for Bengalis and some are too expensive for the average Bangladeshi to acquire);
- consider including a selection of special schools throughout the nation as part of its project to establish computer labs at educational institutions.

- encouraging large companies to donate their old IT hardware to special schools and persons with NDDs to increase their access to such equipment, especially in the impoverished areas of the country;
- encouraging a selection of major employers in the IT sector to give jobs to persons with NDDs and to advertise any success stories among their peers so that more are encouraged to do the same.

7.10 Impact of the Ministry of Youth & Sports

Background

MoYS endeavors to transform the youth of Bangladesh into efficient, capable human resources so that they can contribute to the socio-economic development of the country. MoYS also aims to develop home-grown world-class standard athletes through the development of sports infrastructure as well as fostering natural talents.

MoYS is involved in developing youth through skill development in 74 trades, promoting entrepreneurship, microfinancing, recruiting for national service and forming youth organizations.

Under MoYS are the Department of Youth Development (DYD), the National Sports Council, Bangladesh Krira Shikkha Protishtan (BKSP) and the Directorate of Sports. The DYD operates Youth Training Centers (YTC) in 53 districts of Bangladesh (and eleven more are under construction)

Service provision for persons with NDDs

According to DYD, an awareness-building module on NDDs, has been prepared and disseminated to all YTCs in the country. The ministry aims to sensitize 450,000 youth within five years; thus far, they have trained 73,320 youths.

Adequacy of existing services and supports for persons with NDDs

The investigators were unable to assess the adequacy of the aforementioned module on NDDs, nor has MoYS supplied any data that might indicate any improvements in awareness about NDDs and sensitivity towards persons with such disorders. However, the YTCs have trained over 4.1 million youth since the establishment of the Department of Youth Development. These YTCs are quite adept at conducting awareness drives as evidenced by numerous other drives conducted at these centers, such as about HIV and other STDs, reproductive health, drug abuse, dowry-related issues, environmental protection, violence against women, etc. Therefore, it is fair to surmise that the instruction at these YTCs could very well have a profound effect on the way youth in this country view persons with NDDs, provided that the module that they've been supplied with was diligently developed.

Role and preparedness of MoYS

DYD is on the verge of having YTCs in all 64 districts of Bangladesh, thus allowing them access to all youth nationwide. In addition to those, DYD is also working to set up the "Sheikh Hasina National Youth Center" and a human resource development center both in Savar and four regional human resource development centers. Therefore, there is sufficient infrastructure in place and more are being developed to help build up participation of the youth of the country.

Furthermore, DYD has been running a National Service Program whereby over 200,000 youth have received temporary employment for jobs (earning at least BDT 200 per day).

DYD also maintains close ties with youth organizations that receive a variety of grants from the ministry based on the types and quality of the development activities they engage in.

Recommendations

MoYS is an untapped resource of the government with regards to provision of services to persons with NDDs, as evidenced by the fact that they only joined

NSCAND less than two years ago and by the very few activity reports to NSCAND during that time. They have well-established infrastructure and activities that have proven to be successful in developing a very large number of youth in the country, even though education and skill development are the natural mandates of the education Ministries and MoLE. It is recommended that DYD develop a strategic plan for including youth with NDDs in their existing training programs throughout the country. By training the instructors on how to understand and respond to atypical behaviors, to communicate differently, to create an environment for acceptance and inclusion for those differently abled, and not engage in punitive punishments, youth with NDDs could easily be encouraged to participate in the regular programs.

It is also recommended that an employment quota for persons with NDDs (and other disabilities) be allocated in the National Service Program.

It is also recommended that DYD take the initiative to patron the formation of a national organization for youth with NDDs – i.e. a disabled persons' organization – so that such youth could voice their own opinions and develop their own activities. Young adults and youth with NDDs who are highly verbal may be provided with leadership training, public speaking and other skills to assist them to form DPOs and become self-advocates.

In the sporting arena, the world has established a number of opportunities – namely the Paralympics and Special Olympics – for persons with disabilities to test their abilities and compete against each other. Currently, the Bangladesh National Paralympic Association is suspended from competing in the Paralympic Games. Therefore, it is recommended that the National Sports Council along with other political entities take all necessary measures to reopen this opportunity for PWDs in Bangladesh. Furthermore, it is recommended that the Directorate of Sports works towards developing divisional sports teams comprised of persons with NDDs. This could be done by first conducting talent-hunting drives throughout the country to find naturally gifted, physically capable youth, both male and female. Thereafter, such youth could be brought to divisional training camps – similar to the setup of BKSP –

where they would be trained until they are ready to compete nationally and internationally.

Finally, it should be mentioned that whereas Bangladesh has only managed to send two athletes to the Paralympics since 2004, it sent 54 athletes to the 2015 Special Olympics alone, winning 18 gold medals.[97] Therefore, the Directorate of Sports should build on this overwhelming success and create more opportunities for persons with NDDs to participate in sports by supplying sporting equipment to special schools and to children and youth with NDDs. They could also arrange mini-training camps at such schools (or in public parks) for such individuals in order to foster more enthusiasm to play sports. Alternatively, they could create opportunities where these children with NDDs could participate with other children, or perhaps partner with other able children by giving them some minor assistive devices.

7.11 Impact of the Ministry of Cultural Affairs

Background

MoCA is primarily responsible for the preservation, research and development of the cultural heritage and fine arts of Bangladesh. Among others, the function of the Ministry includes preservation, research and development of archaeology, architecture, sculpture, maintenance of public libraries and to facilitate introduction, proliferation and development of the Bengali language.

Among the organizations under MoCA are the Bangladesh Shilpakala Academy, Bangla Academy, the National Museum, the Directorate of Public Library, the National Book Centre, the Nazrul Institute and Folk Arts and Crafts Foundation.

Service provision for persons with NDDs

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[97] Click Ittefaq. (2015). *Special Olympics: Bangladesh win 18 gold medals*. Retrieved from: www.clickittefaq.com/sports/special-olympic-bangladesh-wins-18-gold-medals/

Along with MoYS, MoCA is assisting MoI in its project to develop a national awareness campaign using some of the nation's most famous celebrities as ambassadors.

Adequacy of existing services and supports for persons with NDDs

MoCA maintains close ties with the nation's film, television and theatre artists and is able to easily call upon them to participate in any nationwide awareness initiative.

Role and preparedness of MoCA

As the official patron of the arts in Bangladesh, MoCA is ideally placed to create opportunities for persons with NDDs of all ages to participate in performing arts or to develop and promote their fine art skills. This year, CWDs were included in the special cultural programs recorded for the Eid festivals. In addition, the Director of Shilpakala Academy (after attending a play arranged by the Parents Forum for Differently Able) has agreed to give those students interested in drama to participate and train with other trainees and artists.

Recommendations

It is a well-known fact that persons with NDDs, particularly those with ASD, possess a unique perspective of the world. Coupled with their innocence and humility, they enthusiastically express that perspective in various forms of art such as drawing, painting, handicrafts and music. Such activities are highly therapeutic for them as well as affording them a sense of belonging in society. Therefore, it is recommended that MoCA create opportunities for them to develop their skills in all of the nation's fine arts institutes. These opportunities could include:

- Special courses for persons with NDDs with specially trained instructors
- Allocations of seats in the advanced courses taken by regular trainees
- Scholarships in the arts for persons with NDDs
- Chances to participate in fine arts training camps and courses
- Exhibiting their art work as a special section during annual exhibitions

- Participating in stage performances (plays and musicals)

MoCA also endeavors to enhance and strengthen the cultural ties and promotional opportunities with all friendly countries. This is done through cultural exchange agreements and sending cultural delegations to different countries. It is recommended that MoCA consider taking the most talented persons with NDDs along with such delegations. Such stalwarts would then become great role models for all persons with NDDs and serve to inspire others to come out of their shells and hone their natural talents.

7.12 Impact of the Ministry of Information

Background

MoI is responsible for formulation and administration of the laws and regulations pertaining to information, broadcasting, the press and the film industry in Bangladesh. It is tasked with releasing government information, media galleries and unclassified data to the public and international communities. Under MoI are broadcasting agencies such as Bangladesh TV and Bangladesh Betar (radio), as well as press agencies such as the Bangladesh Sangbad Sangstha.

Service provision for persons with NDDs

MoI has no established, recurring services for persons with NDDs. However, it has undertaken a major awareness initiative involving some of the nation’s most famous celebrities. In December 2015, MoI reported to the NSCAND that a group of celebrities have already committed to participating, and shooting for TV spots at four special schools has been completed.

Adequacy of existing services and supports for persons with NDDs

The celebrity awareness campaign is an excellent initiative, one that MoI would be able to ensure that it gets maximum nationwide coverage. However, more careful planning and development of the messages that these celebrities would deliver is needed.

Role and preparedness of MoI

MoI occupies a central, overhead position to control and disseminate information throughout the country. Their operation of Bangladesh TV, Bangladesh Betar and the Bangladesh Sangbad Sangstha gives them the ability to transmit information freely and easily across all four major media: TV, radio, the Internet and the press.

Recommendations

MoI is bound by the statutes of the ***Right to Information Act 2009*** to guarantee that information is made available to all citizens in Bangladesh. Therefore, it is recommended that MoI ensure that all national news is made disability-accessible through Bangladesh Sangbad Sangstha.

It is also recommended that Bangladesh Sangbad Sangstha create a separate section in its website specifically for "Disability" or "Disabled Persons." All national news and government initiatives should be posted in that section.

7.13 Impact of the NGO Affairs Bureau

Background

NGOAB was established in 1990 and placed under the Prime Minister's Office the following year with the prime objective to facilitate services to NGOs in the country. Specifically, NGOAB is responsible for the registration of NGOs, processing and approval of NGO projects and their funds, monitoring and evaluation of their activities and liaising between them and foreign donors.

Service provision for persons with NDDs

Aside from registering organizations, NGOAB has no established, recurring services specifically aimed at persons with NDDs.

Adequacy of existing services and supports for persons with NDDs

As there are no services for persons with NDDs, there is no scope for an adequacy assessment.

Role and preparedness of NGOAB

As the apex agency mandated for governing NGOs in Bangladesh, NGOAB is able to ensure that all existing organizations and all new ones meet stringent criteria for registration. Moreover, it undoubtedly has close ties with foreign donors due to the fact that it controls the influx of their project funds (just under USD 750 million in Fiscal Year 2014-15 alone).

Recommendations

One of the issues that has arisen since the 2011 Dhaka Conference is the excessive number of NGOs being launched to provide services for PWDs, especially for persons with ASD. The biggest challenge with these organizations is that there are no regulations to ensure quality of services being provided and the training of service providers working there. The enhanced awareness and desire among family members to seek health and education services has resulted in many unsuspecting people, especially in rural areas, falling prey to fraudulent miracle "cures" for autism being offered by unscrupulous organizations. In addition, many existing NGOs claimed to provide services they were not equipped to do.

Either way, it is recommended that the NGOAB suspend such organizations until they properly build up their credentials via appropriate trainings within a given time frame. To ensure quality control, NGOAB would have to work closely with MoSW to develop strict guidelines and regulations for such NDD-centric organizations. As an added measure, NGOAB could cancel the registrations of fraudulent organizations that provide non-evidence-based treatments.

In addition, it is recommended that NGOAB foster the formation of a special committee of representatives from NGOs specializing in NDDs in Bangladesh to voice collective appeals for funding from foreign donors. NGOAB could then help liaise between this special committee and the donors.

8 FINAL RECOMMENDATIONS

The World Report on Disability makes nine recommendations[98] for Governments to address the disability issue with seriousness and urgency. Using this framework, the research team has reviewed all recommendations from the report and placed our final recommendations within the framework provided by the World Report on Disability.

8.1 Enable access to all mainstream policies (and programs)

It is vital that each Ministry address the inclusion of those with NDDs within their mainstream activities and policies as well as their NDD-specific activities to address the barriers that exclude persons with disabilities from participation in programs and services intended for the general public. Under the UN Convention on the Rights of Persons with Disabilities (CRPD), Member States should “take all appropriate measures, including legislation to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities”[99]. In addition to being in line with international treaties, mainstreaming is also cost effective because it eliminates duplication of services for a separate group of people. Below is a list of near term activities, which will be expanded upon in phase two of the project that can support Ministries in implementing their activities to ensure inclusion:

- Create a quality assurance checklist to ensure Ministerial policies and programs are universally designed and provide reasonable accommodation for persons with disabilities. Include these metrics and participation of persons with disabilities in evaluation of programs and policies.
- Create and widely disseminate a guidebook outlining the roles and responsibilities of each Ministry (and each level of personnel within its purview) to eliminate

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[98] World Health Organization and World Bank Group, *World Report on Disability*, 261 (2011).
[99] See UNCRPD Article 4 General Obligations

duplication of services and answer the question that the investigators were asked, “What precisely is my role?”

- Compile a list of frequently asked questions on NDDs from each Ministry, and utilize the questions to develop a booklet with answers provided by experts which can be used by all staff within the Ministry. This would clear up some of the confusion on NDD-inclusion that emerged from stakeholder interviews and meeting with various levels of government.

8.2 Invest in specific programs and services for people with disabilities

In addition to enabling participation in mainstream programs and policies, persons with NDDs require specific programs and services that address their unique needs throughout the lifespan. Targeted programs and services should be well coordinated and aligned with recommendations outlined in the World Report on Disability for developing countries: These are:

- Health services
- Welfare services
- Counseling for parent or family
- Assistive device services
- Medical rehabilitation
- Counseling for disabled person
- Educational services
- Vocational training/Employment
- Traditional healer

A critical aspect of providing appropriate services to persons with NDD is the cooperation and coordination between the government and relevant agencies. By placing the responsibility for coordinating service delivery, social benefits, and healthcare in one place, efficiency is increased by minimizing government bureaucracy, increasing service delivery to persons with NDD, and minimizing barriers. This concept, a one-stop-shop,[100] would serve as a backbone organization which provides a central location for families and persons with NDD to locate necessary information and services and also provides the government with a central agency to track and hold accountable inter-ministerial efforts related to those with NDD. We recommend the following course of action:

- Create a *backbone support organization* or a one-stop-shop to increase coordination and maximize resources *(refer to pg. 50 for further information)*. This can be overseen be the NSCAND and report directly to the Autism Cell.

Figure 30 One-Stop-Shop Model for Bangladesh

Supplementary Supports

Furthermore, local coordination of services will increase the capability of the one-stop-shop and create synchronization of services provided at a local level. To increase local coordination, we recommend:

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[100] OCED. (2010) Sickness, disability and work: Breaking the barriers. Chapter 6: Getting the Right Services to the Right People at the Right Time.

- Develop a mechanism for community health, integrated disability centers, and schools to communicate and share resources coordinated around the person (i.e. – local planning committees).
- Develop a method for increasing local control and coordination of service delivery mechanisms across sectors
- Develop policy recommendations resulting from data analysis
- Increase the capacity of vocational rehabilitation center that allow for partnerships with local job markets
- Use the one-stop-shop to increase the provision of all therapies, telemedicine, and psychological supports
- Enhance early intervention services by connecting the well-baby clinics with diagnosis and referral
- Develop a coordinated approach across ministries in the development and use of screening tools (i.e. – local community health centers, community-based apps, schools, local physicians, integrated disability centers, mobile vans, etc.) to identify at-risk infants/children
- Develop a registry of individuals who are diagnosed as having NDD (this information will be maintained by the One-Stop Center
- Develop posters, using pictures and icons for parents on developmental milestones emphasizing the need for screening/assessment for at risk infants/children and including where parents can go for additional information.
- Improve referrals method for at risk infants/children for full assessment and diagnosis by developing a protocol to be used by medical and public health care staff
- Develop written competencies for each category of professionals and paraprofessionals and work with educational institutions to create curriculum corresponding to the competencies. This action would be part of a coordinated professional development plan for increasing the number of certified diagnosticians and paraprofessionals who can support early diagnosis and intervention in country

- Validate and adopt diagnostic instruments and policies for relevant NDDs in country (see: http://pediatrics.aappublications.org/content/118/1/405.full)

8.3 Adopt a national disability strategy and plan of action

This situation assessment lays the foundation for the development of an updated plan of action (phase two of the project). The plan of action should operationalize “the strategy in the short and the medium term by laying out concrete actions and timelines for implementation, defining targets, assigning responsible agencies, and planning and allocating needed resources”[101]. In addition, the development of a structured “National Capacity-building Plan” would ensure that need-based knowledge and skills are developed and transferred to the appropriate functionaries.

Improving Preparedness and Coordination at the National Level

Most Ministries have their own internal monitoring systems. The investigators recommend strengthening the monitoring systems that are already in place, rather than establishing new ones, keeping in mind that each Ministry is allocated its own separate budget by MoF. In order to ensure the necessary convergence and monitoring for quality control and a reduction in redundancy, NSCAND could be mandated to utilize a set procedure and protocol. We recommend that Ministerial action plans be accountable to the Prime Minister’s Office.

Project planning

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[101] See World Report on Disability, pg. 18.

Figure 8 – Proposed project planning process for members of NSCAND

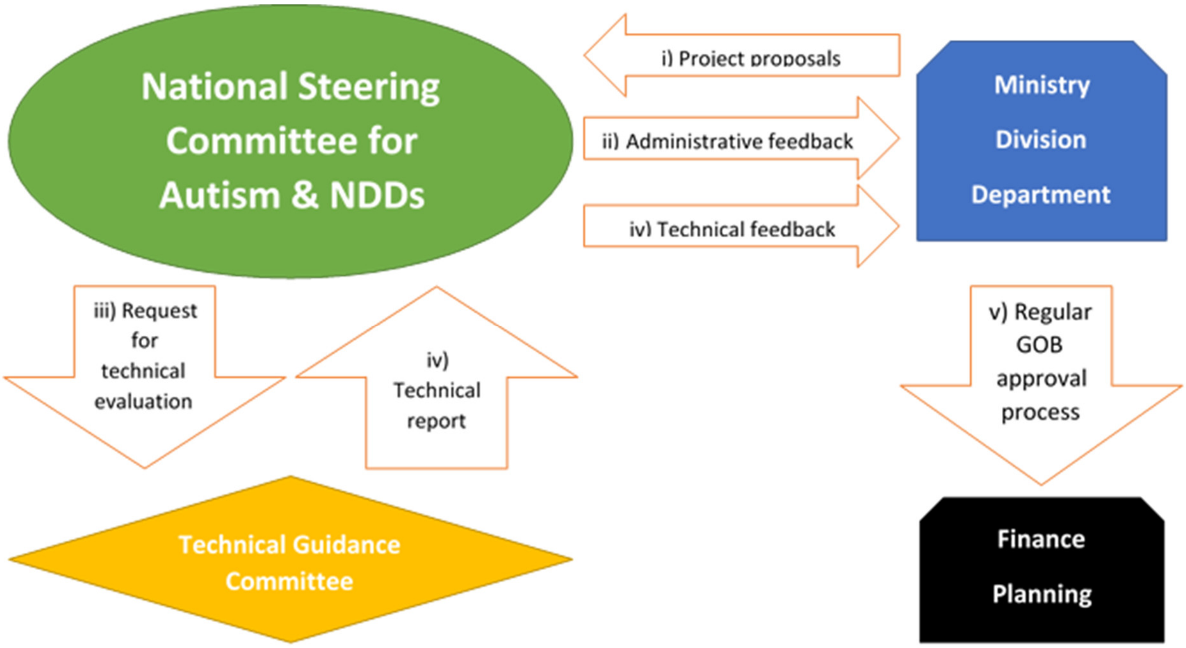

Figure 31Project Planning Flowchart

i) Prior to submitting a project to MoF, NSCAND members are encouraged to present their NDD-related project proposals to NSCAND for review and feedback.

ii) NSCAND would first check the project objectives against all other existing proposals or ongoing activities to determine if there is any evidence of redundancy or scope for collaboration with other Ministries.

   a. If any evidence of redundancy is found, NSCAND would recommend that the proposer consider revising their project objectives and/or parameters, or pursuing alternative NDD-related activities.

   b. If there is any scope for collaboration, NSCAND would recommend that the proposer join forces with potential partners (both from within and outside NSCAND) in order to expand the magnitude of the project, to spread out the financial burden, and to achieve better outcomes from the project by allocating responsibilities based on the specific expertise and capacities of the implementing partners.

iii) After initial review, NSCAND would then forward the proposal to the Technical Guidance Committee to evaluate the project's technical feasibility and parameters, as well as to recommend potential experts and external implementing partners that the proposer could work with on the project.

iv) After a thorough review of the proposal, TGC would submit to NSCAND a report of their evaluation and any recommendations, complete with detailed explanations.

    a. If TGC's report favors the proposal, NSCAND would inform the proposer to proceed with regular Government procedures regarding its proposal.
    b. If TGC's report supports the proposal in principle but suggests amendments, NSCAND would encourage the proposer to revise the proposal in accordance with TGC's recommendations and then re-submit it to NSCAND for final review.
    c. If TGC's report does not favor the proposal, NSCAND would advise the proposer to consider revising their project objectives or pursuing alternative NDD-related activities.

25) Autism Cell (to be renamed the NDD Cell) should be funded independently, developed and repositioned to coordinate the above review process as well as all necessary follow-up actions, and coordinate with NSCAND members during the implementation of approved projects. To successfully bring about inter-ministerial convergence, Autism Cell may wish to organize an inter-Ministry workshop of heads of programs/projects (such as NAAND, RCHCIB, ELCD, etc.) to gain an understanding of resources and activities of the other NSCAND members. Ground-level convergence can also be more effectively organized though regular meetings and sharing of information by the focal points. (The Ministries holds administrative responsibilities whereas the divisions have functional responsibilities. So far, the Ministry and Division officials are the ones who participate in Steering Committee meetings, whereas the main players are those at mid-level positions. The action plans are developed by Ministries in consultation with their Program Heads, but understanding of that planning does not always percolate downwards.)

Figure 9 – Proposed centralized data management system for NDD-related data from key NSCAND members

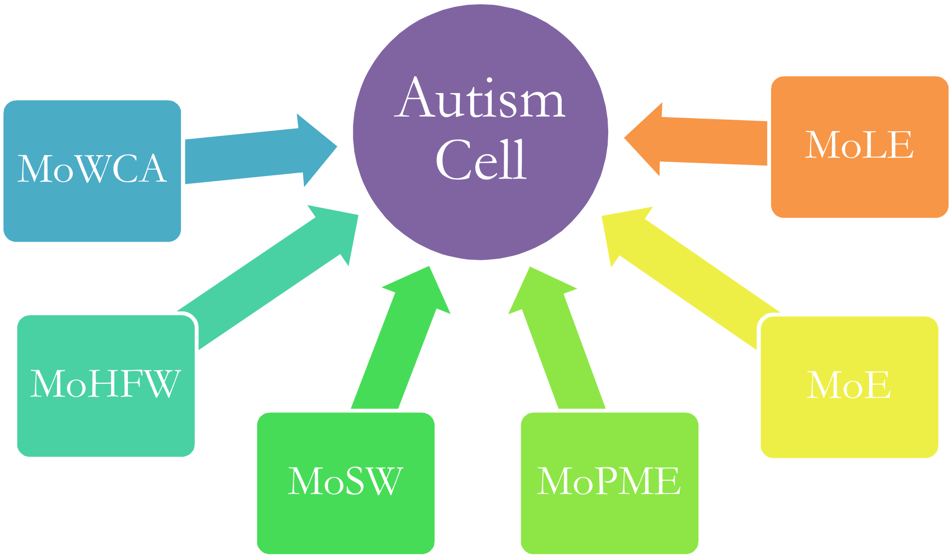

Figure 32 *Organization Autism Cell*

Even though the Ministries are not required by GoB's Rules of Business to seek the counsel of NSCAND or of TGC before initiating a project, this process offers two benefits. First, it will eliminate the need for appointing a specialized consultant for individual projects thereby lowering costs associated with the project. Second, this will ensure that there is no duplication of efforts among NSCAND members, thus enabling funds to be utilized on more pressing needs. Overall, the national NDD agenda as a whole will benefit through improved efficiency and effectiveness.

Supplementary Supports

In addition, inter-ministirial coordination would be improved by the following activities:

- Convergence itself, in its truest sense, is a major recommendation of this report. A fine example would be the child development centers of three different Ministries (MoHFW's CDC, MoSW's IDSC and MoWCA's ELC), where a seamless referral system between them could prove to be very useful for families of persons affected by NDDs.

- For better convergence and coordination among Ministries, there needs to be monthly meetings of the Ministries' NDD focal points and project focal points to discuss execution of NSCAND decisions and any collaborative efforts. Such meetings should be coordinated and minuted by Autism (NDD) Cell. The absence of such meetings has been identified as a barrier to better coordination.

- Create a *common agenda* and common action plans across ministries in areas such as health, early identification, education, data collection, interventions, etc. (see Collective Impact, p. 60), along with a targeted monitoring and evaluation plan reporting to the Principal Secretary to the Prime Minister's office.
    - Develop mandates, operating procedures, policies, procedures, and practices
    - Clarify roles and responsibilities of NSCAND, TGC, and Autism Cell, so that the roles of each are clear and not duplicative, and that efforts are coordinated. This would include protocols in terms of both communication and coordination between these bodies, to maximize their effectiveness, mutual support for each other, and consistency of message.
- Focus on *mutually reinforcing activities*/initiatives such as professional development opportunities, educational initiatives (schools), and media campaigns occurring across ministries.
    - Develop a mechanism for assigning roles, responsibilities, recognition, and pooled funding allocations to relevant ministries/actors.

8.4 Involve people with disabilities

"Nothing about us without us" is the mantra of the international disability rights community and is integral when developing policies and programs to support their needs. Consultation and active involvement of the Bangladeshi disability community is highly encouraged.

In addition, based on experience from neighboring countries, it is recommended that there be a separate Ministry or Division dedicated to the service and empowerment of PWDs, headed by a full Secretary. Wherever this has been done, it has benefited the actual stakeholders the most because of the attention given to their needs alone, their participation, and their larger issues of inclusion.

Supplementary Supports

Community Engagement

- Create continuous feedback loops to promote community engagement within government planning. Consider creating a regulatory or "Watchdog" organization to monitor government services and supports throughout the country.
- Enrich and reinvigorate the Technical Guidance Committee (broaden to NDD)
    - Review members and recruit additional members, etc.
    - Develop and communicate the objectives of the TGC during the recruitment process
    - Provide secretarial support through Autism cell or NDD Trust
    - The TGC may benefit from re-structuring of its TORs, and may need to be headed by a person with expertise in NDDs. It is also recommended that for more effective and efficient functioning, the TGC may benefit from downsizing. It is recommended that the TGC be split into two teams: core members and annex members. The core members would be a small number of key individuals – ideally (but not confined to) those with expertise in NDDs – with long-term memberships. The annex members would be experts from various fields and backgrounds with short-term memberships or recruited for specialized projects or activities in an advisory capacity. The core members would meet regularly (once or twice a month) and be the official representatives of TGC. The annex members would serve in special sub-committees set up to evaluate project proposals or any other function that the core members request of them. All members would meet at least four times a year.

- Define the role of new entities to support efforts of ministry and engage community groups
- Provide parental counseling after diagnosis, addressing the co-morbid condition and follow up service
    - Development of parental master trainers who can train other parents as secondary trainers
    - Create community awareness so that parents seek care at appropriate times in the child's life,
- Create materials and training for siblings and other family members to guide them in positively supporting their family member with NDD

8.5 Improve human resource capacity

Human resource capacity should be developed through a coordinated approach to training and professional development and would include the following activities:

- Identify range of NDD related trainings occurring throughout country
    - Who is being trained, frequency of training, level of impact (Percentage of service providers being trained) impact of training
    - Develop core curriculum and ensure that educators and trainers are using the same curriculum to ensure consistency in service provision –
- Develop a set of competencies for professional staff and utilize these competencies to create a credentialing program for direct service staff, and as a mechanism for certifying training programs as meeting professional standards of quality (See page 56).
- Consider creation of a UCEDD- http://www.aucd.org/template/page.cfm?id=24 model that exists in the United States, with centers focused on ongoing pre-service and in-service training and research on NDD, dissemination of information, and services and supports for individuals and families. Along with training of professionals in the NDD field, these centers would also provide training of medical and health professionals outside the NDD field on NDD awareness and issues

- Collaborate with institutions on higher education to coordinate and develop professionalized education and training programs.

8.6 Provide adequate funding and improve affordability

The affordability and sustainability of the plan of action and its proposed measures should be considered and adequately funded. Each ministry should be responsible for preparing a budget corresponding to its action plan.

The Rules of Business of GoB mandates that all financial transactions be reported directly to the Ministry of Finance. No government agency is under any obligation to submit financial data to any party other than the MoF. However, since the Finance Division of the MoF is also a part of NSCAND, they could be requested to present financial summaries at each NSCAND meeting with the following information:

a) status of project proposals under review of MoF;
b) total amount of funds allocated for NDD-related projects to date;
c) spending broken down by category on NDD-related projects (e.g. awareness, screening, education, training, etc.)
d) any other financial information that MoF is able to share for the benefit of NSCAND members.

This system would allow for a clear picture of the government's allocation of funds to NDD-related initiatives without violating existing regulations.

- NSCAND has evolved into a strong, respectable body that includes a sub-committee for financial vetting of new projects submitted to the Ministry of Finance. But it operates under the auspices of the Health ministry, which limits the extent of its authority in the Government hierarchy. Therefore, it is believed that NSCAND now needs to be instated by the Cabinet to afford it greater authority and ensure sustainability and convergence.

- External Funding:

    a. Governmental funding should be augmented by private funds to fully fund the recommended initiatives. This can be accomplished by working collaboratively with the donor community to develop a shared vision and establish priorities.
    b. Develop a parallel system of safety nets for poor families: Government can utilize the Jakat fund for NDD. Other sources of funding can include tax-based revenues.
    c. Many corporations have a corporate responsibility to give back to the community. Corporations can be sources for funding NDD projects that correspond to their mission. They can also fund raise with their employees and provide opportunities for job training and employment.
- Include disability cost as a part of the budget
    a. Each Ministry should have specific items in their annual budgets for NDD projects. Expenditures should be monitored and the annual budgeting process should correspond to the evaluation of impact of the past activities as well as new priorities.

8.7 Increase public awareness and understanding of disability

In order for a society to be truly inclusive, it is vital to improve understanding and respect for persons with NDDs at both the government and community level. Social marketing campaigns, educational awareness campaigns, and the media should be utilized to reduce stigma, improve attitudes, and present positive stories of persons with NDDs and their families.

Supplementary Supports

- A need exists to clarify the language and understanding of NDDs to ensure that interventions are for all NDDs, and not limited to autism, in order to increase *consistent and open communication.* Other disabilities should not be confused with NDDs Training and informational focus should cover all NDDs and information shared via public media needs to be inclusive.

- Senior officers of every Ministry need customized sensitivity training on NDD-inclusion and how to dovetail NDD work into the existing activities of their Ministry and departments. Training needs to be conducted annually because of the frequent transfer of officials. Several ministries have requested this type of training..
- Functional heads of projects and programs also need to be sensitized on NDD-inclusion. Information from NSCAND meetings is not always distributed down.
- In order to ensure more stringent monitoring of this initiative, it is recommended that the existing reporting formats of officials in all member-Ministries include a question on their role in NDD-inclusion, especially of those in community settings in the health, education, children affairs, and education sectors.

Awareness-Raising and Community Outreach

- A marketing plan should be developed with NSCAND that explains NDDS. The plan should unique messages for each audience.
- Of primary importance is the message that people with NDD are entitled to the rights of citizenship and be expected to benefit from these rights and participate within their communities. People with NDD will benefit from receiving services and supports that are tailored to their specific needs as each person with an NDD is unique as are people without disabilities.
- Also, the plan should include a variety of formats to reach people living in urban and rural areas. Examples of marketing strategies are:
    - Developing a general awareness campaigns in media, via billboards, social media and other advertisements to promote social acceptance and to also raise awareness among families about possible indicators of NDDs (include people with NDD and others in the civil society in the design of the campaigns).
    - Develop awareness campaigns specifically for the medical community to assist them in diagnosing NDD, communicating with parents, and providing referrals for other services.

- Develop materials for use in health clinics and community settings that clearly and simply explain NDD using photos, images and icons.
- Develop posters, videos and social media messages depicting how to positively interact with individuals with NDD, and the critical importance of inclusion of individuals with NDD in mainstream society
- Disseminate information in hospitals, public health clinics and service provider organizations regarding government supports and programs
- Develop awareness campaigns to promote local resources such as coordinated school to community outreach, webpage of local resources for parents, information at health clinics, community resource package, etc.

8.8 Improve disability data collection

As already noted within this report, NDD-related data is not always readily available, and when available is often out-of-date and inaccurate. It would therefore be prudent to establish a centralized data management system (DMS) to ensure that all NDD-related data is gathered and collated in a timely manner, organized logically, and made available to all stakeholders whenever needed. It is suggested that the capacity of Autism Cell be developed in terms of hardware and manpower so that it is able to effectively manage such a system. For such a system to work, the members of NSCAND should commit to support this system by:

i) Installing NDD metrics in their in-house data recording and collecting system (e.g. BANBEIS at MoE, MIS at MoHFW, etc.);
ii) Supplying NDD-related data to the Autism Cell’s DMS without delay.

Having up-to-date, accurate data is indispensable for monitoring the progress and efficacy of individual projects, for charting the overall progress in the national NDD agenda, for identifying gaps in service delivery, and for drafting national action plans.

- It is further recommended that to ensure sustainability of the NDD initiative, data on NDDs is included in the data management systems of all member-Ministries.

Information increases *shared accountability* by flowing up though the government and back down to the local level

A comprehensive data collection system will entail:

- Developing/supporting a national data center for tracking and disseminating NDD data (i.e. – National Autism and NDD Academy)
- Collecting and disseminating targeted census data (disability survey) on individuals with NDD to inform action planning and service coordination
- Assuring that disability registration is part of the data collection and prevalence is measured annually
- Using data at the local level to organize service delivery such as supplies, personnel (e.g. deployment of mobile van)
- Developing feed back processes so that information is shared up to the national level for coordination (feedback loops and *continuous communication*)
- Coordinating and developing parent-centered service delivery models where needed
- Making community-level aggregate data available to increase *shared measurement* (prevalence data, resources, etc.) with the local planning committees for more targeted decision-making and coordination.

8.9 Strengthen and support research on disability

Research is essential for increasing public understanding about disability issues, informing disability policy and programs, and efficiently allocating resources[102]. BSMMU, NIMH&R, NINS and NITOR could be empowered and enabled to identify research priorities and conduct research at national and sub-national levels. Funding should be allocated to encourage the participation of research institutes to pursue this line of research. Research results can be factored into policy development, funding requests, and improving service delivery by focusing on best practices.

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[102] See World Report on Disability, pg. 20.

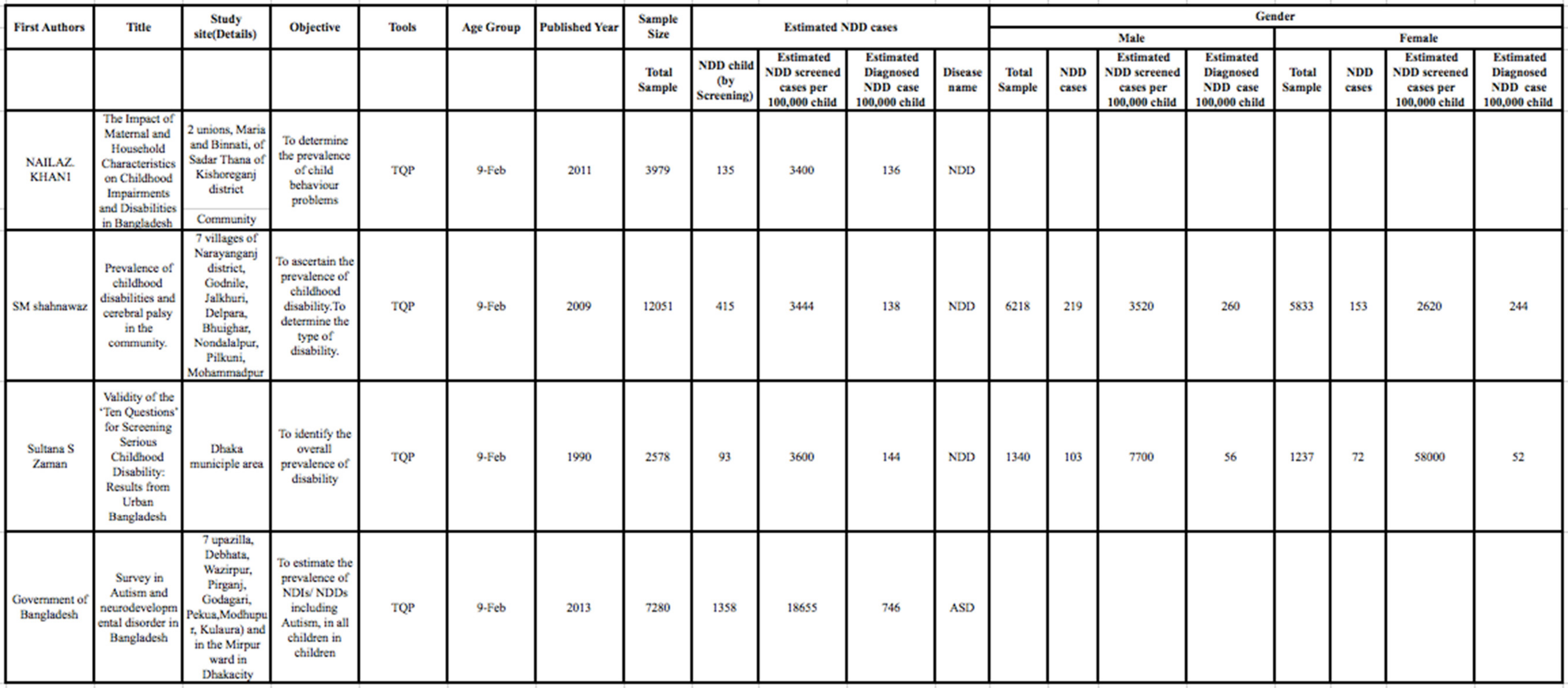
Based on the World Report, “research skills should be strengthened in a range of disciplines, including epidemiology, disability stud- ies, health, rehabilitation, special education, economics, sociology, and public policy.” Bangladesh can improve research on persons with NDDs by undertaking the following:

- The National Academy for Autism & Neurodevelopmental Disorders should begin conducting research on the impact of environmental factors (policies, physical environment, attitudes) on disability. Additional, NAANDD should research the quality of life and well being of people with disabilities in Bangladesh. This would include overcoming barriers and the effectiveness or current services and programs.

9 APPENDICES

Appendix 1: Trends and prevalence rate of NDD cases per 100,000 children 1990-2015

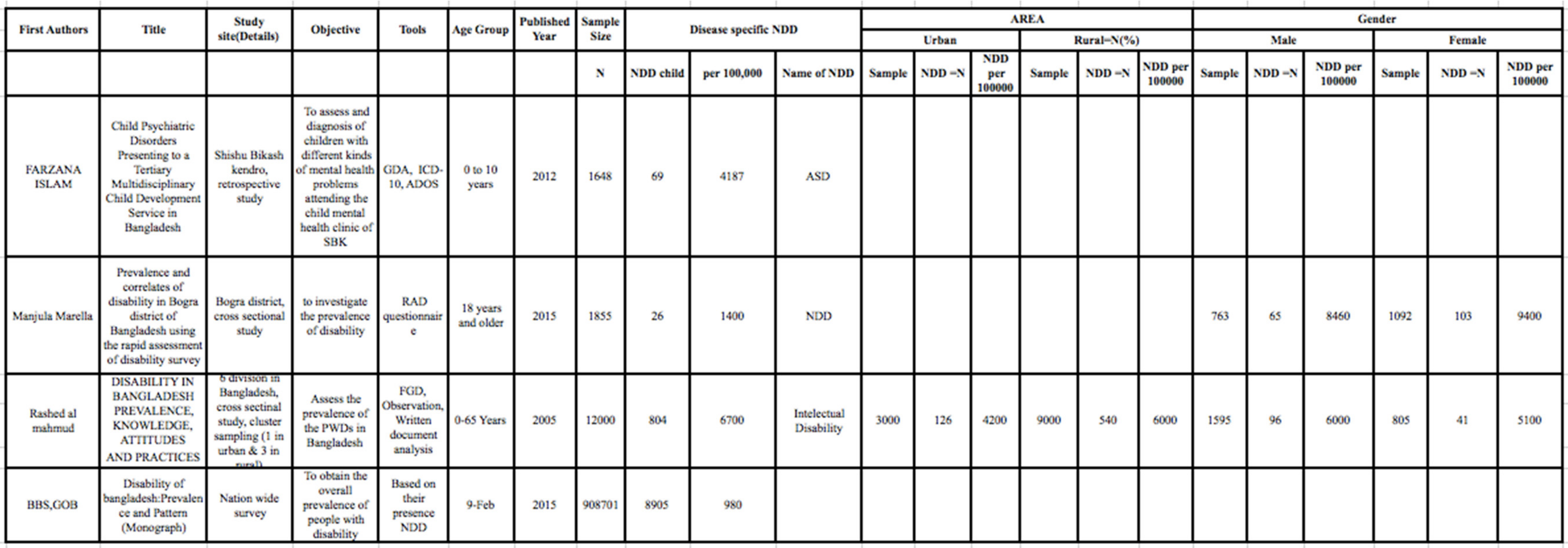
Table-1: Trends and prevalence rate of NDD cases per 100,000 children according to the screening tools and age group from 1990-2015



First Authors	Title	Study site(Details)	Objective	Tools	Age Group	Published Year	Sample Size	Estimated NDD cases				Gender							
												Male				Female			
							Total Sample	NDD child (by Screening)	Estimated NDD screened cases per 100,000 child	Estimated Diagnosed NDD case 100,000 child	Disease name	Total Sample	NDD cases	Estimated NDD screened cases per 100,000 child	Estimated Diagnosed NDD case 100,000 child	Total Sample	NDD cases	Estimated NDD screened cases per 100,000 child	Estimated Diagnosed NDD case 100,000 child
NAILAZ. KHAN1	The Impact of Maternal and Household Characteristics on Childhood Impairments and Disabilities in Bangladesh	2 unions, Maria and Binnati, of Sadar Thana of Kishoreganj district Community	To determine the prevalence of child behaviour problems	TQP	9-Feb	2011	3979	135	3400	136	NDD								
SM shahnawaz	Prevalence of childhood disabilities and cerebral palsy in the community.	7 villages of Narayanganj district, Godnile, Jalkhuri, Delpara, Bhuighar, Nondalalpur, Pilkuni, Mohammadpur	To ascertain the prevalence of childhood disability.To determine the type of disability.	TQP	9-Feb	2009	12051	415	3444	138	NDD	6218	219	3520	260	5833	153	2620	244
Sultana S Zaman	Validity of the 'Ten Questions' for Screening Serious Childhood Disability: Results from Urban Bangladesh	Dhaka municiple area	To identify the overall prevalence of disability	TQP	9-Feb	1990	2578	93	3600	144	NDD	1340	103	7700	56	1237	72	58000	52
Government of Bangladesh	Survey in Autism and neurodevelopmental disorder in Bangladesh	7 upazilla, Debhata, Wazirpur, Pirganj, Godagari, Pekua,Modhupur, Kulaura) and in the Mirpur ward in Dhakacity	To estimate the prevalence of NDIs/ NDDs including Autism, in all children in children	TQP	9-Feb	2013	7280	1358	18655	746	ASD								

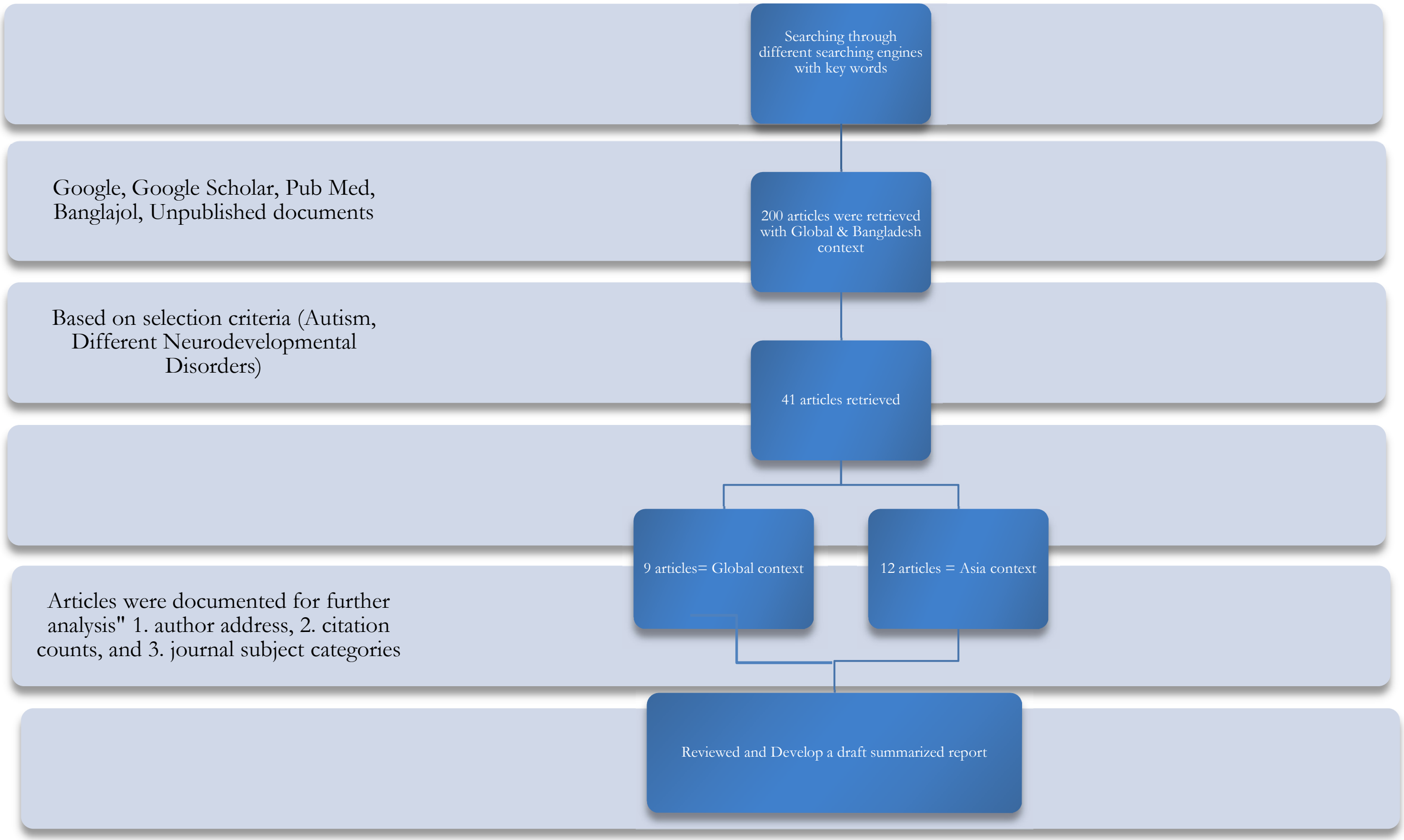
Appendix 2: Trends and prevalence rate of NDD cases per 100,000 children 2012-2015

Table-2: Trends and prevalence rate of NDD cases per 100,000 children according to the confirmatory diagnosed tools from 2012-2015



First Authors	Title	Study site(Details)	Objective	Tools	Age Group	Published Year	Sample Size	Disease specific NDD			AREA						Gender					
											Urban			Rural=N(%)			Male			Female		
							N	NDD child	per 100,000	Name of NDD	Sample	NDD =N	NDD per 100000	Sample	NDD =N	NDD per 100000	Sample	NDD =N	NDD per 100000	Sample	NDD =N	NDD per 100000
FARZANA ISLAM	Child Psychiatric Disorders Presenting to a Tertiary Multidisciplinary Child Development Service in Bangladesh	Shishu Bikash kendro, retrospective study	To assess and diagnosis of children with different kinds of mental health problems attending the child mental health clinic of SBK	GDA, ICD-10, ADOS	0 to 10 years	2012	1648	69	4187	ASD												
Manjula Marella	Prevalence and correlates of disability in Bogra district of Bangladesh using the rapid assessment of disability survey	Bogra district, cross sectional study	to investigate the prevalence of disability	RAD questionnaire	18 years and older	2015	1855	26	1400	NDD							763	65	8460	1092	103	9400
Rashed al mahmud	DISABILITY IN BANGLADESH PREVALENCE, KNOWLEDGE, ATTITUDES AND PRACTICES	6 division in Bangladesh, cross sectinal study, cluster sampling (1 in urban & 3 in rural)	Assess the prevalence of the PWDs in Bangladesh	FGD, Observation, Written document analysis	0-65 Years	2005	12000	804	6700	Intelectual Disability	3000	126	4200	9000	540	6000	1595	96	6000	805	41	5100
BBS,GOB	Disability of bangladesh:Prevalence and Pattern (Monograph)	Nation wide survey	To obtain the overall prevalence of people with disability	Based on their presence NDD	9-Feb	2015	908701	8905	980													

Appendix 3: Flow Chart for Literature Review



Appendix 4: Data matrix of literature review on prevalence of AND & psychiatric disorder in Bangladesh

Literature review was guided by theme. Such as, age and tool using for identification of NDDs. Most of the studies conducted on children with the age of 2 to 9 years old by using Ten Questionnaire plus (TQP) tool. Among these one study done by Bangladesh government to identify NDDs of the children with the age of 0 to 9 years old by using different tools, DSQ for 0 to 2 years children and TQP for 2 to 9 years old. For details matrix is given bellow containing five literatures.

Authors name/ Published year	Objectives	Pop	Study context	tool	Year of conducting study	Overall Prevalence (%)	Area		Gender		Age group	Disease Name
							Urban	Rural	Male	Female		
The Impact of Maternal and Household Characteristics on Childhood Impairments and Disabilities in Bangladesh. / 2012	To examine the risk factors associated with impairments and disabilities in children in Bangladesh	3979	Community. 2 unions Maria and Binnati, Kishoganj	TQP Community based survey	2001-2002	18.10%					2-9	Delay in sitting, standing, walking= 1.4 Seeing =1.6 Hearing =3.8 Understanding others =0.8 Move arms or legs =1.3 Seizures =10.0 Learning= 0.9 Speak and understand words = 1.1% Speech patterns =1.4 Mentally slow =0.8 Behavior Problem =0.6
		1018				4.60%						
Prevalence of childhood disabilities and cerebral palsy in the community./	To ascertain the prevalence of childhood disability			Survey,							2-3=21.5	Motor=9.6/1000

2009	To determine the type of disability. To identify the prevalence & types of cerebral palsy	12051	7 villages of Narayanganj district, Godnile, Jalkhuri, Delpara, Bhuighar,Nondalalpur, Pilkuni, Mohammadpury	TQP	2006-2007	30.80%			35.2/1000	26.2/1000	4-5=36.3 6-7=28.6 8-9=38.8	Speech=16.3/1000 Hearing=6.3/1000 Vision=6.1/1000 Cognitive=11.1/1000 Learning=8.5/1000
						CP=6.1/1000			6.8/1000	5.5/1000	2-3=4.4 4-5=9.8 6-7=4.2 8-9=5.7	

Validity of the 'Ten Questions' for Screening Serious Childhood Disability: Results from Urban Bangladesh. / 1990	To identify the validity of the ten questionnaire in terms of sensitivity, specifity. To identify the overall prevalence of disability.	2576	Dhaka municiple area, community	TQP,		6.90%			7.70%	5.90%	2-9	Vision=0.9 Hearing=1.9 Movement=1 Learning=.7 No speech=.9 Unclear speech=2
		359		Medical assessment form		16/1000						
Behaviour Problems in Young Children in Rural Bangladesh. /2009	To determine the prevalence of behavior or mental health problems in rural Bangladesh children. To assess the relationship between behavior problems and other impairment and with demographic factors	4003 453	Kishorganj rural area, community	TQ, Medical assessment form (MAF), Behavior checklist (BCL) Clinical assessment	2001-2003	1st stage: 0.174 2nd stage: 14.6%						Moto= 21%
		453				Behavior impairment 0.146						Motor, vision, cognitive= 21%
	To determine the validity of home-based screening to identify children at-risk for Neurdevelopmental			1st stage: HF, MCF, Developmental DSQ for 0-<2 yrs, Ten Questions Plus Questionnaire (TQP) for 2-9 yrs. 2nd stage: The Rapid Neurodevelopmental				Pirganj=9.36% Wazirpur=			1st stage: 2-9 year = 6.21%	2nd stage: Cerebral Palsies= 4/1000

Survey in Autism and neurodevelopmental disorder in Bangladesh ./ (2013)	Impairments(NDIs) /Neurodevelopmental Disabilities (NDDs), To estimate the prevalence of NDIs/ NDDs including	7280	7 upazilla, Debhata, Wazirpur, Pirganj, Godagari, Pekua,Modhupur , Kulaura) and in the Mirpur ward in Dhakacity	Assessment RNDA Stage 3: ADOS		Positivity=5.73%	Dhaka city (23%)	2.30%			0-<2 year = 3.82%	Cognitive Disorder= 46/1000 Developmental Motor Disorder 0.012 Expressive Language Disorder= 20/1000 Seizures/Epilepsies = 7/1000 Total ASD=1.55/1000 ASD , Dhaka=30/1000 ASD , Rural=.68/1000
		1201				Mean weighted Prevalence of NDI/NDD: Stage 1: Mean weighted prevalence of any NDI or NDD = 185/1000	Dhaka city =290/1000	Godagari =490/1000 Modhupur =301/1000 Debhata =90/1000				Mean weighted Prevalence of NDI/NDD: Stage 2: Gross motor= 36/1000 fine motor=45/1000 vision=12/1000 hearing=27/1000 expressive language=56/1000 cognition=158/1000 seizures=17/1000

Appendix 5: Summary of Literature Review

Literature review guided by the theme of age (0->65) years and screening tools

Authors name/ Published year	Objectives	Pop	Study context	tool	Year of conducting study	Overall Prevalence (%)	Area		Gender		Age group	Disease Name
							Urban	Rural	Male	Female		
Child Psychiatric Disorders Presenting to a Tertiary Multidisciplinary Child Development Service in Bangladesh. / 2012	To assess and diagnosis of children with different kinds of mental health problems attending the child mental health clinic of SBK	300	Shishu Bikash kendro, DSH	GDA, DSM-IV and ICD-10, ADOS. retrospective study	2004-2006	**94%**	6	2.5	2.4	1	0->10	**Autism spectrum disorder=23**% Developmental delay= 63% Intellectual deficit= 44% Hyperkinetic disorder= 33% Pervasive Developmental Disorders = 29%, Neurological= 61% Psychosocial problems = 54%

Prevalence and correlates of disability in Bogra district of Bangladesh using the rapid assessment of disability survey. 2015	to investigate the prevalence of disability To assess the socio-economic factors associated with disability among people aged 18 years and older	1855	Bogra district, Community	RAD questionnaire Cross sectional study	2010	10.5 % , 95 % CI: 8.8, 12.2)			8.5 %; (95 % CI: 6.8, 10.5)	9.4 %; (95 % CI: 7.8, 11.2)	18 years and older	psychological distress= 4.7 %; (95 % CI: 3.8, 5.7) vision =4.4 %;(95 % CI: 3.6, 5.4) hearing =2.3 %; (95 % CI: 1.7, 3.0)
DISABILITY IN BANGLADESH PREVALENCE, KNOWLEDGE, ATTITUDES AND PRACTICES. 2005 (HI), the National Forum of Organizations Working with the Disabled (NFOWD) and the Unnayan	Assess the prevalence of the PWDs in Bangladesh. find out the causes of disability. Investigate the social status of the PWDs	12000	6 division in Bangladesh, cross sectinal study, cluster sampling (1 in urban & 3 in rural)	FGD, Observation, Written document analysis and Questionnaire survey	*2005*	*5.6%*	4.2%	6%	6%	5.1%	**0-5 =2%** **6-15 =3.5%** **16-30 =3%** **31-50 =6.6%** **51-64 =13.4 %** **≥64=26.4**	hearing =18.6% visual =32.2% speech= 3.9% physical =27.8% intellectual =6.7% multiple =10.7%

Onneshan/ 2005	recommend relevant information for advocacy purposes .											

Appendix 6: Data matrix of literature review on AND & psychiatric disorders in global context including Asia:

No.	Title	Reference	Objective	Methodology	Result	Conclusion/ Recommendation
1	Systematic review of prevalence studies of autism spectrum disorders. **USA, 2006**	Williams, J. G., Higgins, J. P., & Brayne, C. E. (2006). Systematic review of prevalence studies of autism spectrum disorders. Archives of disease in childhood, 91(1), 8-15.	To quantitatively examine the influence of study methodology and population characteristics on prevalence estimates of autism spectrum disorders	**Cross-sectional** study or first phase of a **longitudinal study** **Assessment:** Prospective, retrospective **Screen method:** Routine checks, letter of referrals, questionnaire, records **Literature searches**: systematically searched two databases; **MEDLINE (1966-2004) and EMBASE, (1980–2004)** and bibliographies of previous reviews 77 papers were identified for detailed examination, **Defined diagnostic criteria**: stated for autism (37) or autism spectrum	**The overall prevalence** typical autism was 7.1 per 10 000 (95% CI 1.6 to 30.6) and of all ASD was 20.0 per 10 000 (95% CI 4.9 to 82.1).	Sixty one per cent of the variation in prevalence estimates of typical autism was explained by these models. Diagnostic criteria used, age of children screened, and study location may be acting as proxies for other study characteristics and require further investigation.

				disorder (23) **Sample screened**: Population & clinic based **Tools**: Diagnostic criteria used ICD-10 or DSM-IV, Kanner, Rutter Includes **individuals under 18 years old** **Univariate meta-regression** analyses used to estimate the associations between study covariates and prevalence **Odds ratios (OR)** used to summarized the prevalence **Study locations**: Japan, North America, Europe, Scandinavia		
2	Psychopathology in Children and Adolescents with Autism compared to Young People with Intellectual Disability **Australia, 2006**	Brereton, A. V., Tonge, B. J., & Einfeld, S. L. (2006). Psychopathology in children and adolescents with autism compared to young people with intellectual	This study investigates the level and pattern of emotional and behavioral problems in young people with autism	**Study design**: Cohort study **Target population** were 381 with autism and a representative group of 581(from the Australian Child and	significant differences between the two groups for age (t = -17.567, df = 931, P < .001), sex (χ2=73.602, df = 1, P < .001) Young people with autism were found	Environmental and family responses influenced by the perceptual and interactional distortions of autism Have to improved education, welfare providers and clinicians knowledge of of a range of emotional and behavioural problems.

		disability. Journal of autism and developmental disorders, 36(7), 863-870.	compared with children with intellectual disability (ID)	Adolescent Development Study (ACAD)) with ID aged 4–18 years both urban & rural **Tools**: Developmental Behavior Checklist (DBC-P), DSM-IV to assessment IQ range, TBPS to determine the level of psychopathology **Analysis of variance** (ANOVA) & Multivariate ana\is of covariance (MANCOVA) was computed **Study Location** was across three states of Australia: Victoria, New South Wales and South Australia.	to suffer from significantly higher levels of psychopathology than young people with ID Level of psychopathology in the autism cohort is high (mean 61.2) with 73.5% of the autism cohort subjects scoring well above the clinical case cut-off score of 46 Mean scores on all subscales with the exception of anti-social are also high in comparison with the DBC-P normative sample of ID children	
3	Asperger Syndrome, Autism and Attention Disorders: A Comparative Study of the Cognitive Profiles of 120 Children **Sweden, 1997**	Ehlers, S., Nydén, A., Gillberg, C., Sandberg, A. D., Dahlgren, S. O., Hjelmquist, E., & Odén, A. (1997). Asperger syndrome, autism and attention disorders: A comparative study	To evaluate the discriminating ability of the WISC in respect of **autism,asperger syndrome and attention disorders**. To identify	**Target group** were 120 children for ages 6-15.4 years **Tools**: The Wechsler Intelligence Scale for Children-Revised (WISC-R) was applied (in a Swedish version)	The overall rate of correct diagnostic classification was 63%. The discriminating variables and scores across groups, Comprehension (Asperger syndrome > autism,	The subtest results of the WISC provide cognitive peaks and troughs within and across different clinically defined groups Asperger syndrome and autism share certain WISC cognitive deficits The Asperger syndrome and autism groups show a clear overlap of symptoms in the areas of social interaction, communication and behaviour

		of the cognitive profiles of 120 children. *Journal of Child Psychology and Psychiatry*, *38*(2), 207-217.	characteristic of WISC subscore profiles within each of the three diagnostic groups.	Using stepwise **logistic regression** analysis One-way analysis of variance **(ANOVA**) and least Significant Difference test **(Fisher's PLSD)** were used for descriptive statistics and comparison of mean scaled scores across diagnostic groups, and **unpaired ^tcsts** were used for analyses of differences between clinical and population cases between males and females and across subgroups in the analysis of **Kaufman factors** **WISC profiles** were analyzed within each group. **Study Location** was Sweden	DAMP > autism). Picture Arrangement (DAMP > autism, Asperger syndrome > autism). Information (Asperger syndrome > DAMP) and Block Design (autism > DAMP) differentiated between the groups The Asperger syndrome group scored relatively high on Verbal Comprehension, the autism group relatively high on Perceptual Organisation and the DAMP group relatively low on Freedom from Distractibility. Of the intragroup comparisons, only Verbal Comprehension vs. Freedom from Distractibility in the Asperger syndrome group (p = .005) and in the DAMP group (p = .0004) were significant	

4	Global Prevalence of Autism and Other Pervasive Developmental Disorders **South east Asia, the eastern Mediterranean, Europe, Western pacific, and America** **2012**	*Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcín, C. & Yasamy, M. T. (2012). Global prevalence of autism and other pervasive developmental disorders. Autism Research, 5(3), 160-179.*	To provide a systematic review of epidemiological surveys of autistic disorder and PDDs worldwide To consider the possible impact of geographic, cultural/ethnic, and socioeconomic factors on prevalence estimates and on clinical presentation of PDD	**Systematic Review Methodology** According to **WHO classification** different countries were grouped into sub regions **Search strategy** was to perform extensive region and/or country-specific search of Medline publications **600 studies** were reviewed 95% confidence intervals (CI) for the estimate. **Diagnostic criteria**: Rutter, ICD-9 &10, DSM-iii, DSM-iii-R,DSM-iv, DSM-iv-TR **Case Identification** existing service providers **databases multistage** approach **systematic sampling** techniques	The prevalence estimates of autism spectrum disorders was 62/10 000. prevalence estimates have increased over time and vary in different neighboring and distant regions	**Rational of the study:** The first attempt to review available evidence from different world regions, including low and middle-income countries where research capacity is limited **Recommendation:** Critical need for further research for more evidence Capacity building in low- and middle-income countries

				Case Evaluation After completed the **screening** identified as positive screening for more **in-depth diagnostic** evaluation Source of information Used **randomly selected** sub sample **Age**: 0-21 **Study Period**: 1966-2012		

05	**Prevalence of Autism Spectrum Disorders- Autism and Developmental Disabilities Monitoring** **Network, United States, 2006**	Baio, J. (2012). Prevalence of Autism Spectrum Disorders: Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. Morbidity and Mortality Weekly Report. Surveillance Summaries. Volume 61, Number 3. *Centers for Disease Control and Prevention*	01. To identify the presence of Neuro developmental disorder 02.To estimate the prevalence of Autism Spectrum Disorders	**Systematic retrospective review, Cross-sectional study** Data were collected from existing records in 11 ADDM Network sites **Study area-** Alabama, Arizona, Colorado, Florida, Georgia, Maryland, Missouri, North Carolina, Pennsylvania, South Carolina, and Wisconsin, 2006 To identify ASD prevalence, CDC compared the 2006 data with data collected from 10 sites (all sites noted above except Florida) in 2002. **Poisson distribution binomial** was used to calculate 95% confidence intervals (CIs) for prevalence rates. **Chi-square tests** were used to compare	Overall average **prevalence of 9.0 per 1,000 population** (95% confidence interval [CI] = 8.6--9.3). ASD prevalence per 1,000 children aged 8 years ranged from **4.2 in Florida to 12.1 in Arizon**a and **Missouri**, with prevalence ranging between **7.6 and 10.4.** For 2006, ASD prevalence was significantly lower in **Florida (p<0.001)** and **Alabama (p<0.05)** and higher in **Arizona and Missouri (p<0.05)** The ratio of males to females ranged from 3.2:1 in Alabama to 7.6:1 in Florida. Of 10 sites that collected data for both the 2002 and 2006 surveillance years, nine observed an increase in ASD prevalence (range: **27%--95%**	**These results indicate an increased prevalence of identified ASDs among U.S. children aged 8 years and urgent public health concern.** **Recommendation:** **01. Need to regard ASDs as an urgent public health concern.** **02. Continued monitoring is needed to document and understand changes over time, including the multiple ascertainment and potential risk factors.** **03. Research is needed to ascertain the factors that put certain persons at risk are essential to provide support for persons with ASDs, their families, and communities to improve long-term outcome.**

				prevalence estimates	increase; **$p<0.01$**), with increases among males in all sites and among females.	
06	Trends in the Prevalence of Developmental Disabilities in US Children, 1997–2008 **United States, June 2011**	Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M. ... & Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997–	01. To determined the prevalence of developmental disabilities in US children. 02.To determined the prevalence of selected	**Interview Surveys,** National Health,1997–2008 **Participant-** children aged 3 to 17 years **Study area-** ongoing nationally representative samples of US households	Boys had a higher than selected disabilities compared with girls. Hispanic children had the lowest prevalence compared with non-Hispanic white and black children.	The number of children with selected developmental disabilities has increased, requiring more health and education services which are bearing on the need for health, education, and social services, including the need for more specialized health services (mental health services, medical specialists, therapists, and allied health professionals). **<u>Recommendation</u>**: 01. The consequent burden on families and

		2008. *Pediatrics*, peds-2010.	populations for a recent 12-year period 03.To assessed secular trends for each disability over 4-3 year time intervals	- **Sample-** multistage probability sample - **Tools**-NHIS Questions on Developmental Disabilities, 1997–2008 - **Parent-reported diagnoses**: attention deficit hyperactivity disorder; intellectual disability; cerebral palsy; autism; seizures; stuttering or stammering; moderate to profound hearing loss; blindness; learning disorders; and/or other developmental delays - **Analysis- χ^2 Tests** were used to determine the prevalence estimates. **Wald-F tests** were used to assess linear trends over the 4-calendar-year time periods	- Low income and public health insurance were associated with a higher prevalence of many disabilities. - Prevalence of any developmental disability increased from 12.84% to 15.04% over 12 years. Autism, attention deficit hyperactivity disorder, and other developmental delays increased, whereas hearing loss showed a significant decline. These trends were found in all of the sociodemographic subgroups, except for autism in non-Hispanic black children.	caregivers will need to be considered. 02. More detailed study of risk factor shifts, changes in acceptance, and benefits of early services are needed to better understand why these shifts have occurred.

07	**Prevalence of autism according to maternal immigrant status and ethnic origin** **Canada, 2011**	Dealberto, M. J. (2011). Prevalence of autism according to maternal immigrant status and ethnic origin. *Acta Psychiatrica Scandinavica*, *123*(5), 339-348.	**To examine the rates of autism separately according to maternal immigrant status and ethnic origin in respect to the vitamin D insufficiency hypothesis**	**Observational studies in epidemiology.** **Tools-Articles were identified by electronic searches** **Analysis-Relative Risk, Attributable Risk multivariate techniques use**	**The risk was highly significant of autistic disorders than other developmental disorders.** ARR = 1.6 vs. RR = 1.2 ARR = 2.3 vs. = 1.1 ARR = 0.91 overall, 0.65 for autism and 1.22 for other disorder	**Results are consistent with the maternal vitamin D Insufficiency hypothesis.** **This review stresses the importance of monitoring vitamin D levels in pregnant women, especially those who are immigrant, dark-skinned or veiled, and the urgency of randomized controlled trials**
08	**Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)** **UK, 1991**	Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The lancet*, *368*(9531), 210-215.	**To prevalence of disorders of the autism spectrum in a south east children**	**Study- cohort study** **Total population- 56 946 children aged 9–10 years** **Sample-A stratified sample** **Study area-**South East, UK	**The prevalence of childhood autism was 38·9 per 10 000 (95% CI 29·9–47·8) and that of other ASDs was 77·2 per 10 000 (52·1–102·3), making the total prevalence of all ASDs 116·1 per 10 000 (90·4–141·8). Provided a prevalence of 24·8 per 10 000 (17·6–32·0).** **The male to female ratio for all ASDs (3 · 3:1)**	Whether the increase is due to better ascertainment, broadening diagnostic criteria or increased incidence is unclear. **Recommendation:** **Services in health, education, and social care will need to recognize the needs of children with some form of ASD, who constitute 1% of the child population.**

09	The prevalence of autism spectrum disorders: impact of diagnostic instrument and non-response bias. **Norway**, 2010.	Posserud, M., Lundervold, A. J., Lie, S. A., & Gillberg, C. (2010). The prevalence of autism spectrum disorders: impact of diagnostic instrument and non-response bias. *Social psychiatry and psychiatric epidemiology*, *45*(3), 319-327.	To estimate prevalence of autism spectrum disorders (ASD) To validate the Development and Well-Being Assessment (DAWBA) ASD diagnoses To explore the impact of non-response on ASD prevalence estimates	A total population (N= 9,430) of 7- to 9-year olds was screened for ASD with the **autism spectrum screening questionnaire (ASSQ).** Children scoring above the 98th percentile on parent and/or teacher ASSQ were invited to participate in the **second** and subsequently in the **third phase** where they were assessed for ASD using the **Development and Well-Being Assessment (DAWBA),** and the **Diagnostic Interview for Social and Communication disorders (DISCO),** respectively.	DISCO-generated minimum prevalence for ASD was 0.21% whereas estimated prevalence was 0.72%, increasing to 0.87% when adjusting for non-responders. The DAWBA estimate for the same population was 0.44%	Large variances in prevalence rates across studies can be explained by methodological differences.
10	Epidemiological and clinical study of autistic children in Yogyakarta, Indonesia	Wignyosumarto, S., Mukhlas, M., & Shirataki, S. (1992). Epidemiological and clinical study of	To estimate the prevalence of autistic children	A **cross-sectional** study on non-verbal intelligence, social maturity behavior or	**The prevalence** rate of autism within the birth cohort was **12** per 10,000	Autistic children showed more attachment, directed more social-interaction and more physical contact toward their mothers than to strangers during the reunion situation

	Yogyakarta, Indonesia 1992	autistic children in Yogyakarta, Indonesia. The Kobe journal of medical sciences, 38(1), 1-19.		adaptive skills test by using statistical or sampling controls **Target population** were 5,120 children **Study Period: Jnue 1984- May 1991** **Tools** used for autistic children evaluation Bryson's screening scale , CARS to diagnosis **For social interaction used two groups (6 autistics and 6 normal children)**		
11	Trend study of autistic spectrum disorders at Queen Sirikit National Institute of Child Health **Bangkok, Thailand, 2005**	Plubrukarn, R., Piyasil, V., Moungnoi, P., Tanprasert, S., & Chutchawalitsakul, V. (2005). Trend study of autistic spectrum disorders at Queen Sirikit National Institute of Child Health. Journal of Medical Association of Thailand, 88, 891-897.	To estimate the trend in autistic spectrum disorder patients To find the factors that correlate with the incidence of this disorder.	A hospital-based **prospective trend study** **Study population**: 610 new patient **Study period**: January 1998 to December 2002 **Aged less than 12 years** old **Study Location**: Child and Adolescent Department, Queen Sirikit National Institute of Child	The increasing trend in the **incidence of autistic spectrum disorder** is observed (r = 0. 935, p = 0. 02). The incidence rate of autistic spectrum disorders among out patients has **increased** from **1.43** per 10, 000 in 1998 to 6.94 per 10, 000 in 2002. The correlation factors "**an only**	A significant increase in the incidence of autistic spectrum disorders was observed **Rational of the study:** There are only a few reports on the trend of this problem in Thailand though the incidence and prevalence increased in USA and Europe **Recommendation:** Need further study to explain the increase by a solid evidence

				Health, Bangkok, **Study design**: Related factors were recorded and analyzed Aged-adjusted incidence rate in both sexes Used **Standard t-test and correlation coefficient**	**one child in the family**" is observed (r = 0.9, p = 0.038).	
12	Prevalence of Autism Spectrum Disorder in a total population sample **South Korea, 2011**	Kim, Y. S., Leventhal, B. L., Koh, Y. J., Fombonne, E., Laska, E., Lim, E. C., ... & Song, D. H. (2011). Prevalence of autism spectrum disorders in a total population sample. American Journal of Psychiatry, 168(9), 904-912.	To estimate the prevalence and describe the clinical characteristics of ASDs in school-age children	**Target population** was 7- to12-year-old children (N=55,266); all children born from 1993 through 1999 **Study location**: Ilsan district of Goyang City, South Korea **Study period:** 2005 and 2009 **The study used** a high-probability group (special education schools) a disability registry and a low-probability, (regular schools) **Procedure**: Four stages **Screening** tools **ASSQ (September 2005–August**	The **estimated prevalence** of ASDs was 2.64% (CI=1.91–3.37), with 1.89% (CI=1.43–2.36) in general-population sample and 0.75% (CI=0.58–0.93) in the high-probability group. **Sex-specific prevalence** 3.74% for **boy**s 1.47% for **girls** male-to female ratios were 2.5:1 and 5.1:1 in the general population sample and high probability group, **Previously**	Sensitivity analyses indicate that these differences are minimal **Rational of the study:** To overcome the uncertainty of experts disagree about the causes and significance of the recent increases in the prevalence of ASDs for limited data on population base rates **Recommendatioon:** For better detection, assessment, and services Need rigorous screening Need comprehensive population coverage

				2006) **Sampling** **Diagnostic assessment (February 2006–July 2009)** tools : the Autism Diagnostic Observation Schedule (**ADOS**), the Autism Diagnostic Interview–Revised (**ADI-R**), and **cognitive tests** **quality control** (reliability and validity) Analytical tools used **SAS;** **Sensitivity analysis (95% confidence interval)**	**reported** estimates ranging from 0.6% to 1.8% Estimated prevalence **0.75%** in the **high-probability** group. Prevalence for ASD subtypes were 0.94% = **autistic disorder** ii.1.70% = other ASDs; **.** Prevalence estimates of any ASD diagnosis Highest= 2.69% I]=2.20–3.18) to 2.74% (CI=2.25–3.24) Lowest= 2.44% (CI=1.81–3.07) to 2.75% (CI=1.96–3.55	
13	Neurodevelopmental outcome of high risk newborns discharged from special care baby units in a rural district in **India**. **2015**	Chattopadhyay, N., & Mitra, K. (2015). Neurodevelopmental outcome of high risk newborns discharged from special care baby units in a rural district in India. Journal of public health research, 4(1).	To assess the neuro-developmental outcome of high-risk newborns To identify the factors associated with neuro-developmental	Observational **cohort study** **Target population**: n=427 (sex: male=269/ 62.9%, female=158/ 37.1%) **Age distribution: 0-24 months** **Study period**:	Developmental delay was **detected in 31.6%** of study population **Sex distribution** among the children with developmental delay 67.9% male 32.1% female, Prevalence of NDD	Incidence of NDD among high risk newborns is significantly high with LBW prematurity and neonatal illnesses are major contributors Developmental delay showed male predominance, but the ratio does not vary significantly from that of the general study population **Recommendation:** Timely detection with proper screening Need early community intervention

			delay in the study population.	January 2010 to June 2012 **Study Location**: District Hospital, Purulia (India) **Tools used**: Denver Developmental Screening Tool (DDST) II, Trivandrum Developmental Screening Chart (TDSC)and Amiel-Tison method of tone assessment. **Study procedure: 20 blocks in the district** **A meticulous door to door tracking** **Target population was tracked to their home address by the hospital**	was significantly higher in low birth weight (LBW, >2 kg), preterm (<36 weeks) and twins	
14	Neurodevelopmental outcome of high-risk newborns discharged from NICU in a tertiary-care hospital of **western India ,2015**	Modi, R., Patel, J., & Mishra, A. (2016). Neurodevelopmental outcome of high-risk newborns discharged from NICU in a tertiary-care hospital of western India. International Journal	To assess the level of NDD using standard scale Association between the risk factors and level of developmental delay	prospective, observational study **Target population: n=50** **Age**: Neonate to 12 months **Study location**: Neonatal intensive care unit (NICU) of a tertiary-care hospital in	**Developmental delay was detected in 50%** of study population **Type of neuro developmental delay** by TDSC **Moderate=32%** **Severe=68%**	Incidence of NDD among high-risk newborns is significantly high, with LBW, prematurity, and birth asphyxia being major contributors **Rational of the study:** Not enough awareness about the abovementioned facts and that neurodevelopment assessment, often fail to recognize the delay to start early intervention.

		of Medical Science and Public Health, 5(7).		Ahmedabad city, Gujarat, India **Study period**: January 2010 and June 2012 **Tools**: Developmental Screening Chart (TDSC, Denver Developmental Screening Test (DDST), Bayley developmental screening tool, developed and validated in India **Procedure**: Enrolled the child 2011 and call for follow up at 3, 6, 9 and 12 months Used Epi-info 7 for data analysis t- test for frequency distribution		**Recommendation:** Most NDDs go undetected in the early years of life At the grass-root level improved Perinatal care Early detection, Early inter-vention to bring down incidence of developmental challenges
15	Infant Motor Delay and Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations in **Japan ,2016**	Hatakenaka, Y., Kotani, H., Yasumitsu-Lovell, K., Suzuki, K., Fernell, E., & Gillberg, C. (2016). Infant Motor Delay and Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical	To explore early motor delay is often an indication of ESSENCE	One-year **cohort study (**April 1, 2007, to March 31, 2008**)** **Target population** were **30** Study location: Kochi Prefectural Medical and Welfare Centre, Kochi City in southern Japan	**Prevalence of ESSENCE*** disorders was **(87%)** 13 (8 boys and 5 girls) * **ESSENCE=Early symptomatic Syndromes Eliciting Neurodevelopment**	Young children, presenting with motor problems always need a broad clinical assessment, not just related to motor function, and systematic follow-up Few, studies have been performed with a view to following up a clinically representative cohort of children coming for assessment of motor delay before age 2 years

		Examinations in Japan. Pediatric neurology, 54, 55-63.		Children who came to a Japanese neurodevelopmental center before their second birthday because of **delayed or abnormal gross motor development** Retrospective and prospectively data Tools: followed up from the ESSENCE viewpoint	**al Clinical Examinations** - including attention-deficit/hyperactivity disorder (ADHD), ASD, speech and language disorder (SLD), intellectual developmental disorder (IDD) and epilepsy	
16	Exploring the Underdiagnosis and Prevalence of Autism Spectrum Conditions in Beijing **Beijing, China, 2015**	Sun, X., Allison, C., Matthews, F. E., Zhang, Z., Auyeung, B., Baron-Cohen, S., & Brayne, C. (2015). Exploring the Underdiagnosis and Prevalence of Autism Spectrum Conditions in Beijing. Autism Research.	to apply current screening and standardized diagnostic instruments to a Chinese population to establish a prevalence estimate of ASC in an undiagnosed population in mainland China	Target population: n= 737 aged 6-10 (primary school pupils) **Diagnostic assessments**: The Mandarin Childhood Autism Spectrum Test (**CAST**) for screening, Autism Diagnostic Observation Schedule and the Autism Diagnostic Interview-Revised 95% confidence interval Kolmogorov–Smirnov test, inear	The preliminary **prevalence** estimated 9.3 **(95% CI: 1.9,16.7)** Using the UK cutoff (≥15), **CAST performance has 84% sensitivity and 96% speci**ficity [CI]: 46, 98, and 96, 97, respectively).	Need to development of research, healthcare, and education services , policy for children with ASC Large population based study is needed

				regression		
17	A review of the prevalence of Autism Spectrum Disorder in Asia **Asia, October 2009**	Sun, X., & Allison, C. (2010). A review of the prevalence of autism spectrum disorder in Asia. *Research in Autism Spectrum Disorders*, *4*(2), 156-167.	**To estimate the over time of prevalence of Autism Spectrum Disorder in Asia**	**Three databases were used in this review (1980 to November 2008)** **After full examination, data were extracted from each study including first author, year of publication, country, region and area of study, screening strategy and information source, diagnostic criteria and strategy, age of diagnosis, size of population, reported prevalence estimate of ASD**	**The prevalence of ASD in these studies selected in this review ranged from 0.32/10,000 to 250/10,000 Chinese study 250/10,000 and Iranian study 190/10,000** After excluding these three studies, the reported prevalence was between **1.1/10,000 and 21.8/10,000**. The average prevalence of ASD before 1980 was around 1.9/10,000 while It was **14.8/10,000 from 1980 to present**. The median prevalence of ASD among 2–6-year old children who are reported in China from 2000 upwards was 10.3/10,000. ASD is	The major difficulties surrounding estimating the prevalence of ASD in Asia are in the differences in screening instruments and diagnostic criteria within different countries. **<u>Recommendations</u>:** . **More research in the prevalence of ASD is required in those countries.** . **Preferable to have common methodology in future research.** . **There is a need to address this issue in order to obtain more reliable information, worldwide.** . **More high quality surveys are required.** . **Countries in Asia such as Korea and Singapore conducted etiological research on autism while prevalence data are lacking.**

					probably more common in Asia than previously thought	
18	Prevalence of autism in mainland China, Hong Kong and Taiwan: a systematic review and meta-analysis. **Asia, 2013**	Sun, X., Allison, C., Matthews, F. E., Sharp, S. J., Auyeung, B., Baron-Cohen, S., & Brayne, C. (2013). Prevalence of autism in mainland China, Hong Kong and Taiwan: a systematic review and meta-analysis. *Mol Autism*, *4*(1), 7.	**To estimate the Prevalence of autism in mainland China, Hong Kong and Taiwan**	Systematic review and meta-analysis study **Study area:** mainland China, Hong Kong and Taiwan. The effects of research methodology on the **Tools:** Systematic literature searches well as relevant papers from 1987 to 2011 Behavior Checklist (ABC) Clancy Autism Behavior Scale (CABS) **Analysis:** Estimates of prevalence were calculated with a random effects model and **assessed using a meta-regression model**	There were 25 studies eligible for review, 18 were suitable for inclusion in a meta-analysis. ▪ Pooled prevalence of childhood autism was **11.8 per 10,000** individuals (95% confidence interval (CI): 8.2, 15.3) in mainland China. ▪ Pooled prevalence of ASC was **26.6 per 10,000** (95% CI: 18.5, 34.6) in three areas. Substantial heterogeneity was identified between studies (I2>75%). ▪ The prevalence estimate of childhood autism was most strongly associated with the choice of screening instrument and after adjustment for age	Prevalence of ASC in China, Hong Kong and Taiwan have focused mainly on childhood autism rather than the whole spectrum. The prevalence of estimates is lower than estimates from developed countries. Studies using more recently developed screening instruments reported higher prevalence than older ones. **<u>Recommendations</u>:** Available studies have methodological weaknesses and therefore these results lack comparability with those from developed countries. Our findings indicate a potential under-diagnosis and under-detection of ASC in mainland China, Hong Kong and Taiwan, and a need to adopt more advanced methods for research of ASC in these areas.

					group, the odds ratio when using the Autism Behavior Checklist (ABC) as the screening instrument compared with those using the Clancy Autism Behavior Scale (CABS) was **0.29** (95% CI: 0.12, 0.69), and **1.79** (95% CI: 0.70, 4.55; P= 0.20) when using the Checklist for Autism in Toddlers (CHAT) compared to the CABS.	
19	Attention-deficit hyperactivity disorder in children chronically exposed to high level of vehicular pollution. **India, 2011**	Siddique, S., Banerjee, M., Ray, M. R., & Lahiri, T. (2011). Attention-deficit hyperactivity disorder in children chronically exposed to high level of vehicular pollution. *European journal of pediatrics*, *170*(7), 923-929.	To identify the prevalence of attention-deficit hyperactivity disorder (ADHD) To explore whether sustained exposure to high level of urban air pollution has any impact on the behavior and activities of	In a cross-sectional study 969 school-going children (9–17 years) and 850 age- and sex-matched children from rural areas were assessed, following the criteria of Diagnostic and Statistical Manual of conduct disorders (DSM-IV) of American Pediatric Association.	ADHD was diagnosed in 107 children (11.0%) of Delhi, in contrast to 2.7% (23/850) of control children. It was prevalent among **18.0% of the boys** enrolled in Delhi against **4.0% of the girls**, giving a **male/ female** ratio of **4.5:1**. In the control group, 4.3% of the boys and 1.0% of the girls	Though gender, socioeconomic status, and age play a very important factor in ADHD prevalence, the association is highest between particulate pollution and prevalence of ADHD. Policies are necessary to reduce environmental exposure and adverse health effects in children. Researchers and pediatricians may contribute to the improvement of children's environmental health by risk communication and health advocacy at community and government levels.

			the children.	Data of ambient particulate matter with a diameter of less than 10 µm (PM10) were obtained from Central Pollution Control Board and aerosol monitor.	had the disorder, giving a male/female ratio of 4.3:1.	
20	Challenges for Transformation: A Situational Analysis of Mental Health Care Services in Sehore District, **Madhya Pradesh**	Shidhaye, R., Raja, A., Shrivastava, S., Murhar, V., Ramaswamy, R., & Patel, V. (2015). Challenges for transformation: a situational analysis of mental health care services in Sehore District, Madhya Pradesh. *Community mental health journal*, *51*(8), 903-912.	What is the broader policy environment and overall programme context for implementation of mental health programme in Sehore district? What is the current status of the organization of the mental health services, availability of human and financial resources and to what extent are the mental health services integrated in the primary health care system?	The situational analysis was conducted in two parts. Document review was conducted to capture the information related to broader socio-economic and cultural context, mental health policies and plans, treatment coverage, district level health services, community factors and monitoring and evaluation of mental health services. **FGD:** FGDs with the community health workers and the members of	Service delivery and demand related findings are presented. The service delivery side results are presented using the domains of World Health Organization's Assessment Instrument for Mental Health Systems (WHO-AIMS) including policy and legislative framework, mental health services, mental health in primary care, human resources, public education, and monitoring and research (WHO 2005)	

			What are the gaps in mental health service delivery and what are the reasons for these gaps?	community covering the topics including knowledge of the mental disorders, type and quality of the services provided, accessibility and acceptability of the services, adequacy of training and capacity building, and resource constraints and needs. **IDI**: 11 IDIs were conducted, four with the State level policy makers, three specialists working in the Department of Health Services and four general health service providers and health managers.		

Appendix 7: Literature on situation analysis on AND in Bangladesh:

	Title	Reference	Objective	Methodology	Results	Conclusion/recommendation
13	Disability in Bangladesh: situation analysis 2004.	Danish Bilharziasis Laboratory for the World Bank, People's Republic of Bangladesh, 2004. Disability in Bangladesh: A Situation Analysis.	To assess current prevalence, severity, causes of disability with a particular focus on children. To map and assess the scope of the current situation and initiatives in the public sector, the private sector, among Non-Governmental Organizations (NGOs) and in communities as well as the linkages between initiatives To offer short and longer term recommendations for further research, policy development and support for interventions in relevant sectors (health, education, labor etc)	**Study site:** Dhaka, Jessore, Jhenaidah districts to visit. **Data collection method**: Desk review based on Internet sources and input from stakeholders in Bangladesh. A series of meetings with selected key stakeholders, disabled children and adults in three districts. Visits organizations and intervention sites.	In Bangladesh Prevalence 10% (According to the WHO estimation) Based on the assessment of WHO & World Bank, In Bangladesh the prevalence of disabilities in children below 18 years can be estimated to 6% and for the age group above 18 years the prevalence to about 14% or corresponding to 3.4 million children with disabilities and 10.2 million adults with Disabilities. In 2007, Disability ranges among the population are 1.4%-9%. And	Disability in Bangladesh: situation analysis 2004.

					The children range 1.4 – 17.5%. Globally mental and intellectual disabilities are assumed to represent 1-1.5% of the total population in any population. From the national census in 1982, 1986 & 1991 the prevalence rate of disability between .77 and .47 In 1989, A survey among 2576 children 2 to 9 years age in Dhaka found prevalence for Severe disability =8.2%. Cognitive=36%, Speech= 27% Hearing=18%, Movement=9%, Vision=7% and	

					Epilepsy=2% A survey on prevalence of disability from 1994 by the Bangladesh Bureau of Statistics shows a rate of 10.62 disabilities per 1000 population. Survey conducted between 1995-1997 by action aid Bangladesh showed the corresponding prevalence of disability were 14.4% and 13.34%. .	
16	Situation analysis on children with disabilities in **Bangladesh, by UNISEF 2014**		To assess the situation, progress achieved and key Challenges in Bangladesh related to realization of a number of specific rights of children with disabilities based on the convention on rights of children (CRC) and the convention on rights of person with disability	**Desk review:** **Study site:** Six government-run centres and Five non governmental programmes in **Dhaka, Chittagang, Gazipur, Savar and Manikgang**. **Data collection Method:** **Literature review:** helps To assess the global and regional standards & guidelines, data and monitoring structure in regional and global context.	In 2010 and 2011, according to BBS, The proportions of children with disability are varied ranging from less than 1.4%to 17.5% and the ranges of people with disability is 1.4% to 9%.	

			(CRPD). To support the development of policy and programming towards realizing the rights of children with disabilities in all relevant sectors. To guide the work of the UNICEF Bangladesh country office. Strengthen support to the Government of Bangladesh to meet its obligations to promote the rights of children with disabilities.	**Key stakeholder meetings:** Two meetings were held with key stakeholders. One with civil society stakeholder to obtain their cooperation and inputs. The second was with individuals representing the Government, UN agencies, NGOs and civil society organizations to discuss preliminary findings and recommendations. **KII:** Interview was held with government and nongovernment officials. **FGD:** Three focus group discussions were held with adolescents with disabilities and parents of children with disabilities in Dhaka.	Interaction between poverty, low household income, food security, education, access to sanitation and disability were found. According to Household Income and Expenditure Survey 2010, higher prevalence in rural areas(10%) than in urban areas(8%)	
17	Extent and Background Factors of Physical and Mental Disability in Bangladesh. **2015**	Sultana, A., & Gulshan, J. (2015). Extent and Background Factors of Physical and Mental Disability in Bangladesh. *Dhaka University Journal of Science*, *62*(1), 55-58.	To examine the current scenario of different types of disabilities in Bangladesh To examine differentials of disability To identify the background factors related to disability	**Data collection method:** Secondary data collection from Sample vital Registration system (SVRS) a continuous surveillance system in 2010, collected by Bangladesh Brue of statistics (BBS). **Population/Households:** 206522 **Sampling:** stratified cluster design in three area, urban , rural and SMA	Male are 15% more likely to be mentally disabled as compared to female. The reasons for disabilities are diverse: inherent, accident,	

				Data analysis: Chi square test was used to find out the association of type of disabilities with area, sex of respondent, division and religion.	disease, old age etc. Area, sex of respondent, division and religion have significant association with type of disability. Rural people are less likely to be physically or mentally disabled as compared to their urban counterparts.	
18	Validation of a home-based neurodevelopmental screening tool for under 2-year-old children in Bangladeshcch_1 2013	Khan, N. Z., Muslima, H., Shilpi, A. B., Begum, D., Akhtar, S., Parveen, M., ... & Darmstadt, G. L. (2013). Validation of a home-based neurodevelopmental screening tool for under 2-year-old children in Bangladesh. *Child: care, health and development*, *39*(5), 643-650.	To validate a screening tool for use by frontline workers (FWs) to identify under 2-year-old children at risk for neurodevelopment impairments (NDIs) in Resource-poor home settings.	Study population :**mother of children from birth to** < 2 **years old.** Study site :two urban wards Mirpur (ward number **(7**and Malibag (ward number **(54** within Dhaka city, Tool: The Developmental Screening Questionnaire (DSQ) and Rapid Neurodevelopmental Assessment **instruments were used**	17% screened positive among 197children.	

Appendix 8: Members of the Expert Working Group

Dr. Golam Rabbani
Chairperson, Neurodevelopmental disability protection trust,
Ministry of Social Welfare
Government of the people's Republic of Bangladesh
Mr Saaeed Nur Alam
Joint secretary, Ministry of Health & Family Welfare
Dr. Shamim Matin Chowdhury
Child Psychiatrist, Beautiful Mind
Dr. Md. Anwar Ullah
Director –JPUF, Ministry of Social Welfare
Md. Rajib Hasan
Deputy Director, planning, JPUF
Ministry of Social Welfare
Rowshan Ara Begum
Joint Secretary, Urban Development-2
Ministry of LGRD
Professor Shaheen Akhter,
Project Director, IPNA, BSMMU
Dr. Narayan Chandra Saha
Associate Professor, NINS
Dr. Rownak Hafiz
Chair person, Autism Welfare Foundation
. **Dr. Helal Uddin Ahmed**
Assistant Professor, NIMH
. **Ms. Sajeda Rahman Danny**
President
Parents Forum
. **Ms. Farida Yeasmin**

Executive director
DRRA, Vocational center

. **Marufa Hossain**
Director, Tauri Foundation
. **Md. Mofijul islam**
Administration and Finance
Society for the Welfare of Autistic Children
. **Begum Nur Jahan Dipa**
Vice- Principal
PFDA- Vocational Training Center
. **Anima Das Nupur**
Occupational Therapist
CRP-Savar, Rehab center for disability
. **Dr. Shirin zaman Munir**
Expert in Special Educator & Disability Issues
. **Dr. Maruf Ahmed Khan**
Deputy Program Manager
Mental Health, Autism, tobacco, Alcohol & substance abuse
NCDC
. **Brig. Gen Md Tofayel Ahmed, psc**
Commander
24 Artillery Brigade and Region Commander Guimara Region

Appendix 9: Meeting Minutes for Expert Working Group

Situation Assessment of Autism and Neuro-developmental Disorders in Bangladesh

Organized by: Non-Communicable Diseases programme, DGHS

Technical support provided by: icddr,b & Shuchona Foundation

Chairperson: Professor A.H.M Enayet Hussain

Additional director General (Planning & Development)

Venue: BRAC Centre Inn

Date: 26 January, 2016

Time: 9.00 a.m. to 2.00 p.m.

Facilitator:

Dr. Aliya Naheed
Dr. Kamrun Nahar Koly
Dr. Sabrina Ahmed
Mr. Md. Saimul Islam
A.K.M. Solayman
Jewel Ahmed
Sarmin Akter
Sanjida Binta Ali
Atia Arfin
Shamim Hasan
Rifat Hasan Shammi

Participants:

Dr. Golam Rabbani
Mr Saaeed Nur Alam
Dr. Shamim Matin Chowdhury

Dr. Md. Anwar Ullah
Md. Rajib Hasan
Rowshan Ara Begum
Dr. Narayan Chandra Saha
Dr. Rownak Hafiz
Brig. Gen. Md. Tofayel Ahmed, psc

Dr. Helal Uddin Ahmed
Ms. Sajeda Rahman Danny
Marufa Hossain
Anima Das Nupur

Md. Mofijul islam
Begum Nur Jahan Dipa
Md. Rokibul Hossain

Shuchona Foundation

Aloka Guha
Dr. Muzharul Mannan
Saad Mustafa Zaman
Nazish Arman
Dr. Shirin Zaman Munir

DGHS

Dr. Tanveer Ahmed Chudhury
Dr. Maruf Ahmed Khan

Appendix 10: Indicators of Comprehensive set of services

Situation Assessment of Autism and Neurodevelopment Disorder in Bangladesh

Indicators of Comprehensive set of services:

1. Type of diseases:

   a. Autism
   b. CP
   c. Down Syndrome
   d. ADHD
   e. Speech Delay
   f. Sensory Processing Disorder
   g. Learning Disability
   h. Child Stroke
   i. Others

1. Type of program:

   I. Special Education-

      a. Flexible curriculum of regular
      b. Group work
      c. Creative play
      d. Computer training
      e. Activities include functional learning
      f. Fine motor solving
      g. Reading

- h. Study tour
- i. Painting exhibition
- j. Picnic
- k. Special Day observation
- l. Outing
- m. Shopping
- n. Cultural program
- o. Sports
- p. Residential Facilities

II. Inclusive Education - Class Activities:

- a. Assembly
- b. Attendance chart
- c. Functional chart
- d. Toilet training
- e. ADL training
- f. Improve communication shills
- g. Reading and writing
- h. Tiffin
- i. Class party
- j. Free play in door
- k. Drawing and coloring
- l. Cutting and pasting
- m. Rhymes and story telling
- n. Group work
- o. Individual children times

- p. Dance and music class
- q. TV time

III. Early intervention Programme

i. Counseling-

- a. Parents and family counseling
- b. Individuals counseling
- c. Others counseling

ii. Psychological support

iii. Assessment

iv. IEP goal plan (Individual Educational Plan & Goal Plan)

v. Ambulant Teacher service

vi. Others

3. Rehabilitation:

- a. Medical
- b. Physical assessment
- c. Pre-vocational
- d. Vocational

- e. Educational
- f. Social
- g. Employment Opportunity for AND
- h. Others

4. Training and capacity building:

- a. Activity of daily living (ADL)
- b. Teachers/Principal/Administrative Training
- c. Parents Training- Hands on training
- d. Caregivers and siblings training
- e. Tele-medicine parents training
- f. Individual AND child Training
- g. Work skill development-
- h. Social Integration Program
- i. Others

5. Therapy:

- a. Occupational Therapy
- b. Physiotherapy
- c. Speech and Language Therapy
- d. Behavioral therapy management
- e. Cognitive behavior Therapy
- f. Sensory Integration therapy
- g. Music Therapy
- h. Play Therapy

- i. Dance Therapy
- j. Group therapy for Socialism
- k. Home visit services
- l. Referral
- m. Others

6. Others facilities-

- a. Parents support group
- b. Underprivileged Disabled section
- c. Co-ordination with others organizations
- d. Intensive learning Enhancement program
- e. Well baby clinic
- f. Focus Group/ Peer Group discussion
- g. Countrywide seminars, Workshop and conference
- h. Mass awareness and campaign
- i. Media sensitization for awareness program
- j. Dental & Eye Check-up
- k. Free Clinic (Outdoor)
- l. Day care Centre
- m. Residential Facility
- n. Financial Support
- o. Others

Appendix 11: Organizations Contact List

Sl no	Name of the organization	Organization Category	Address	Contact no	Mail address
1	Dhaka Shishu Hospital, Child Development & Neurology department,	Diagnosis, Therapy	Syed Mahbub Morshed Avenue, Sher-e-Bangla Nagar, Dhaka, Bangladesh	(0)9104217	
2	Society for the Welfare of Autistic Children (SWAC)	Special Education, Therapy	70/KA, Pisciculture, Shyamoli,Dhaka-1207, Bangladesh	Tel:88 02 8118836, Cell + 88 01712793662	info@autism-swac.org, mofijul@autism-swac.org, rislam_26@yahoo.com
3	Institute of Neurodevelopment & Research (INDR)	Diagnosis, Therapy, Rehabilitation	18 Dilu Road , New Eskaton, Dhaka-100	Mob: 01931405986	autismbd24@gmail.com
4	Jatio Protibondhi Unnoyon Foundation (JPUF)	Special Education, Diagnosis, Therapy, Rehabilitation	House # A/2, Section # 14, Mirpur,Dhaka-1206, Bangladesh	028035052, 0088 02 8035045	jpuf38@yahoo.com
5	Centre for the Rehabilitation of the Paralyzed (CRP) :	Vocational, Therapy	Branch : Mirpur-14, Dhaka,	Tel : +88 028020178, +88 028053662	
6	Autistic Children's Welfare Foundation, Bangladesh (ACWFB)	Special Education	House #74, Line #3, Block E, Kalshi, Mirpur-12,Dhaka-1216, Banglades	880-02-8019838 / 01914403331/4	acwfbdmirpur@gmail.com
7	Center for Special Care(CS Care)	Therapy, Rehabilitation	Plot-5,Avenue-1,Block-B,Section-10 Mirpur, Dhaka,	01779-990066	cscaredhk@gmail.com

			Bangladesh		
Sl no	Name of the organization	Organization Category	Address	Contact no	Mail address
8	SWID Bangladesh	Therapy, Rehabilitation	Dhanmondi Branch 6/6 Block-D, Lalmatia, Dhaka-1207, Bangladesh	+880 2 912 3937 | +880 181 922 1016	
9	School for Gifted Children	Special Education, Therapy, Rehavilitation	6/9, Block # E,Lalmatia, Dhaka – 1207, Bangladesh.	88 – 02 – 8122453, Mobile: +88 – 01552348087, +88 – 01711272607	info@taurifoundation.org, taurif @agnionline.com
10	Schools for Autistic children	Special Education, Therapy	Autism Welfare Foundation, Shamoly,Autism welfare Foundation , Shamoly, House# 38/40,Road#4, "Kha"block, Pisiculture housing society , Ring road , Mohammadpur, Dhaka-1207	Phone: +88 02 8121759, Mobile: +88 0181947233 , +88 01552-363575	rownak_awf@yahoo.com
11	Alokito shishu, A treatment based school for autism & other special needs children	Special Education, Therapy, Rehabilitation	House: 16, Road: 10, P C Culture Housing Society, Kha-Block, Shekhertek, And Mohammedpur	+88 01814091733, +88 01190639702	zuakanda@gmail.com
12	Beautiful Mind	Special Education	Sector 5, Uttara	28959478	
13	Parents Forum For Differently Able	Special Education, Vocational	House-B/173(2nd floor)Rd-23, New DOHS, Mohakhali,Dhaka-1206	01730089088, 01714245122, 01713443601	Vice-principle@parentsforum-bd.org

Sl no	Name of the organization	Organization Category	Address	Contact no	Mail address
14	Society for Assistance Hearing Impaired Children (SAHIC)	Special Education	Ishtiaq Ahmed, General Secretary,Mohakhali, Dhaka	Tel : 8822007, 9881535 (ext: 132)	
15	Speech and Language Therapy Service in Dhaka, Bangladesh	Therapy, Rehabilitation	116, Shantinagar (opposite of White House Hotel)Dhaka, Bangladesh	01717276810, 01680050784	
16	Smiling children special school - SCSS	Special Education, Therapy	The new address is Smiling Children Special School Kamal House, Jahurul Islam City,House # 40, Road # 06, Block # E,Sector # 01, Aftab Nagar, Badda,	Cell: 04477960897, 01938240167, 01677441827,	
17	HICARE	Hearing Impaired	3/2, North Road, Vuter Goli, Dhanmondi,Dhaka	01714004906	hicare@dhaka.net
18	Society for Education & Inclusion of the Disabled (Seid Trust)	Special Education, Vocational, Therapy	6/5,4th floor, Block-B, Humayun Road, Mohammadpur, Dhaka	01720097575	seidtrust@bdcom.net
19	Emergency Response and disaster Handicap Children	Special Education, Therapy, Rehabilitation	Road#4, House#(swf-f)1/4, Gulshan,Dhaka	01711964448	shafiqul@handicap-internationalbgd.org
20	Angels Care Foundation	Special Education, Therapy, Rehabilitation	16/5, Block-C, Tajmahal Road, Mohammadpur, Dhaka-1207	01713365302	contact@angelscarebd.org

Sl no	Name of the organization	Organization Category	Address	Contact no	Mail address
21	Caring Glory	Special Education, Therapy, Rehabilitation	House# 4/18, Block-B, Humaun Road, Mohammadpur,Dhaka-1207	01714049376	aringglory@gmail.com
22	Exceptional Mind	Special Education, Therapy, Rehabilitation	House#MA-48 (Near by Hatirjhil)/west Merul Badda, Dhaka-1212	01711462728, 01823210798, 01558088964	exceptionalmind.bd@gmail.com
23	Scholars Special School	Special Education, Therapy, Rehabilitation	9/17, Block-C, Tajmohal Road, Mohammadpur, Dhaka-1207	01710376001, 01777689591	scholarsdhaka@gmail.com
24	International Specialized School	Special Education	House# 13, Road# 5(D Block) ,Sector#11, Uttara	01717552995	mayonhoquue@gmail.com
25	Unique gift-Norda	Special Education, Rehabilitation, Therapy	Advance Rainbow, KA-40/A/1, Shahid Harez Sorok, South Baridhara, Nadda (Near Foot Over Bridge), Dhaka.	01712227610	tanzima.7878@gmail.com
26	Autistic Children Development School and Rehabilitation Center	Special Education, Rehabilitation, Therapy	Mirzapool, Muradpur, Chittagong	01819324579	acwfbddhaka@gmail.com
27	Special Schooling-NISHPAP Autism School	Special Education, Rehabilitation, Therapy	12/12 Nizam Road chittagong		

Sl no	Name of the organization	Organization Category	Address	Contact no	Mail address
28	Institute of Paediatric Neurodisorder & Autism (IPNA)	Therapy, Rehabilitation	3rd Floor, Block - E, BSMMU		office@ipnabsmmu.edu.bd
29	CDD : Centre for Disability In Development	Diagnosis, Therapy, Rehabilitation, Vocational	A-18/6, Genda, Savar, Dhaka–1340, Bangladesh.	cell : +88 01713021695	cdd@bangla.net
30	Village Association For Social Development (VASD)		77/3, Bloch -A, Talbagh,Savar,Dhaka	01711563174	vasd1999@yahoo.com
31	Access Bangladesh Foundation		10, Tarapur,Savar, Dhaka-1340	01727365594	paulmohua@yahoo.com
32	Protibondhi Shishu Shikha o sheba songstha(Prosises)		91/I, 6th Floor, Road# 7/A, Dhanmondi,Dhaka	01711320578, 01552319839	proshises@gmail.com
33	Bangladesh Protibondhi Sohojogita Songstha		564, Sewrapara, Kazipara, Mirpur, Dhaka	01916940748, 01715778782	bpss_net@yahoo.com
34	Association for the welfare of the Disabled People(AWDP)		192, Ahmed nagar, Paikpara, Mirpur-1, Dhaka	01672305525, 01711341003	
35	Disabled Child Foundation		551, Peyar bag. Mogbazar, Dhaka-1217	01732675775	dcf05@yahoo.com
36	Fulbaria Protibondhi Kollan Songstha		Sundorba Square(4th Floor), 122/A, Lutfar Rahman Lane, Bongshal, Dhaka-1000	01199127472	

Sl no	Name of the organization	Organization Category	Address	Contact no	Mail address
37	Disabled welfare Society		House#39, Road# 3, Nichtola, Pisiculture Housing Society, Sekhertec, Mohammadpur, Dhaka	01921456127	morjinaahmed@gmail.com
38	National Grassroots Disability Organization (NGDO)	Work for Disability Right	Plot#B-1, Flat#02/04, Gate no#8, Arambag, Mirpur#7	01726257377	
39	Vision Physiotherapy center- Uttara		House -47 , Road-02, Sector-5, Uttara	01932-797229	
40	ADD		House# 56, Road# 11, Block# C, Dhaka-1212	01733522293	safiqul.islam@add-bangladesh.org
41	Bangladesh Protibondhi Foundation (BPF) Kalyani	Therapy, Rehabilitation	12 New Circular Road,West malibagh, Dhaka-1217	09351625	
42	Proyash,Dhaka Cantonment	Special Education, Therapy	Proyash, Dhaka Cantonment, Dhaka-1206, Bangladesh.	Tel: PABX: 880-2-8871234 (Ext: 7452/8404), Direct: 8715230	info@proyash.edu.bd
43	School for Intellectual Disabled Children, Ramna	Special Education, Therapy,	Ramna Budhi protibondhi School		
44	Centre for the Rehabilitation of the Paralyzed (CRP) :	Vocational, Therapy	PO CRP-Chapain, Savar,Dhaka 1343, Bangladesh	(880)2 7745464-5	

Sl no	Name of the organization	Organization Category	Address	Contact no	Mail address
45	Gram sompod Unnayan Kendro		46, Cresent Road, Dhanmondi, Dhaka	01675101100	ngo_grasuk@yahoo.com
	Welfare Society for Mental Health and Rehabilitation		14,Green Way, Mogbazar, Dhaka-1217	01913520123, 01672976022	rajan@bangla.net
46	Manusher jonno Foundation		House# 47, Road no# 35/A, Gulshan -2, Dhaka	01711636552	hira@manusher.org
47	Disabled Rehabilitation and research Association (DRRA)		House# 2/5,Road#1, Shaymoly, Dhaka	01711536517	sila@agni.com
48	Sight Savers		Flat#5b and c, Shelteckh, House#7, Road#33, Block-CWS(B), Gulshan-1, Dhaka	01711378138	kariful@sightsavers.org
49	Center for Disease Prevention & Health Promotion - CDPHP	Therapy,	35/B (B1), Road 3, Shyamoli, Dhaka, Bangladesh	01712-796699	
50	Uttara Physiotherapy & Rehabilitation Center	Therapy, Rehabilitation	House-3(Sector 11, Uttara, Dhaka	01688-139996	
51	Advanced School For Special Children (ASSC) deals with Autistic Children	Special Education, Therapy	14/22 Babor Road, Mohammadpur Dhaka 1207	01819199795 / 01735501995	

Sl no	Name of the organization	Organization Category	Address	Contact no	Mail address
52	Special Education, Rehabilitation, Therapy	Mirzapool, Muradpur, Chittagong	1819324579	acwfbddhaka@gmail.com	
53	Special Education, Rehabilitation, Therapy	12/12 Nizam Road Chittagong			
54	Autism Management Institute	Special Education, Therapy	Sylhet		
55	School of Joy	Special Education, Therapy	Sylhet		
56	Sylhet Art & Autistic School	Special Education, Therapy	House : 35, Road : Mainroad : A , Kumarpara, Sylhet, Bangladesh, Sylhet	01712737399, 01977 737399	
57	Dhaka Medical College Hospital	Therapy,	Dhaka	01727201094	
58	Sir Solimullah Medical College Hospital	Therapy	Dhaka	01816472383	
59	MA.G Osmani Medical College Hospital	Therapy	Sylhet	01617415191	
60	Ser-E-Bangla Medical College Hospital	Therapy	Barisal	01765626901	
61	Chittagong Medical College Hospital	Therapy	Chittagong	01558679718	

Sl no	Name of the organization	Organization Category	Address	Contact no	Mail address
62	Khulna Medical College Hospital	Therapy	Khulna	01193289359	
63	Rajshahi Medical College Hospital	Therapy	Rajshahi	01195267525	
64	Rangpur Medical College Hospital	Therapy	Rangpur	01773081293	
65	Mymensingh Medical College Hospital	Therapy	Mymensingh	01191848482	
66	Dinajpur Medical College Hospital	Therapy	Dinajpur	01722694862	
67	Faridpur Medical College Hospital	Therapy	Faridpur	01791989839	
68	Comilla Medical College Hospital	Therapy	Comilla	01795828217	
69	Saheed Ziaur Rahman Medical College	Therapy	Bogra	01792475969	
70	Cox’s Bazar Medical College	Therapy	Cox’s Bazar	01818197450	

Appendix 12: Summary of Service Providers

Situation Assessment of Autism and Neurodevelopment Disorder in Bangladesh
Summary of service providers

	Type of services	Provide services	Total institutions	Remarks
Type of diseases	Autism	45	46	
	CP	39	46	
	Down Syndrome	39	46	
	ADHD	28	46	
	Speech Delay	36	46	
	Sensory Processing Disorder	29	46	
	Learning Disability	20	46	
	Child stroke	5	46	
	Hearing Disability	19	46	
	Multiple Disability	6	46	
	Others Disabilities	2	46	
Type of program	Special Education	28	46	
	Inclusive Education	25	46	
	Early Intervention Programme	26	46	
	Psychological support	34	46	
	Assessment	41	46	
	Individual Educational Plan & Goal plan	28	46	
	Ambultant teacher Service	2	46	
	Transportation Facilities	1	46	
Counseling	Parents & Family counseling	44	46	
	Individuals Counseling	45	46	
	Others Counseling	5	46	
Rehabilitation	Medical	26	46	
	Physical Assessment	24	46	
	Pre Vocational	16	46	
	Vocational	17	46	
	Educational	21	46	
	Social	18	46	
	Employment opportunities for AND	15	46	
Training & Capacity Building	Training on ADL	29	46	
	Teachers/ Administrative/ Principle Training	28	46	

	Parents Training	31	46	
	Caregivers and Siblings Training	26	46	
	Tele Medicine parents training	6	46	
	Individual AND child Training	13	46	
	Work skills development	28	46	
	Social Integration Program	26	46	
Therapy	**Type of services**	**Provide services**	**Total Institution**	Remarks
	Occupational Therapy	43	46	
	Physiotherapy	37	46	
	Speech and Language Therapy	44	46	
	Behavior Therapy Management	39	46	
	Cognitive Behavior Therapy	34	46	
	Sensory Integration Therapy	31	46	
	Music Therapy	16	46	
	Play Therapy	38	46	
	Dance Therapy	17	46	
	Group Therapy for Socialism	22	46	
	Home visit services	23	46	
	Referral	37	46	
Others	Parents support group	19	46	
	Under privileged Disabled Section	12	46	
	Co-ordination with others organization	21	46	
	Intensive learning Enhancement program	19	46	
	Well baby clinic	0	46	
	Focus Group/ Peer Group discussion	8	46	
	Countrywide Seminars, Workshop and Conference	37	46	
	Mass Awareness and Campaign	20	46	
	Media sensitization for awareness program	19	46	
	Dental & Eye check-up	11	46	
	Free clinic(Out door)	6	46	
	Day care centre	4	46	
	Residential Facilities	2	46	
	Financial Support (Stipend)	3	46	

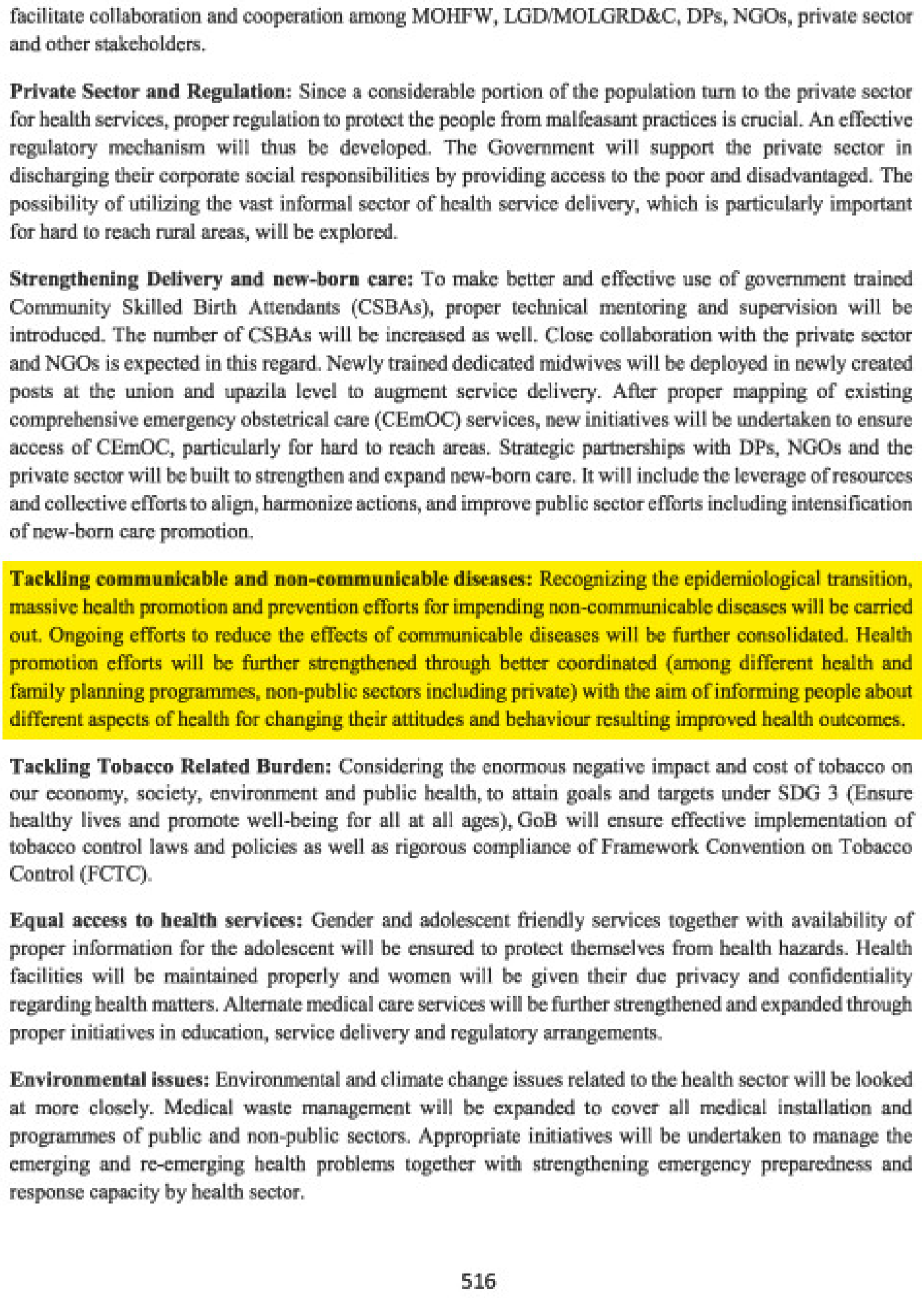
Appendix 13: List of the members of NSCAND

SN	ORGANIZATION	OFFICER
1	Ministry of Health & Family Welfare	Secretary *(Chairperson)*
2	Ministry of Social Welfare	Secretary *(Co-Chairperson)*
3	Ministry of Education	Secretary *(Co-Chairperson)*
4	National Advisory Committee for Autism & NDDs	Vice Chairperson
5	NDD Protection Trust	Chairperson
6	Ministry of Primary & Mass Education	Additional Secretary
7	Ministry of Labor & Employment	Additional Secretary
8	Finance Division	Additional Secretary
9	Economic Relations Division	Additional Secretary
10	Ministry of Women & Children's Affairs	Joint Secretary
11	Local Government Division	Joint Secretary
12	Ministry of Youth & Sports	Joint Secretary
13	Ministry of Cultural Affairs	Joint Secretary
14	Ministry of Information	Joint Secretary
15	Directorate General of Health Services	Director General
16	Directorate of Social Services	Director General
17	NGO Affairs Bureau	Director
18	National Foundation for Development of Disabled Persons	Managing Director
19	ICT Division	Deputy Secretary
20	Socio-Economic Infrastructure Division	Division Chief
21	Bangabandhu Sheikh Mujib Medical University	Vice Chancellor
22	Rapporteur	

Appendix 14: List of the government focal points for autism and NDDs

FP	OFFICER	MINISTRY/DIVISION/DEPARTMENT
3	Secretary	Health & Family Welfare, Social Welfare, Education
8	Additional Secretary	Health & Family Welfare, Education, Primary & Mass Education, Labor & Employment, Finance Division, Information, Economic Relations Division, Defense
15	Joint Secretary	Social Welfare, Education, Women & Children Affairs, Local Government Division, Cultural Affairs, Youth & Sports, Information, Legislative & Parliamentary Affairs Division, Planning Division, Statistics & Informatics Division, Liberation War Affairs, Defense, Food, Road Transport & Highways Division, Foreign Affairs
13	Deputy Secretary	ICT Division, Cultural Affairs, Economic Relations Division, Agriculture, Internal Resources Division, Posts & Telecommunications Division, Industries, Civil Aviation & Tourism, Land, Science & Technology, Expatriates Welfare & Overseas Employment, Textiles & Jute
4	Senior Assistant Secretary	Rural Development & Cooperatives Division, Law & Justice Division, Commerce, Chittagong Hill Tracts Affairs
1	Director General	Autism Cell, DGHS, DSS,
3	Director	Autism Cell, NGO Affairs Bureau, Implementation Monitoring & Evaluation Division
3	Deputy Director	Autism Cell (2), Religious Affairs
1	Managing Director	JPUF
1	Division Chief	Socio-Economic Infrastructure Division
1	Deputy Chief	Labor & Employment

Appendix 15: Excerpts from the 7th Five Year Plan that covers NDDs and mental health



facilitate collaboration and cooperation among MOHFW, LGD/MOLGRD&C, DPs, NGOs, private sector and other stakeholders.

Private Sector and Regulation: Since a considerable portion of the population turn to the private sector for health services, proper regulation to protect the people from malfeasant practices is crucial. An effective regulatory mechanism will thus be developed. The Government will support the private sector in discharging their corporate social responsibilities by providing access to the poor and disadvantaged. The possibility of utilizing the vast informal sector of health service delivery, which is particularly important for hard to reach rural areas, will be explored.

Strengthening Delivery and new-born care: To make better and effective use of government trained Community Skilled Birth Attendants (CSBAs), proper technical mentoring and supervision will be introduced. The number of CSBAs will be increased as well. Close collaboration with the private sector and NGOs is expected in this regard. Newly trained dedicated midwives will be deployed in newly created posts at the union and upazila level to augment service delivery. After proper mapping of existing comprehensive emergency obstetrical care (CEmOC) services, new initiatives will be undertaken to ensure access of CEmOC, particularly for hard to reach areas. Strategic partnerships with DPs, NGOs and the private sector will be built to strengthen and expand new-born care. It will include the leverage of resources and collective efforts to align, harmonize actions, and improve public sector efforts including intensification of new-born care promotion.

Tackling communicable and non-communicable diseases: Recognizing the epidemiological transition, massive health promotion and prevention efforts for impending non-communicable diseases will be carried out. Ongoing efforts to reduce the effects of communicable diseases will be further consolidated. Health promotion efforts will be further strengthened through better coordinated (among different health and family planning programmes, non-public sectors including private) with the aim of informing people about different aspects of health for changing their attitudes and behaviour resulting improved health outcomes.

Tackling Tobacco Related Burden: Considering the enormous negative impact and cost of tobacco on our economy, society, environment and public health, to attain goals and targets under SDG 3 (Ensure healthy lives and promote well-being for all at all ages), GoB will ensure effective implementation of tobacco control laws and policies as well as rigorous compliance of Framework Convention on Tobacco Control (FCTC).

Equal access to health services: Gender and adolescent friendly services together with availability of proper information for the adolescent will be ensured to protect themselves from health hazards. Health facilities will be maintained properly and women will be given their due privacy and confidentiality regarding health matters. Alternate medical care services will be further strengthened and expanded through proper initiatives in education, service delivery and regulatory arrangements.

Environmental issues: Environmental and climate change issues related to the health sector will be looked at more closely. Medical waste management will be expanded to cover all medical installation and programmes of public and non-public sectors. Appropriate initiatives will be undertaken to manage the emerging and re-emerging health problems together with strengthening emergency preparedness and response capacity by health sector.

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Tribal heath: The problem with service delivery in the CHT will be tackled in collaboration with MOCHTA and other relevant authorities. District-specific health service system will be developed along with institutional arrangements for respective Hill District councils to facilitate the system operation. Tribal-friendly health services will be ensured through appropriate initiatives for tribal population residing in plain lands.

Autism: Autism or more commonly known as autism spectrum disorder (ASD) is a complex developmental disorder that affects a person's ability to communicate, form relationship with others, and respond appropriately to their environment. In 2007, the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD) addressing the human rights of all persons with disabilities, signed by 150 countries and ratified by 100. Bangladesh was one of the first countries to ratify the CRPD and has also signed its Optional Protocol. In recognition of ASD as a global health crisis, the UN designated in 2008 April 2nd as World Autism Awareness Day. Since then, several regional and international resolutions have been adopted urging countries to coordinate efforts, implement public health initiatives and develop multi-sectoral opportunities for social inclusion and economic emancipation of persons with ASD.

Bangladesh has addressed the issue of ASD in a planned manner. It hosted the first Regional Conference on Autism in 2011, which was attended by over 1000 national & international delegates. A National Steering Committee on Autism and Neurodevelopment Disabilities, comprising representatives of 15 ministries/divisions (Health and Family Welfare, Social Welfare, Education, Primary and Mass Education, Labour and Employment, Women and Child Affairs, Local Government Division and Finance Division). where Ministry of Information, Economic Relations Division, Ministry of Youth and Sports, Ministry of Cultural Affairs, Planning Commission and NGO Affairs Bureau) Has been formed.. The National Steering Committee is guided by a National Advisory Committee and a Technical Guidance Committee comprised of both parents and experts. A Strategic and Convergent Action Plan on Autism and Neurodevelopment Disabilities (SCAPAND) has been developed and incorporated within the current sector programme. The national level 17-member Autism Technical Guidance Committee's responsibility is to provide technical support to the Advisory and Steering Committees. Working in specialized group, members are responsible for translating appropriate materials for use in Bangladesh, collating existing materials available in the country and region, identifying needs in the community and setting priorities.

During the 7th FYP period, the exponential increase in the prevalence of ASD across the country including other disability issues will be properly addressed through appropriate advocacy campaign, effective coordination among concerned ministries, departments, and NGOs for proper preventive, curative and rehabilitative services including expansion of services to cater the need of different types of disabled along with making health-facilities disable-friendly. To uphold health rights and ethics, such issues will be incorporated in all medical, nursing and other education curricula along with proper sensitization initiatives for the existing health service providers.

Mental health: Mental health and well-being are fundamental to a healthy nation. During the 7th FYP, MOHFW will promote mental health and well-being including access to essential care. The priority areas to be addressed include: depression, psychosis, bipolar disorders, epilepsy, developmental and behavioural disorders in children and adolescents, dementia, drug use disorders, self-harm/suicide, etc. To address this problem, a comprehensive mental health service delivery plan will be developed with the aim of gradual expansion of service to address the growing need of psychological aspects of health. To uphold health rights and ethics, such issues will be incorporated in all medical, nursing and other education curricula along with proper sensitization initiatives for the health service providers.

Geriatric care: Population aging is an inevitable consequence of fertility decline and the demographic bonus in Bangladesh. People over sixty years constituted over 11% of total population in 2011 and are estimated to grow to 14.4% in 2021 and to 21.3% in 2031. Health is a major component for addressing the challenges posed by increasing proportion of aging population. MOHFW recognizes the need for reorienting the existing institutional arrangements for health service delivery and intends to increase investment – both financial and human resources – in this sub-specialty. As part of that effort, a National Institute for Physical and Geriatric Medicine and Rehabilitation is proposed to be set up during the 7th FYP. MOHFW will also promote multi-sectoral collaboration with other ministries (e.g., Ministry of Social Welfare), NGOs, CSOs, etc. for improving geriatric health care.

Health education: Creating and maintaining a healthy nation requires proper dissemination of knowledge regarding factors that affect health outcome. This wide spectrum of knowledge includes, among others, dietary issues, lifestyle choices and sanitation. To instil good practices from an early age, health education will be included in primary schools. Steps will be taken to impart health education through mass media and raise awareness at the community level. The necessity of proper nutrition and food diversification to include iron, vitamin A, and carotene rich food in regular dietary intake will be particularly expounded. Lifestyle choices such as smoking, excess calorie consumption and lack of physical activity pose a serious threat to the well-being of people, particularly the urban youth. To tackle this issue, preventive and promotional health education services will be ensured for all.

Governance and Health Sector Management

In addition to addressing service delivery issues, the 7th FYP will also take into account the deficiencies in governance and management of the health sector. Issues related to the inadequacies in the health workforce, finance, surveillance, drugs and equipment, information and research will be addressed. Table 10.4 provides the details.

Table 10.4: 7th FYP Strategies for Governance and Management in the Health Sector

Health workforce	▪ Develop a national health workforce strategy ▪ Implement an HR action plan to ensure adequate number of personnel with appropriate skill mix, deployment with terms and conditions, retention, career progression, job satisfaction, etc.
Information	▪ Implement the M&E Action Plan ▪ Further improve health information systems through strengthened collaboration of DGHS and DGFP by scaling up RHIS initiative ▪ Ensure timely reporting from all reporting units ▪ Use information to make management decisions at different levels. ▪ Explore full potential of ICT to facilitate service delivery, education, information gathering and management efficiency ▪ Build capacity of health managers and at district and sub-district levels, particularly on data analysis, heath planning and monitoring.
Drugs and Equipment	▪ Strengthen Directorate General of Drug Administration for ensuring production and dispensing of quality drugs, promotion of rational use of drugs and elimination of harmful and useless drugs ▪ Strengthen Bangladesh Pharmacy Council to support regulatory role of DGDA ▪ Develop a national policy on management of health care technology in which all stages of the procurement process is identified in the Planning, Supply and Ownership Management (PS&OM) model are addressed.

Appendix 15: Results of Parent and Family Interviews and Discussions

The following information provides the results of three workshops and forums with parents and family members, and details the methodology utilized to gather this information. This information was summarized within the text of the main report under in the discussion of social response.

To gain an understanding of social response, two workshops were held on Dhaka and Sylhet division to assess social response of the individual and families to NDD in Bangladesh, including perception and attitude of individuals, families, community and society towards the disorder and their response towards people with the disorders. The Dhaka divisional meeting was conducted on 15 December, 2015. To assess the social response, icddr,b invited the parents of Dhaka and Chittagong division. The list of parents was recommended by the expert working group. A total of 20 parents joined the workshop. Three teams were formulated based on three different perspectives including family environment, services and role of government regarding NDDs. Every team had 6 or 7 members to discuss the selected thematic areas in brainstorming sessions and was supported by one moderator and one note taker.

Another meeting was held on Sylhet division on 14 February, 2016. To assess the social response of the community and society, icddr,b invited the parents, family members and neighbors from Sylhet division. A list of organizations recommended by DGHS were received through the special school. A total of 27 parents,7 family members, and 3 neighbors joined the workshop. Four teams were formulated based on four different perspectives such as parents and family environment, services and role of government regarding NDDs. Every team had 9 to 10 members to discuss whe selected thematic areas in a brainstorming session. Each group was supported by one moderator and one note taker.

A third meeting was held with 150 parents in Dhaka organized by the parent forum. A video document based on that meeting was sent by Shuchona Foundation to icddr,b, which supported the development of a report on NDDs. The purpose of this meeting was to identify the existing situation, describe the priority of the problem, and recommendations on NDDs in Bangladesh. The meeting was organized with the parents, family members and neighbors sharing the same platform, discussing preliminary findings and recommendations in order to achieve the objective.

Brainstorming session with parents and families (Dhaka)

Group A: Family environment around NDD

The families at the Dhaka meeting identified a number of issues in terms of their existing situations. A primary issue identified is diagnosis of NDDs. Families report that doctors cannot diagnose autism and other NDDs properly and distinctly, as, as the symptoms can lead to consideration of a variety of other disorders, and autism and other NDDs are not always readily identifiable. In addition, there is often a delay in detection as children do not display behavior indicative of autism or NDDs until 2.5 to 3 years old. The impact on family dynamics and structure are also an issue. These include the need for mothers who are educated and employed to give up their jobs to become the child's caregiver, blaming by the father of the maternal side of the family, significant levels of depression in mothers, siblings not always supportive of the child with autism or NDD, and both positive and negative attitudes from relatives. The reaction from the larger community also poses challenges: a participant noted neighbors who considered an autistic child as "mad", school teachers with a negative attitude towards children with NDDs, and relatives, friends and community members who won't allow children with NDDs in social and community activities and have negative attitudes.

The challenges and gaps identified correlate with these issues. Related to the issues regarding diagnosis, is the lack of appropriate and reliable screening tools. When diagnosis does occur, there is a lack of an appropriate, clear, and definitive referral system. Lack of knowledge about NDDs among parents and family members is also a major issue, resulting in a lack of understanding of how to best assist and support their child, and manage the overall family dynamics. Lack of knowledge by the general community is also a major gap, resulting in stigma, and a lack of social acceptable by society. Costs associated with treatment, doctor visits, medication, and transportation for children with NDDs are a major challenge, as these are very expensive, made more challenging by the socio-economic circumstances in which many of these families.

The group had a number of recommendations to address the issues and challenges identified. These included the development of an early screening tool for early detection of NDDs in every hospital, accompanied by early intervention after early detection. If autism or other NDD is diagnosed, it is critical that the doctor be explicit without hesitating with parents regarding the diagnosis, so that parents understand the specifics of the situation and how to best manage, and ensure their child's needs are taken care of. The group also recommended the establishment of a center where children with NDDs can get services for less cost. Training for parents, siblings, and relatives was also recommended, to ensure they have the necessary information to provide care for their family member and manage the various challenges involved within the home and community. In order to combat the issues of lack of community acceptance and stigma, general awareness campaigns for the general public via television, billboards, and other media were recommended. In addition, it was recommended that awareness of NDDs be integrated within school curriculums. Parental support recommendations included establishment of parent-to-parent peer groups, which may help to socialize a baby and child with autism or other NDD, and reduce the mental depression of parents. In addition, there is a need for a day care system for children with autism whose mothers are employed. Lastly, the group discussed the need for assistance with employment as individuals with NDD enter adulthood.

Group B: Services for NDD

In terms of services for individuals with NDD, the group in Dhaka noted a variety of issues regarding the current situation. Support and care from existing organizations is not of sufficient quality to meet the needs of individuals and families. Services are not based on an individual plan, and not based on the child's level. Both the service providers and families are not aware about services specific to NDD, and echoing the comments from the previous group, there is a lack of tools for diagnosis of NDD. Referrals for medical care take place, but referrals for therapeutic care are not working. The group also felt that the government's strategic plan on NDD has not been implemented.

Challenges and gaps identified by the group included lack of availability of treatment in remote areas. Challenges in terms of education were also noted, including a lack of coordination between parents and teachers, a lack of flexibility in school curriculum to respond to the needs of students with NDD, and a lack of the three essential supports in many schools (medical, therapeutic, and special education). As with the previous group, the high cost of services was identified as a challenge for many families. The lack of proper infrastructure in existing service centers was also noted.

The group had a variety of recommendations for services to address these issues and challenges. The group felt there was a need for minimum service standards and well-designed infrastructure for schools and service centers. There is also need for extensive training of staff providing supports, including medical staff, community services staff, and educators to ensure consistent quality. Services should also be based on an individualized treatment plan. As with the previous group's recommendations, availability and implementation of proper diagnostic tools is needed with a universal tool used across the country. This would not only assist on an individual basis, but would allow for accurate collection of data so that there is full understand regarding the extent of NDD among the population. Counseling, training, and guidance to parents on an ongoing basis using common platform is also needed. In terms of schools, the group recommended training to improve both teacher knowledge and attitudes towards students with NDD. As with the previous group, awareness campaigns via media, etc. to various groups (medical community, general public) were also recommended. This group echoed the need for services and supports focused on preparing individuals for employment (pre-vocational) as well as actual vocational supports.

Group meeting (Sylhet)

Group A: Family environment around NDD

In the group meeting conducted by Sylhet examining the family environment, the existing situation was examined. It was noted that although the majority of the population lacks knowledge regarding autism, parents may identify the manifestations of NDD in their children and consult a physician. Parents, especially mothers, may experience being blamed for their child's NDD. There is a general sense of negativity regarding NDD throughout the community, and children with NDD are often excluded by their siblings and peers.

There are numerous challenges in improving the family environment of children with NDD. Many parents lack knowledge about NDD, and have limited means to gain information or support. There is a dearth of qualified healthcare providers, as well as teachers and caregivers, who have the knowledge and training to support families and children with NDD. In addition to a lack of referral system, there is insufficient infrastructure such as specialized schools and/or service centers, to provide adequate services. Families often also face financial challenges to accessing costly treatments and services, and to having time to care for their child with NDD.

Some recommendations that emerged from the group meeting were to develop a system, such as an identity card, to enable children with NDD to access services. Another is for parents to be informed of NDD during pregnancy so that they are able to recognize its manifestations early on. The group also recommended hiring qualified healthcare providers, establishing and maintaining a reliable patient referral system, and utilizing cost effective interventions and treatments. Additionally, it recommended creating and expanding opportunities for children with NDD to attend mainstream schools, as well as establishing additional specialized schools offering services such as 1:1 education. Finally, the group recommended the creation of NDD training centers where knowledge is developed, and information can be accessed.

Group B: Service for NDDs

The Shuchona Foundation's parent group meeting on services for children with NDD discussed current services that are available. They noted that special schools are currently providing speech and occupational therapy along with conventional education programming. Dissatisfaction was expressed regarding the lack of experience of many teachers being recruited into schools, and the high costs associated with attending mandatory parent meetings at some schools. There was a range of satisfaction with the amount of time healthcare providers are able to spend with children with NDD varying widely. Some children with NDD are supported through the use of hired help, such as maids, resulting in differing experiences ranging from positive to negative.

The group discussed current challenges in service provision. Some challenges include an absence of suitable diagnostic instruments in schools and healthcare settings, a lack of related medical services available within special schools, and an insufficient number of trained therapists and healthcare providers resulting in services being provided by untrained/unqualified individuals. The group also noted financial challenges to accessing services, such as a lack of government provision of speech and occupational therapy, high costs of attending school for children with NDD, and the limited availability and high cost of parent training programs. Additional challenges include a lack of retention of trained teachers in special schools, nonexistent provisions for transportation to and from school, and a lack of post-school work opportunities for children with NDD.

The recommendations that resulted from the group meeting focused on several key areas: a) therapy, children with NDD must have access both financially and logistically to therapy services; b) education, additional specialized schools are needed, specialized schools must ensure they are utilizing qualified trained personnel, that they are providing the services their students require, and that students are able to access and utilize the services provided; c) training for caregivers and providers, the government must provide training for parents, caregivers, and other service providers of children with NDD; d) healthcare and educations costs, high costs are limiting access to these necessary services and must be addressed. The group also recommended the use of a system, such as ID cards, to enable children with NDD to more efficiently access services. Finally, the group noted the need to establish policies that ensure parent workplaces provide facilities that accommodate children with NDD.

Report on parents meeting organized by Shuchona Foundation

Shuchona Foundation organized a parents meeting conducted by Sajeda Rahman Danny President of Parent Forum. Chief Guest was Saima Hossain, the daughter of honorable Prime Minister, and Chairperson of Global Autism and National Steering Committee in Bangladesh. Invited parents discussed various issues affecting their children with NDDs which were experienced in a variety of settings.

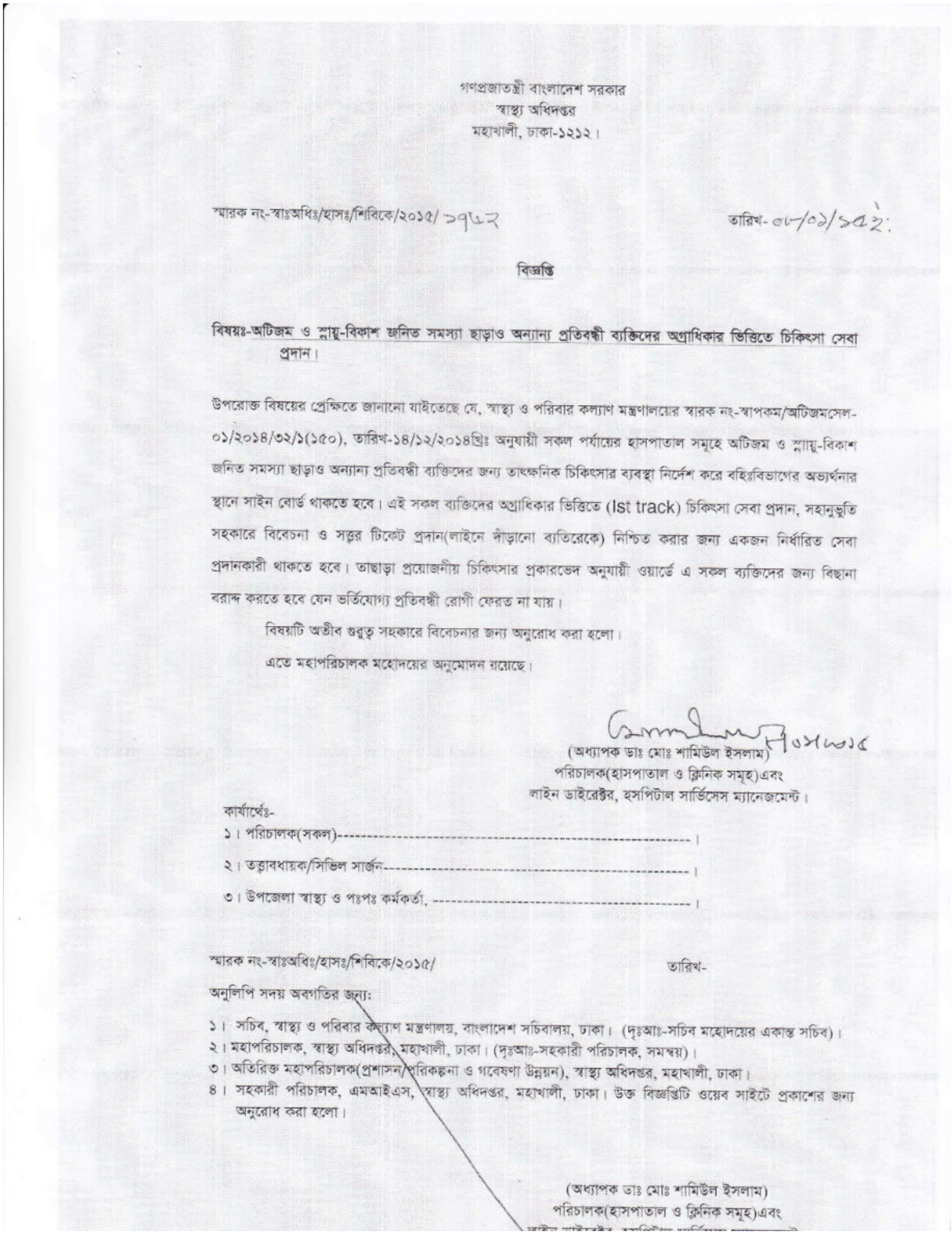
Parents noted that existing infrastructure, such as the current training centers, are a benefit to children with NDDs. In addition, the Neurodevelopmental Disability Protection Trust Policy is of value to parents. Parents cited that creating a curriculum for NDD children would be beneficial to the current schools.

Many challenges currently exist in Bangladesh. The social stigma about autism and NDDs are a continuous battle for parents. In the area of employment, parents mentioned a lack of employment facilities for children with NDDs, especially since many have received training for work according to their talents. The education system in Bangladesh has no standardized rules and regulation regarding mainstreaming children with NDDs, or parents are unaware of them. Furthermore, because children with NDDs have a lack of basic education for the Primary School Certification, and Junior School Certification, their attainment of higher education is often limited; this is exacerbated in the rural areas because of limited schools and rehabilitation centers. In addition, there is a lack of appropriate teacher training and no training courses available to receive appropriate training. In reference to services for children with NDD, many parents noted that services are expensive and there is a shortage of therapists at the upazila (sub-district) level.

Recommendations that ensued from the discussion center around a few main themes: (a) employment, every child has a right to work and use their talents, (b) education, every child has a right to higher education, a modified curriculum, improved teacher training, grants for funding tuition, and monitoring and quality assurance of existing schools, (c) access to health services, every family has the right to affordable treatments and care for their child, access to service provider’s information through electronic media, an improved referral system, a call center to answer questions about services and disabilities, parent counseling, and the establishment of service centers for early detection in entire the country, (d) therapies and rehabilitation, every child has the right to a local rehabilitation center supported by the government, well-trained, service providers, and access to psychiatrists and therapies.

Appendix 16: Copies of important government circulars

DGHS’s circular of 8th of January, 2015, instructing all Government hospitals to establish for persons with NDDs a “fast-track service”.



গণপ্রজাতন্ত্রী বাংলাদেশ সরকার
স্বাস্থ্য অধিদপ্তর
মহাখালী, ঢাকা-১২১২।

স্মারক নং-স্বাঃঅধিঃ/হাসঃ/শিবিকে/২০১৫/ ১৭৬২ তারিখ- ০৮/০১/১৫ইং

বিজ্ঞপ্তি

বিষয়ঃ-অটিজম ও স্নায়ু-বিকাশ জনিত সমস্যা ছাড়াও অন্যান্য প্রতিবন্ধী ব্যক্তিদের অগ্রাধিকার ভিত্তিতে চিকিৎসা সেবা প্রদান।

উপরোক্ত বিষয়ের প্রেক্ষিতে জানানো যাইতেছে যে, স্বাস্থ্য ও পরিবার কল্যাণ মন্ত্রণালয়ের স্মারক নং-স্বাপকম/অটিজমসেল-০১/২০১৪/৩২/১(১৫০), তারিখ-১৪/১২/২০১৪খ্রিঃ অনুযায়ী সকল পর্যায়ের হাসপাতাল সমূহে অটিজম ও স্নায়ু-বিকাশ জনিত সমস্যা ছাড়াও অন্যান্য প্রতিবন্ধী ব্যক্তিদের জন্য তাৎক্ষনিক চিকিৎসার ব্যবস্থা নির্দেশ করে বহিঃবিভাগের অভ্যর্থনার স্থানে সাইন বোর্ড থাকতে হবে। এই সকল ব্যক্তিদের অগ্রাধিকার ভিত্তিতে (Ist track) চিকিৎসা সেবা প্রদান, সহানুভূতি সহকারে বিবেচনা ও সত্ত্বর টিকেট প্রদান(লাইনে দাঁড়ানো ব্যতিরেকে) নিশ্চিত করার জন্য একজন নির্ধারিত সেবা প্রদানকারী থাকতে হবে। তাছাড়া প্রয়োজনীয় চিকিৎসার প্রকারভেদ অনুযায়ী ওয়ার্ডে এ সকল ব্যক্তিদের জন্য বিছানা বরাদ্দ করতে হবে যেন ভর্তিযোগ্য প্রতিবন্ধী রোগী ফেরত না যায়।

বিষয়টি অতীব গুরুত্ব সহকারে বিবেচনার জন্য অনুরোধ করা হলো।

এতে মহাপরিচালক মহোদয়ের অনুমোদন রয়েছে।

৮/০১/২০১৫
(অধ্যাপক ডাঃ মোঃ শামিউল ইসলাম)
পরিচালক(হাসপাতাল ও ক্লিনিক সমূহ)এবং
লাইন ডাইরেক্টর, হসপিটাল সার্ভিসেস ম্যানেজমেন্ট।

কার্যার্থেঃ-
১। পরিচালক(সকল)--।
২। তত্ত্বাবধায়ক/সিভিল সার্জন--।
৩। উপজেলা স্বাস্থ্য ও পঃপঃ কর্মকর্তা, --।

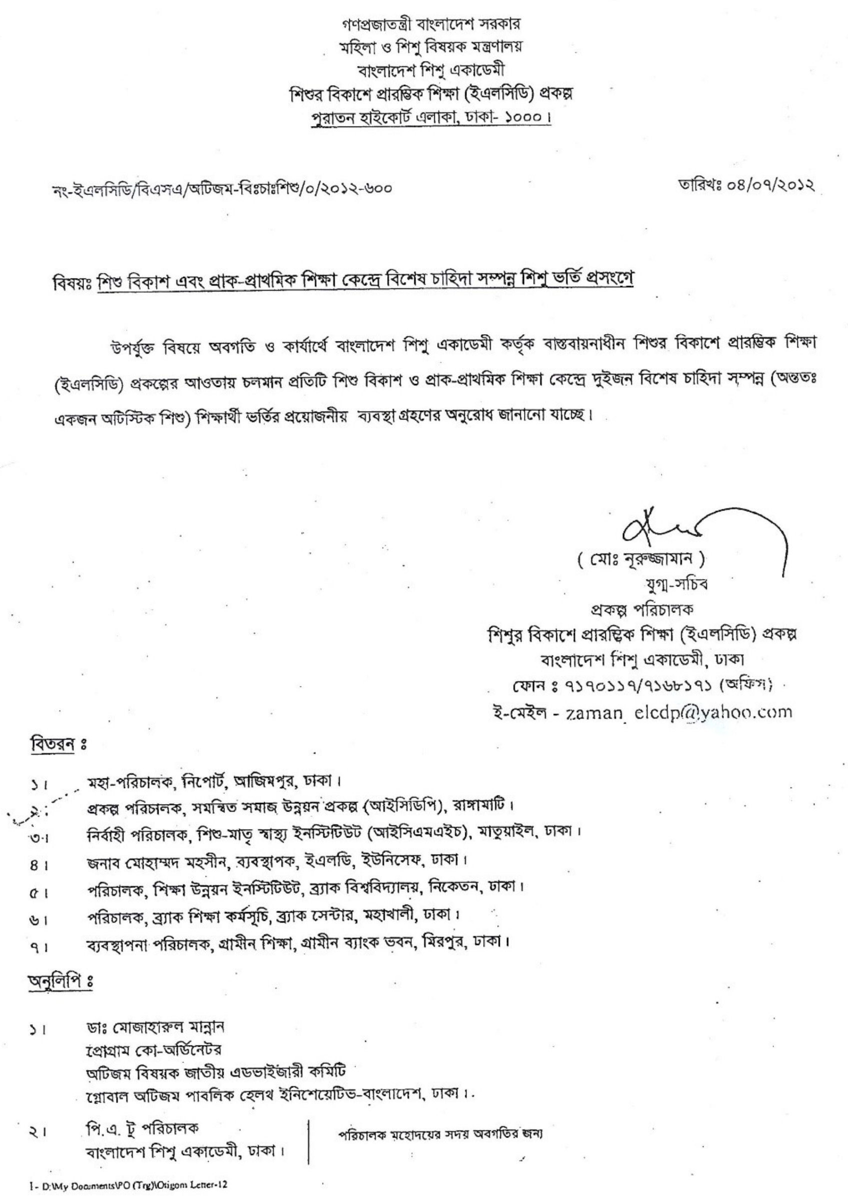
স্মারক নং-স্বাঃঅধিঃ/হাসঃ/শিবিকে/২০১৫/ তারিখ-

অনুলিপি সদয় অবগতির জন্যঃ

১। সচিব, স্বাস্থ্য ও পরিবার কল্যাণ মন্ত্রণালয়, বাংলাদেশ সচিবালয়, ঢাকা। (দৃঃআঃ-সচিব মহোদয়ের একান্ত সচিব)।
২। মহাপরিচালক, স্বাস্থ্য অধিদপ্তর, মহাখালী, ঢাকা। (দৃঃআঃ-সহকারী পরিচালক, সমন্বয়)।
৩। অতিরিক্ত মহাপরিচালক(প্রশাসন/পরিকল্পনা ও গবেষণা উন্নয়ন), স্বাস্থ্য অধিদপ্তর, মহাখালী, ঢাকা।
৪। সহকারী পরিচালক, এমআইএস, স্বাস্থ্য অধিদপ্তর, মহাখালী, ঢাকা। উক্ত বিজ্ঞপ্তিটি ওয়েব সাইটে প্রকাশের জন্য অনুরোধ করা হলো।

(অধ্যাপক ডাঃ মোঃ শামিউল ইসলাম)
পরিচালক(হাসপাতাল ও ক্লিনিক সমূহ)এবং

Bangladesh Shishu Academy's circular of 4th of July, 2012, instructing all early learning centers and pre-primary centers to admit at least two children with special needs, one of which has to be a child with ASD.



গণপ্রজাতন্ত্রী বাংলাদেশ সরকার
মহিলা ও শিশু বিষয়ক মন্ত্রণালয়
বাংলাদেশ শিশু একাডেমী
শিশুর বিকাশে প্রারম্ভিক শিক্ষা (ইএলসিডি) প্রকল্প
পুরাতন হাইকোর্ট এলাকা, ঢাকা- ১০০০।

নং-ইএলসিডি/বিএসএ/অটিজম-বিঃচাঃশিশু/০/২০১২-৬০০ তারিখঃ ০৪/০৭/২০১২

বিষয়ঃ শিশু বিকাশ এবং প্রাক-প্রাথমিক শিক্ষা কেন্দ্রে বিশেষ চাহিদা সম্পন্ন শিশু ভর্তি প্রসংগে

উপর্যুক্ত বিষয়ে অবগতি ও কার্যার্থে বাংলাদেশ শিশু একাডেমী কর্তৃক বাস্তবায়নাধীন শিশুর বিকাশে প্রারম্ভিক শিক্ষা (ইএলসিডি) প্রকল্পের আওতায় চলমান প্রতিটি শিশু বিকাশ ও প্রাক-প্রাথমিক শিক্ষা কেন্দ্রে দুইজন বিশেষ চাহিদা সম্পন্ন (অন্ততঃ একজন অটিস্টিক শিশু) শিক্ষার্থী ভর্তির প্রয়োজনীয় ব্যবস্থা গ্রহণের অনুরোধ জানানো যাচ্ছে।

(মোঃ নূরুজ্জামান)
যুগ্ম-সচিব
প্রকল্প পরিচালক
শিশুর বিকাশে প্রারম্ভিক শিক্ষা (ইএলসিডি) প্রকল্প
বাংলাদেশ শিশু একাডেমী, ঢাকা
ফোন ঃ ৭১৭০১১৭/৭১৬৮১৭১ (অফিস)
ই-মেইল - zaman_elcdp@yahoo.com

বিতরন ঃ

১। মহা-পরিচালক, নিপোর্ট, আজিমপুর, ঢাকা।
২। প্রকল্প পরিচালক, সমন্বিত সমাজ উন্নয়ন প্রকল্প (আইসিডিপি), রাঙ্গামাটি।
৩। নির্বাহী পরিচালক, শিশু-মাতৃ স্বাস্থ্য ইনস্টিটিউট (আইসিএমএইচ), মাতুয়াইল, ঢাকা।
৪। জনাব মোহাম্মদ মহসীন, ব্যবস্থাপক, ইএলডি, ইউনিসেফ, ঢাকা।
৫। পরিচালক, শিক্ষা উন্নয়ন ইনস্টিটিউট, ব্র্যাক বিশ্ববিদ্যালয়, নিকেতন, ঢাকা।
৬। পরিচালক, ব্র্যাক শিক্ষা কর্মসূচি, ব্র্যাক সেন্টার, মহাখালী, ঢাকা।
৭। ব্যবস্থাপনা পরিচালক, গ্রামীন শিক্ষা, গ্রামীন ব্যাংক ভবন, মিরপুর, ঢাকা।

অনুলিপি ঃ

১। ডাঃ মোজাহারুল মান্নান
প্রোগ্রাম কো-অর্ডিনেটর
অটিজম বিষয়ক জাতীয় এডভাইজারী কমিটি
গ্লোবাল অটিজম পাবলিক হেলথ ইনিশেয়েটিভ-বাংলাদেশ, ঢাকা।

২। পি.এ. টু পরিচালক
বাংলাদেশ শিশু একাডেমী, ঢাকা। | পরিচালক মহোদয়ের সদয় অবগতির জন্য

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