JANUARY 2019

DEFINING DISABILITY

A GUIDELINE FOR MEDICAL DOCTORS AND PRIMARY HEALTH CARE WORKFORCE

Non Communicable Disease Control Programme
Directorate General of Health Services
Health Services Division, Ministry of Health & Family Welfare

NCDC

স্বাস্থ্য ও পরিবার কল্যাণ মন্ত্রণালয়

drra

BOARD OF EDITORS

Writing and Compilation
Rifat Shahpar Khan, Director, Creative Pathways
Dr Khaleda Islam, former Director, Primary Health Care, Directorate General of Health Services

Published by
Non Communicable Disease Control Programme
Directorate General of Health Services
Mohakhali, Dhaka, Bangladesh
Phone: +88-02-9899207, E-mail: ncdc@ld.dghs.gov.bd
ISBN: 978-984-34-5733-2

Date: January 2019

MESSAGE

Given the population of Bangladesh there is no doubt that our country has a reasonably large proportion of people who are affected with different forms of impairment and/or disabilities. The Directorate General of Health Services under the Leadership of the Ministry of Health & Family Welfare, Government of Bangladesh has a pivotal role to ensure basic health care to all people of the country. Over the last decades DGHS with other national and local partners and sister-concerns has made significant progresses towards achieving the MDGs. Life expectancy has increased; between 1993 and 2014, under 5 mortality decreased from 133/1000 to 46/1000 Live births (LBs), exceeding the MDG 4 target of 48/1000 LBs. During the same period the infant mortality rate fell from 87 to 38 deaths per 1000 LBs; neonatal mortality fell from 52/1000 LBs to 28/1000 LBs. People are living longer and healthier, with an increased access to primary health care and the functioning community clinics located across the country. Bangladesh is now thriving towards achieving the SDG which specifically includes persons with disabilities under five goals in seven targets.

On the basis of the Household Income and Expenditure Survey (HIES, 2010) Bangladesh has an estimated 14 million people (9.1% of the total population) who have some form of disability. Bangladesh is a party to the United Nations Convention on the Rights of Persons with Disabilities (CRPD), having signed the treaty on 9 May 2007 and ratified it soon after on 30 November 2007. In order to remove all form of barriers and create access of people with disabilities, our country has enacted the Rights & Protection of Persons with Disabilities Act, 2013, which among other things, calls upon the state to make service provisions including health care and assistive devices available free of cost for persons with disabilities. It has bestowed the responsibility of verifying disability upon the public sector medical doctors. Therefore, it is the time for the public sector, the non-governmental and private sectors to work together to prepare the primary and secondary health care workforces to early identify, diagnose, and refer impairment and disability of children and adults so that it can reduce the risk to further disability, and cost of health care for people with disabilities in Bangladesh. DGHS is pleased to work with all stakeholders towards making health services disability inclusive gradually.

Professor (Dr) Abul Kalam Ajad
Director General
Directorate General of Health Services (DGHS)
Ministry of Health & Family Welfare

MESSAGE

Persons with disabilities have the same need to access health as others. They need to access specialized and health-related rehabilitation services. It is essential that mainstream health services are accessible, and that our primary health care (PHC) workforce and medical doctors have both the aptitude and attitude to screen & diagnose impairment and disabilities. It is also necessary that they are provided with the needed health care services and specialized care through appropriate referral.

Even if we refer to only available national statistics (9.1% disability prevalence rate; HIES 2010), Bangladesh has 15 million or more people, who have one or other form of disabilities. The figure is large enough to demand the attention of the public health sector. In recent years, Bangladesh has been applauded internationally for achievements made particularly by its health sector initiatives – that includes the country's tremendous successes in reducing child and maternal mortality in the face of many socioeconomic challenges. The country is already reaping the benefit of an excellent immunization programme e.g. Polio has been eliminated and a vast majority of one year olds are immunized against blindness due to measles. And yet the country has to go far in tackling undernutrition of mothers and children, some communicable and non-communicable disease, delivery and congenital conditions as well as accidents – which are some of the key causes of preventable disabilities.

The public health sector in Bangladesh is the first key actor with the responsibility of policy formulation, financing, providing leadership and playing regulatory roles and even extending comprehensive health services by utilizing its primary, secondary and tertiary level facilities and workforces. The health workforces in Bangladesh is skewed with a ratio of doctors to nurses to technologists of 1:0.4:0.24, in stark contrast to the WHO recommended ratio of 1:3:5 (WHO, Bangladesh Health system Review, 2015). Health associate or allied health professionals such as physiotherapists, occupational therapists, speech & language therapists are largely absent in the Primary Health Care sector of Bangladesh. Therefore, in order to address the short-comings of providing a more comprehensive primary health care in short to medium-term time-frame, it is necessary to equip existing health workforces at primary and secondary levels (i.e. PHC paramedics, field workforce & medical doctors) with essential knowledge on early identification, diagnosis, referral and some other service deliveries in context of impairment and disability. Where needed, the trained doctors will seek support/ refer patients to specialized doctors/allied health professionals to ensure maximum benefit of the patient/person with disabilities. Health care and health-related rehabilitation and access to health is inherent entitlement of persons with disabilities. All of these are very much in compliance with the Rights & Protection of Persons with Disabilities Act, 2013 of Bangladesh, which among other things, has bestowed the responsibility of verifying disabilities, upon the public sector medical doctors stationed at UHC & district level hospitals. Only then we will be able to achieve the Sustainable Development Goals (SDG) and ensure universal health care.

Professor AHM Enayet Hussain
ADG (Planning and Development)
Directorate General of Health Services (DGHS)
Ministry of Health & Family Welfare

MESSAGE

The percentages of people with disabilities as indicated by the national HIES (2010) data and the WHO estimation (2010) – both point out to a reasonably large proportion of population of Bangladesh to have some form of disability and/or at risk of disability. Low- and middle-income countries including Bangladesh thus have a large and growing Non-communicable diseases (NCDs) burden, which is a major cause of preventable disability worldwide. And yet efforts to monitor and manage the growing burden of NCD-related disability and people who are already living with a disability remain relatively limited. In addition, there is limited scope or the provision of long-term rehabilitation services within the public health care structure for people with disabilities. Key aims of NCD care are also to improve functional status and quality of life, instead of just cure – therefore, DGHS has taken the initiative with one of its non-governmental partners DRRA to translate impairment and disability in relatively easier term for both a wide range of primary health care workforce and medical doctors stationed in different tiers to promote early identification, diagnosis, referrals and service provisions. This can in future provide the scope for integrating preventive and curative health care better with rehabilitative aspects of health care. This can enhance the opportunities for both the public sector and the non-governmental sector to work together to improve the quality of life of people with disabilities, and augment scopes for inter-sectorial cross referrals for the health & well-being of children & adults with disabilities in Bangladesh.

Dr Nur Mohammad
Line Director
Non-Communicable Disease Control (NCDC)
Directorate General of Health Services (DGHS)

MESSAGE

People with disabilities are one of the largest and most medically underserved populations. Because of a range of systemic challenges, including inadequate trainings and inaccessible facilities, they tend to have less access to quality healthcare and health promotion programmes.

Inclusion of all people, including people with disabilities, in mainstream health policies and laws, programming, services, training programmes, research and funding streams will help reduce the rates of preventable diseases and other health issues among the people with disabilities.

While there have been improvements over the years, the fact remains that people with disabilities still face significant health disparities – not associated with their conditions but the result of inadequate access to services and programmes.

Various data states that nearly 15% population of Bangladesh is affected by different forms of disability. In our country, medical professionals are involved for disability identification, screening and issuing certificates for the persons with disabilities. But still there is no uniform diagnosis and screening tools for identification of disabilities in line with the Persons with Disabilities Rights and Protection Act 2013.

Considering the reality, the Directorate General of Health Services (DGHS) and Disabled Rehabilitation and Research Association (DRRA) decided to collect existing identification/screening tools practicing nationally and globally.

Starting up the process and on priority basis indicators, definition and tools for 6 major groups of disabilities are accumulated through consultation engaging experts/subject specialists of reputed and experienced government and relevant NGOs.

A guideline on 'Defining Disability: A Guideline for Medical Doctors and Primary Health Care Workforce' also developed through a series of consultation covering the six types of disabilities. DRRA was involved in its full development process from conceptual framework to implementation level.

Through the guideline a direction to right to health and aims to understand the facilities of existing health services and service delivery system that boost up people with disabilities for accessing quality health services in Bangladesh.

On behalf of DRRA, I am delighted to be a part as knowledge partner and gratefully acknowledge the hard work and dedication of the team of NCDC of DGHS and also thankful to all other participants with their contribution for making the guideline an effective one.

Farida Yesmin
Executive Director
Disabled Rehabilitation and Research Association (DRRA)
House no: 2/5; Road no: 01, Shaymoli; Dhaka-1207

ACKNOWLEDGEMENT

‘Defining Disability: A Guideline for Medical Doctors and Primary Health Care Workforce’ is a result of extensive consultation processes with a range of medical professionals (includes specialized and general) and allied health workforces (e.g. physiotherapists, occupational therapists, speech & language therapists), disability & development service providers, people with disabilities & their organizations, and legal professionals in Bangladesh. Literature review of a wide range of secondary documents and web-based information published by acclaimed institutes have fed into the processes of compilation and writing of this document. The document has used graphics/illustrations of various acclaimed institutes, including WHO, IAPB from web-sources. We gratefully acknowledge the contributions made to this document by resource persons of all participating organizations, individuals, and particularly all the reviewers.

We wish to acknowledge the crucial leadership of the Additional Director General (Planning & Development), DGHS without whose direction and initiative this piece of document, one of the most preliminary steps to gradually make our primary & secondary health workforce disability-sensitive would not come forth. We are thankful to the respective Directors of NIENT, NINS, NITOR, NIMH, NIOH & IPNA for extending their assistance. We are thankful to veteran disability organizations including CRP, CDD, DRRA, SWID Bangladesh, SAHIC, HiCare, HI, ADD, Sightsavers, and Disabled Peoples Organizations including SDSL, PNSP and BVIPS for their contributions. Thanks goes to Md Musherrraf Hossain Mazumder, Advocate, Appellate Division, Bangladesh Supreme Court for his advice. Special thanks to those individuals who have sent their feedback on the document. We acknowledge them all. We are open to any advice to improve this document further, in future.

CONTENTS

ABBREVIATION

ABI	Acquired Brain Injury
ADLS	Activities of Daily Living Skills
AMD	Age-Related Macular Degeneration
AAIDD	American Association on Intellectual and Developmental Disabilities
ABC	Assistance for Blind Children
AHI	Assistant Health Inspector
ASD	Autism & Autism Spectrum Disorder
BSMMU	Bangabandhu Sheikh Mujib Medical University
BJAKS	Bangladesh Jatiya Andha Kallyan Somiti Hospital
BNSB	Bangladesh National Society for the Blind
BPA	Bangladesh Physiotherapy Association
BPF	Bangladesh Protibondhi Foundation
B-SCAN	Bangladesh Society for the Change and Advocacy Nexus
BERDO	Blind Education and Rehabilitation Development Organization
BVIPS	Bangladesh Visually Impaired Peoples' Society (BVIPS
BLBC	BRAC Limb and Brace Centre
CDD	Centre for Disability in Development
CRP	Centre for Rehabilitation of the Paralyzed
CSID	Centre for Services & Information on Disability
CP	Cerebral Palsy
CSF	Cerebrospinal Spinal Fluid
CEITC	Chittagong Eye Infirmary and Training Complex
COPD	Chronic obstructive pulmonary disease
CMH	Combined Military Hospital
CC	Community Clinic
CHCP	Community Health Care Provider
CBC	complete blood count
CT Scan	computed tomography Scan
CTEV	congenital talipes equinovarus
dB	Decibel
DB	Deaf-Blindness (DB)
DASE	Denver articulation screening examination
DSS	Department of Social Services
DPLEH-N	Dhaka Progressive Lions Hospital, Narshingdi
DSM-5	Diagnostic & Statistical Manual of Mental Disorders-V
DGHS	Directorate General of Health Services
DPE	Directorate of Primary Education
DALY	Disability adjusted life years
DPO	Disabled Peoples Organizations
DRRA	Disabled Rehabilitation and Research Association
DHIS2	District Health Information System Version 2
DS	Down Syndrome
DMD	Duchenne Muscular Dystrophy
ELM Scale-2	Early Language Milestone Scale-Second Edition
EEG	Electroencephalogram
EPI	Expanded Programme on Immunization
FW	Family Welfare Assistants
FWV	Family Welfare Visitor
FIM	Functional Impairment for adult
S. GGT	Gamma-glutamyl transferase
GERD	Gastro-esophageal Reflux Disease
GO-NGO	Government & Non-Government Organizations GO-NGO
HI	Handicap International
HA	Health Assistant
HI	Health Inspector
HD	Hearing Disability
HMIS	Health Management Information System
HIES	Household Income and Expenditure Survey
IMR	Infant Mortality Rate (IMR)
IEC materials	Information, Education and Communication Materials
IDSC	Integrated Disability Service Centre
ID	Intellectual Disability (ID)
IQ test	Intelligence Quotient test
IAPB	International Agency for the Prevention of Blindness
ICD-10	International Classification of Disease, Tenth Edition
ICF	International Classification of Functioning, Disability and Health
IPNA	Institute of Paediatric Neuro-disorder & Autism
IIEIH	Ispahani Islamia Eye Institute and Hospital
JPUF	Janiya Protibondhi Unnayan Foundation
KSPT	Kaufman Speech Praxis Test for Children
LV	Low Vision
LF	Lymphatic filariasis
MRI	Magnetic resonance imaging
MD	Mental Illness Leading to Disability
MSE	Mental State Examination
MDG	Millennium Development Goals
MMSE	Mini–Mental State Examination
MoHFW	Ministry of Health and Family Welfare
MoSW	Ministry of Social Welfare
NIENT	National Institute of Ear-Neck-Throat
NFOWD	National Forum of Organizations Working with the Disabled
NIMH	National Institute of Mental Health
NINS	National Institute of Neurosciences & Hospital
NIOH	National Institute of Ophthalmology & Hospital
NCV	Nerve Conduction Velocity Testing
NSA	Non State Actor (includes non-government organizations, civil society & other private sectors)
OP	Operational Plan
OFC	Occipital Frontal Circumference
OT	Occupational Therapist
OSB	Ophthalmological Society of Bangladesh
ALPHA	Phonology and Articulation
PD	Physical Disability (PD)
PT	Physiotherapist
PHC	Primary Health Care
PNSP	Protibondhi Nagorik Shongsthaner Parishad
QOL	Quality of Life Questionnaire
RBS	Random Blood Sugar
RAD	Rapid Assessment of Disability
RMO	Resident Medical Officer
ROP	Retinopathy of Prematurity
S.Creatinine	Serum Creatinine
SBK	Shishu Bikash Kendra (SBK)
SAHIC	Society for Assistance to Hearing Impaired Children
SWID	Society for the Welfare of the Intellectually Disabled
SDSL	Society of the Deaf & Sign Language Users
SD	Speech Disability
SLT	Speech & Language Therapist
SCI	Spinal Cord Injury
SDG	Sustainable Development Goal
TSH	Thyroid stimulating hormone
UNCRPD or CRPD	United Nations Convention on the Rights of Persons with Disabilities
USTC	University of Science & Technology Chattagram
UHFPO	Upazila Health and Family Planning Officer
UHC	Upazila Health Complexes
VD	Visual Disability
WG	Washington Group on Disability Statistics
WDDF	Women with Disabilities Development Foundation
WHO	World Health Organizatio

EXECUTIVE SUMMARY

1. Bangladesh has an estimated 15.1 to 24.9 million people, who are affected with one or other form of disability. These figures are large enough to demand national attention. There are some noteworthy progresses and health related gains achieved by Bangladesh over the last decade, which have made significant contributions to preventing certain impairments. Yet under-nutrition of mothers and children, communicable and non-communicable diseases, delivery and congenital conditions, and accidents remain high, which are some of the key causes of preventable disabilities in Bangladesh.

2. The country's health workforce, health structure & system, particularly those at the primary to secondary facilities are not adequately skilled to reach out to children and adults at risk of impairment and disabling conditions with appropriate health & health-related rehabilitation services and referral mechanism. The medical curriculum in Bangladesh barely includes issues related to disabilities and their rehabilitation. Medical professionals at primary & secondary tiers, and primary health workforces are not adequately sensitized, educated and trained on disability issues. Medical doctors at these tiers have limited knowhow to support early identification, diagnosis, appropriate referral and/or provide services to a majority of children, adults and older people with disabilities. Quality health services for children and adults with disabilities exists as 'specialized services' in a limited number of tertiary and mainly urban-based public facilities instead of the mainstreamed service mechanism. The number of non-governmental facilities with the capacities to provide support is also limited in the country and many of them are located in urban or semi-urban areas mainly. Whereas the public health care facilities with its extensive network are well-placed and has the potential to make both general and specialized health & rehabilitation care more accessible for children and adults with disabilities. The Rights & Protection of Persons with Disabilities Act, 2013 of Bangladesh (henceforth referred to as the Act) has bestowed the responsibility of verification/certification of disability on public medical doctors at upazila health complexes and above-facilities (Article 31).

3. The Directorate General of Health Services, Ministry of Health & Family Welfare, as part of its commitment to implement the Rights & Protection of Persons with Disabilities Act, 2013, and to achieving the Sustainable Development Goal (SDG) has stepped forward to bring about a significant change around health services and facilities making these disability inclusive. "Defining Disability: A Guideline for Medical Doctors and Primary Health Care Workforce" therefore, is one of the earliest steps to move toward this direction. This is planned to become a guideline - geared towards creating scope for increasing interaction, identifying training needs and need-based referrals to available services in the public and private/non-government sectors. The document 'Defining Disability: A Guideline for Medical Doctors and Primary Health Care Workforce' is a result of extensive consultation with a wide range of multi-disciplinary stakeholders from health, disability, development, social development and legal sectors, and disabled peoples organizations (DPOs). This has tried to demystify disability definitions. And it lists down a number of signs, symptoms/indicators for early identification of impairment & diagnosis of disabilities by relevant public health workforce at some of the lowest health tiers to create possibilities of better and faster health service deliveries and or health related-rehabilitation & management where necessary through referral. This has created the possibility of taking a pilot phase approach to train relevant health workforce and also test out the indicators for incorporation into the DHIS2/HMIS.

4. The document endeavours to 'demystify' or 'translate' disability for PHC workforces at UHCs level and below, as well as district hospitals and above. It attempted to analyze & collate information, e.g. i) what is disability & define various categories of disabilities, ii) list signs/symptoms of disabilities, iii) list available tools to assist identification by a range of 'trained' PHC workforce particularly 'trained' medical doctors, and iv) list possible referral points/pathways. It tries to promote needs-based referral to primary, secondary &/or to tertiary health & rehabilitation facilities, and other social & education sectors. This is to help our PHC workforces fulfill their roles by assisting children/adults with impairment and/or disability access health care and health-related rehabilitation to improve their quality of life.

5. The document specifically deals with 10 out of 12 categories of disabilities as listed in the Bangladesh' Act, 2013; and it is open to adopt the recommendation on Autism & Autism Spectrum Disorder (ASD) being addressed by a separate task-group with the DGHS, MoHFW. The definitions are in alignment with the overall definitions of disability as in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and the International Classification of Functioning, Disability and Health (ICF). The document focuses the bio-social model of ICF which is in close alignment with both the UNCRPD and the spirit of the Rights & Protection of Persons with Disabilities Act, 2013 of Bangladesh (Act, 2013).

THE DISABILITIES SPECIFICALLY FOCUSED BY THIS DOCUMENT ARE:

A) CEREBRAL PALSY - listed in Articles 3 & 12 in the Act has been addressed in the Module as CP

B) HEARING & SPEECH DISABILITY AND DEAF-BLINDNESS - listed in Articles 3 & 8 as Speech Disability, Articles 3 & 10 as Hearing Disability, and Articles 3 & 11 as Deaf-blindness in the Act. Indicators set follows the hearing, speech and deaf-blindness sequentially.

C) INTELLECTUAL DISABILITY - covers both ID in Articles 3 & 9, and Down Syndrome in Articles 3 & 13 in the Act.

D) MENTAL ILLNESS LEADING TO DISABILITY - listed in Articles 3 & 6 in the Act and referred to as MD in the Module.

E) PHYSICAL DISABILITY – listed in Articles 3 & 5 in the Act and referred to as PD in the Module.

F) VISUAL DISABILITY – listed in Articles 3 & 7 in the Act and referred to as visual disability or VD in the Module.

6. In order to maximize the health, well-being and quality of life of the concerned child/adult with impairments/disabilities, international standard grading has been used (where possible e.g. for hearing loss). Some curable illnesses e.g. clinical depression, post-traumatic stress, problems associated with anxiety & phobia were taken out of the list of illness leading to mental or psycho-social disability from the definition agreed for mental/psycho-social disability for this document to avoid stigmatization. As for issuance of disability certification by concerned committee (in reference to the Act), careful consideration will be required. Disabled Peoples' Organisations & legal aid providers are alerted to maximize the benefit to people with disabilities.

7. Literature review of a wide range of secondary documents and web-based information published by acclaimed institutes have fed into the processes of writing and compilation. The document contains a detail lists of symptoms, tools, and action points for PHC workforces and doctors to follow for identification and diagnosis of children and adults with impairments and/or disabilities.

8. The document has the following key recommendations to mainstream disabilities within a specific time-frame to enable Bangladesh meet its commitments towards achieving the SDGs and move towards a disability inclusive health care:

- Review/agree on minimum quality standards i.e. develop operational guideline and protocol for health and related rehabilitation professionals and services in Bangladesh.
- Where needed, field test & roll out agreed tools to be used by PHC workforces & trained doctors.
- Establish functional referral points involving public sector & NSA (includes NGOs& private service providers); consider a cross-sectoral approach.
- Consider a consortium approach to improve the effectiveness of training to optimize quality, resources (including human resources), and avoid duplication.
- Pilot, and then take the learning to roll out across the country.
- Strengthen monitoring & supervision of disability services; and include disability indicators in HMIS/ District Health Information System (DHIS2).
- Consider licensing & monitoring options for allied workforces e.g. PT, OT, SLT & other providers to streamline services.
- Review existing Human Resources structure within public health sector to create needs-based positions of PT, OT, SLT & counsellors etc. at relevant levels of health & rehabilitation facilities in Bangladesh.
- Introduce a rehabilitation service and referral protocol for individual, public and private service providers.

A BRIEF STATE OF DISABILITY IN BANGLADESH

CHAPTER 1

1.1 A BACKGROUND

1.1.1 The World Report on Disability 2011[1] estimates over a billion people to live with one or other forms of disability globally. Stating that people with disabilities generally have poorer health, higher rates of poverty than those living without disabilities, and that they face significant barriers and lack of access to services, it aptly emphasized the need for strategy to "overcome these barriers to health care, rehabilitation, education, employment" and other support services.

1.1.2 The Household Income and Expenditure Survey (HIES) of Bangladesh (2010) puts the prevalence rate of disability at 9.1%[2]. A Rapid Assessment of Disability (RAD)[3], puts a prevalence rate of 8.9% of disability in Bangladesh. Taking the population estimate of Bangladesh as over 166[4] million and utilizing the national HIES (2010) estimate of 9.1% and the global i.e. WHO estimation of 15% prevalence rate of disabilities, Bangladesh has an estimated 15.1 million to 24.9 million people, who have one or other form of disability. These figures are large enough to demand national attention.

1.1.3 Bangladesh has made commendable progress towards achieving the Millennium Development Goals (MDGs) 4 and 5 as the country has reduced Infant Mortality Rate (IMR) from 87 in 1993 to 31 in 2015 per 1000 live births[5]. Polio has been eliminated and 'Polio Free Certification' received in March 2014. Eighty-six per cent of one-year-olds are immunized against measles blindness. These are notable progresses that has contributed to prevent impairments through various initiatives by the Ministry of Health and Family Welfare (MoHFW) on Community Maternal and Neo-natal Health and Expanded Programme on Immunization (EPI). Despite all these, the priority remains for children with disabilities to have access to the services they require in the most inclusive settings in their communities[6]. Under nutrition of mothers and children, communicable and non-communicable diseases, delivery and congenital conditions, and accidents remain high, which are some of the key causes of preventable disabilities in Bangladesh.

1.1.4 The country's health workforce, health structure & system, particularly at primary to secondary levels are still not adequately prepared to deal with children and adults at risk of impairment and disabling conditions with appropriate health & health-related rehabilitation services and referral mechanism. The medical curriculum in Bangladesh barely includes issues related to disabilities and their rehabilitation. Medical professionals at primary & secondary tiers, and other PHC workforces are yet not adequately sensitized and/or trained on disability

issues. In most cases, quality health services for children and adults with disabilities exists as 'specialized' instead of the mainstreamed health care service mechanism. This often affects the availability and accessibility of health care services for all. Absence or inadequacy of capacity and mechanism to early identification, early diagnosis, early intervention and/or referral across the country, thus, has become an obstacle to prevent disabling conditions and also secondary disabilities. In addition, health-related rehabilitation, which is often required to manage disabling condition and optimize functioning in individuals with impairment/disability is near to absent in the wide network of public health care, particularly at primary and secondary tiers in Bangladesh. Rehabilitation is yet to take place in 'all levels of care like community, primary, secondary and tertiary level along the continuum of care'.

1.1.5 The number of non-governmental facilities with the capacities to provide support to children/adults with disabilities is limited in Bangladesh; and many of them are also urban or semi-urban based. Whereas the public health care facilities with its extensive network across the country are well-placed and has potential to make health & rehabilitation care more accessible for people with disabilities – and The Rights and Protection of Persons with Disabilities Act, 2013 has rightly recognized this possibility.

1.1.6 The Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD or CRPD) calls for state parties to "recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation". Among meeting other aspects of health care, the CRPD asks state parties to "Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons[7]."

1.1.7 In Bangladesh, Article 31 (Clause 1 & 5) of The Rights and Protection of Persons with Disabilities Act, 2013[8] ordains responsible medical doctors of Upazila Health Complexes (UHC) or District Sadar/General Hospitals (in rural or urban area) to verify disability of the person so as to facilitate the process of his/her obtaining registration and disability identity card from concerned authority. Schedule (Article 2 (7) under point no. 3 on Health Services) of the Act, among other matters, calls upon the state party to take various measures in relation to:

a. Ensuring food safety and nutrition of children and adults with disabilities
b. Take preventive measures to reduce the risk to further disabling conditions of children, women and older population with disabilities; and people with multiple disabilities
c. Make service provisions including health care and assistive devices available free of cost for persons with psycho-social or mental disabilities and persons with disabilities of ultra-poor background who require long-term health care. Where needed, and subject to pre-approval of the National Board of Revenue, tax rebate provisions may be considered.
d. Take measures to reduce cost of health care for people with disabilities of ultra-poor background at privately run hospitals and clinics

e. Take measures to train medical doctors, primary health care (PHC) workforce and social workers to provide services and make necessary medical requisites and equipment avail able for health care services provisions for people with disabilities at the publicly run hospitals and health centres

1.1.8 In addition, Article 36 and Article 37 of the Act'13 states about compensation measures and way forwards in case of any discrimination committed or discriminatory attitudes shown, or in case of inaction by any individual or organizations or authority as a result of which a person with disabilities may be affected in relation to his/her rights, inclusion and access to services as described in the Act. The Act has elaborated various measures to safeguard the interest of affected persons by provision of legislative framework, and where applicable provisions of compensation, punishment and mechanisms to be followed.

1.1.9 It is, therefore, essential for health sector to make health care more accessible and of quality for children and adults with disability by taking initiative to demystify disability issues for medical doctors and primary health care workforces. It is essential to ensure accurate identification and referral by health workers, and diagnosis by medical doctors of various forms of disabilities, and make both general and specialized health care and health-related rehabilitation services gradually available to people with disabilities.

1.2 A STEP TOWARDS IDENTIFYING DISABILITY FOR PUBLIC HEALTH SERVICES

1.2.1 Among its many efforts, DGHS under Ministry of Health & Family Welfare (MoHFW), Bangladesh has stepped forward to bring about a significant change around health services and facilities making these disability inclusive. This is in alignment with both national and international commitment to achieve sustainable development goals (SDG), which calls for the disaggregation of all relevant targets/indicators by disability[9]. Thus, this document is one of the earliest steps to move toward this direction. This is initiated to become a working module - geared towards creating scope for increasing interaction and need-based referrals to available services in the public and private/non-government sectors. Furthermore, this initiative is in alignment with the agenda of the UNCRPD[i] and the Rights and Protection of Persons with Disabilities Act, 2013 of Bangladesh.

1.2.3 It is to be noted that data concerned with health sector at national level are not disaggregated by disability, making children with disabilities 'invisible' as well as inhibiting disability inclusion planning in the mainstream programmes. For example, HMIS in Bangladesh generates data on Under-five mortality rate, but it does not generate data on 'Under-five mortality rate for children with disabilities', or 'Percentage of persons with disabilities receiving needed health services'. This is the case despite there is a web-based data collection system called District Health Information System Version 2 (DHIS2)[10], established by DGHS, to collect routine health data from government health facilities of Bangladesh. The DHIS2 allows collection, validation, analysis and presentation of aggregate statistical data, tailored to integrated health information management activities and it potentially contribute to strengthen the health system at all levels.

[i] Bangladesh has signed the UNCRPD on 9th November 2007 and ratified it on 30th November 2007.

Once the disability indicators are tested, DGHS will take initiative to select a minimum number of required indicators to gradually introduce to the DHIS2 to regularly collect data on all categories of disabilities including for Autism. A pilot phase approach may be considered to introduce the set of total indicators in field and for Health Management Information System (HMIS).

1.2.4 Moreover, this will contribute to integrate disability and health-related rehabilitation within the health sector policies and interventions in Bangladesh. With the introduction of appropriate/needs based training programmes, the initiative has the scope to equip PHC and district level health workforce, particularly doctors in the public sector with the right knowledge, skills, capacities and attitudes toward disability and people. This will strengthen health sector, particularly the primary and secondary health care provided by the public sector across the country.

1.3 DEFINING DISABILITY

1.3.1 According to the UNCRPD, persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others [11]. Also, the World Report on Disability 2011 notes that 'almost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties in functioning'.

1.3.2 On a similar tone, the International Classification of Functioning, Disability and Health (ICF) [12], World Health Organization's (WHO) framework for health and disability puts its foot firmly on the bio-social model of disability whereby the interactions between impairments, activity limitations and participation restrictions results in disability. According to ICF the term 'disability' is thus defined as follows: "*an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).*" (WHO 2001:213)

1.3.3 According to the Washington Group on Disability Statistics (WG)[ii] disability is the interaction of a person's functional status with their physical, cultural, and policy environments [13]. It goes as far as stating "*if the environment in which one lives is designed for the full range of human functioning and incorporates appropriate accommodations and support mechanisms, then people with functional limitations would not be "disabled" in the sense that they would be able to fully participate in society*".

1.3.4 The Rights and Protection of Persons with Disabilities Act, 2013 of Bangladesh defines 'disability' *as a condition whereby a person having long-term or permanent physical or psychological* or intellectual or sensory impairment, cannot fully and effectively participate in the society due to attitudinal and environmental barriers and obstacles (Article 2, Clause 9). The Act,

[ii]The Washington Group on Disability Statistics (WG) is a UN city group established under the United Nations Statistical Commission. The WG was constituted to address the urgent need for cross-nationally comparable population based measures of disability.

perhaps for the first time in Bangladesh has undertaken the task of promoting and ensuring the 'rights' instead of just 'welfare' of people with disabilities within a legislative framework. This has put more emphasis than ever on all sectors including the health sector to address the issue to make services more inclusive and accessible for people with disabilities in the country. The Rights and Protection of Persons with Disabilities Act, 2013 defines disability as following:

"Disability refers to a situation where any person who is affected with long-term or permanent physical, psychological, intellectual, developmental and sensory-related damages or obstacles which in interaction with attitudinal and environmental barriers toward the person restricts the person's equal and effective participation in society."

1.4 CATEGORIES OF DISABILITIES AS IN THE ACT 2013

1.4.1 In Bangladesh, The Rights and Protection of Persons with Disabilities Act, 2013 acknowledges and declares the following 11 categories of known disabilities and keeps itself open to a twelfth category of disability to benefit from its jurisdiction, if needed.

1. Autism or Autism Spectrum Disorders
2. Physical Disability
3. Mental Illness Leading to Disability
4. Intellectual Disability
5. Visual Disability
6. Speech Disability
7. Hearing Disability
8. Deaf-Blindness
9. Cerebral Palsy
10. Down Syndrome
11. Multiple Disability
12. Other Disability

[ii] The Washington Group on Disability Statistics (WG) is a UN city group established under the United Nations Statistical Commission. The WG was constituted to address the urgent need for cross-nationally comparable population based measures of disability.

However, for the necessity of effectiveness and simplicity, without affecting the quality and/or compliance to the Rights and Protection of Persons with Disabilities Act, 2013, this document addresses the following categories of disabilities as listed in the Act, 2013 under the following broad headings.

Multiple disabilities (listed at Article 3 and 14) are not separately covered under any chapter following the Act, but any individual affected with more than one form of the above other disabilities and/or autism will be considered a person with multiple disabilities. Multiple disabilities is given the same degree of importance in this document, as in the Act.

In respect to the Act, this document too is open to a 12th i.e. the 'other' category of disability.

The disabilities focused by this document are:

a) Cerebral Palsy - listed in Articles 3 & 12 in the Act has been addressed in the Guideline as CP

b) Hearing & Speech Disability and Deaf-Blindness - listed in Articles 3 & 8 as Speech Disability, Articles 3 & 10 as Hearing Disability, and Articles 3 & 11 as Deaf-blindness in the Act. In the Guideline, these three categories have been merged together as HSD, given their relative closeness; Indicator set follows the hearing, speech and deaf-blindness sequentially.

c) Intellectual Disability - covering both ID in Articles 3 & 9, and Down Syndrome in Articles 3 & 13 in the Act. In the Guideline, these two have been merged together as ID, considering that Down Syndrome is a conditions that also causes ID.

d) Mental Illness Leading to Disability - listed in Articles 3 & 6 in the Act and referred to as MD in the Guideline.

e) Physical Disability – listed in Articles 3 & 5 in the Act and referred to as PD in the Guideline.

f) Visual Disability – listed in Articles 3 & 7 in the Act and referred to as visual disability or VD in the Guideline.

Note:
a) The type of disabilities above have been listed following English alphabetical order.
b) Autism or Autism Spectrum Disorders (listed at Articles 3 and 4 of the Act) is not covered by this Module as it is already being addressed by DGHS under a separate initiative.

Better health for people with disabilities

World Health Organization

Over **1 BILLION** people globally experience disability

1 in 7 people

People with disabilities have the same general health care needs as others

But they are:

2x more likely to find health care providers' skills and facilities inadequate

3x more likely to be denied health care

4x more likely to be treated badly in the health care system

1/2 of people with disabilities cannot afford health care

They are:

50% more likely to suffer catastrophic health expenditure

These out-of-pocket health care payments can push a family into poverty

Rehabilitation and assistive devices can enable people with disabilities to be independent

970 MIL people need glasses and low vision aids

75 MIL people need a wheelchair; Only **5-15%** have access to one

466 MIL people have disabling hearing loss

Production of hearing aids only meets:

10% of global need

3% of developing countries' needs

Making all health care services accessible to people with disabilities is achievable and will reduce unacceptable health disparities

remove physical barriers to health facilities, information and equipment

make health care affordable

train all health care workers in disability issues including rights

invest in specific services such as rehabilitation

Source: World report on disability: www.who.int/disabilities/world_report

HOW THE MODULE HAS BEEN DEVELOPED: METHODOLOGY

CHAPTER 2

2.1 THE FOLLOWING DESIGN WAS FOLLOWED TO DEVELOP THE GUIDELINE

Advisory Team Formation	Broad categories of disabilities selected to match 10 categories of disabilities as in the Act
Concept agreed & Execution	- Template developed & distributed to collect feedback - Inputs received from Civil Surgeons - (10), Inst./org.(GO-NGO); Participants(4; 9)
Literature Review & Guideline formulation begins	- 1st Consultative Workshop held (Apr.1, '18) - Organization/ Resource:(23; 38) - Literature review (80 to 90 sources consulted) - Draft document circulated, & Feedback received
Guideline formulation begins	- Workshop with Sector Specialists (May 9 onward) (Organization/ Resource: (18/33) - Meeting with sector specialists (team/ individual -6, (Apr.- June; 4;10) - Review by selected persons/ organizations
Prepare to finalize Guideline	- National Dissemination Seminar (June 26, 2018) - Organization/ Tech. & Disability, Development, Legal Resources - Document finalised

Extensive Consultation Processes took place (Period: April – June'18)	2 Workshops held with Subject & Technical Experts. Resource persons included: - Specialist Doctors of various Sub-specialties - Practicing/teaching Physiotherapists, Occupational Therapists, Speech & Language Therapists, - Disabled Peoples' Organizations representatives, - Development Practitioners 23 Organizations/ Institutes & Departments Participated in Workshop 1 involving 38 resource persons. 18 Organizations Institutes & Departments Participated in Workshop 2 involving 33 resource persons plus 10 Civil Surgeons
Inputs/ Feedback received Stage 1 involved inputs received on tabular format during Jan./Feb. 2018 Stage 2 involved inputs received on narrative form during April – June 2018 Stage 3 National Dissemination Seminar Held	Inputs received on at a glance template and narrative document on following areas: - Symptoms, Indicators, Tools to be used - Services including diagnosis & rehabilitative service providers - Required actions for PHC health workforce and medical doctors - Referral points (GO-NGO) Narrative document circulated twice to resource persons i.e. before workshop 2 (May 9) & before dissemination seminar (June 26)
Literature review Stage 1: January 2018 Stage 2: April – June 2018	**Over 80 sources, mostly web-based sources consulted. Key Sources included:** - Rights & Protection of Persons with Disabilities act, 2013 - WHO & other UN documents - Centre for Disease Control & Prevention (CDC) website - Nationally done studies & resources / resources on hearing & speech and mental disabilities, signs/symptoms of impairment/disability - Cerebral Palsy Alliance website - American Association on Intellectual and Developmental Disability website - American Psychiatric Association, 2013 website - Ethics in Medicine; University of Washington School of Medicine

2.1.1 The Guideline is a result of consultation processes with a wide range of multi-disciplinary stakeholders from health, disability, development, social development, disabled peoples organizations, and legal sectors representatives. (ref: list of participants). Two consultative workshops, several meetings, and feedback received through email before the national dissemination seminar for finalization of the document.

2.1.2 A draft document including a narrative section and six templates on broad types of agreed disabilities was shared to all participating organizations and individuals for feedback before the workshop on May 9 and the National Workshop on June 26, 2018. At least 7 meetings were arranged with the following individuals:

- In-charge, Department of Physiotherapy, CRP Mirpur
- Press Secretary, Bangladesh Physiotherapy Association (BPA)
- Executive Director, Bangladesh Protibondhi Foundation
- An Associate Professor (Psychiatry) of NIMH
- Programme & Technical Team members of Handicap international
- Executive Council Members of Society of Speech & Language Therapists (SSLT)
- Two practicing legal professionals, one of who is involved in the disability movement

2.2.3 Definition has been developed and reviewed to address at least 10 categories of disabilities listed in the Act, 2013. Attempt was taken to keep the definitions as close as possible with both the UNCRPD, and the Rights & Protection of Persons with Disabilities Act, 2013. Care was taken to ensure consistency of the definitions with the WHO International Classification of Disability, Functioning and Health (ICF). The definitions per disability were shared with relevant resource persons for getting feedback.

HOW TO ADDRESS CEREBRAL PALSY

CHAPTER 3

3.1 DEFINITION

3.1.1 Cerebral palsy (CP) is caused by brain injury or disease occurring in a developing brain that starts from conception and extends usually to 5 years after birth. The damage caused by CP in the brain of the person does not change / deteriorate over time but the physical condition improves as age advances because of inherent brain plasticity. Thus CP appears as a group of permanent disorder affecting posture and movement that presents in early childhood. It affects body movement, posture, balance, coordination of movements, muscle tone, reflexes, and activities of daily living of affected individual. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems. The condition can be managed through appropriate health & health-related rehabilitative care to enhance his/her activities of daily living skills. A person affected with CP may experience disability/multiple disabilities if the affected individual does not have sufficient access to support service system, and face barriers such as discrimination/ altered attitudes that acts as a barriers or physical/ environmental inaccessibility from fellow people, colleagues/ systems and cultures they belong to, and that affect their daily living.

3.2 GENERAL INFORMATION

Classification:

A. Topographical i.e. parts of the body affected

- Quadriplegic/ Tetraplegia (4 limbs severely affected)
- Diplegic (Lower limb affected more than upper limb; LL>UL)
- Double hemiplegia (Upper limb affected more than Lower limb; UL>LL)
- Hemiplegic (One side of the body affected; Rt / Lt)
- Monoplegic (any limb affected)

B. Physiological classification

- Spastic cerebral palsy: 65%
- Hypotonic
- Dyskinetic: 30%
  - Choreo-athetosis
  - Tremor
  - Rigidity
  - Dystonia

Ataxic

Mixed

Cerebral Palsy: Aetiology or risk factors

- Perinatal asphyxia
- Birth trauma
- Intraventricular haemorrhage
- Hypoglycaemia
- Infection
- Kernicterus
- Congenital brain malformations

Cerebral Palsy: Co-morbidities

- Mental retardation: 30%
- Epilepsy: 30%
- Visual Problem: Squint,$Visual acquity
- $Hearing
- Speech difficulty
- Cortical sensory deficits: Abnormalities of proprio ception and tactile sensory deficits
- Feeding difficulty
- Behaviour problem
- Sleep problems

Cerebral Palsy: Diagnosis is Clinical

- H/O problem related to posture and movement (difficulty in neck holding, sitting, crawling, standing, and walking)
- Sign's related to centre's controlling posture and movement : should demonstrate neurological sign's related to pyramidal, extrapyramidal or cerebellar involvement depending on type of cerebral palsy
- Delayed miles stone of development

In addition there may be

- Developmental delay: which is improving over time indicating static encephalopathy .This can be assessed from developmental velocity
- H/O brain insult (±)
- Persistance of primitive reflexes

Signs[14] of spastic CP include i) abnormal muscle tone (two most common signs are hypotonia, which is decreased tone or tension (flaccid and relaxed limbs) and hypertonia, which is an increased muscle tone or tension (stuff or rigid limbs).

Dyskinetic CP presents with tremor, dystonia, rigidity etc. Ataxic CP presents with imbalance while walking.

3.2.1 It is necessary to pay attention symptoms e.g. if a baby is unable to lift its neck, while on their stomach; if a baby is unable to hold their head up, despite support; if the baby has muscle stiffness; irritability (usually from uncomfort); or has affected motor skills creating problems in e.g. for eating, using their hands, sucking, chewing and swallowing; if a child isn't meeting the developmental milestones; if a child is overly docile/passive (which may be due to e.g. vision or hearing issues relating to cerebral palsy causing them to be overly passive and quiet; if a baby favours one side, and tend to push off of one hand and leg, while the other side drags; if the baby/child has inability to move and maintain balance and posture.

3.2.2 Risk factors[15] to CP include: Being born prematurely; being born with low birth weight; viral or bacterial infection during pregnancy; viral infections during early pregnancy; bacterial infections during and after pregnancy damaging the central nervous system of the baby; untreated severe newborn jaundice; medical condition causing blood-clotting problems; difference in blood type between the mother and baby; problems with placenta in supplying the baby with oxygen and nutrients; and prolonged loss of oxygen for the baby during pregnancy or birth. Disruption of Blood and Oxygen Supply to the Developing Brain e.g. During ischemic stroke, when a blood clot blocks a blood vessel in the brain, is recognized to cause brain damage that can result in CP. It can occur in the developing fetal brain during pregnancy or shortly after birth. Untreated newborn[16] jaundice (high levels of bilirubin in blood during the first few days after birth) can cause a type of brain damage known as kernicterus. Children with kernicterus are more likely to have CP, hearing and vision problems, and problems with teeth. Early detection and treatment of newborn jaundice can prevent kernicterus. Disruption of the oxygen supply during birth (birth hypoxia) is estimated to account for less than 10% of CP cases[17].

3.2.3 70-80% of individuals with cerebral palsy have motor cortex damage. They have spasticity, which is the most common form of cerebral palsy where muscles feel stiff and tight. There is a mixed type where there is a combination of damage to the brain[18].

3.3 KEY FACTS ON CEREBRAL PALSY

- It is an umbrella term for a group of disorders - a permanent condition but not unchanging. It is a life-long physical disability due to damage of the developing brain.
- In most cases, brain injury leading to CP occurs during pregnancy.
- CP, except in its mildest forms, can be evident in the first 12-18 months.
- It is more common among boys than among girls
- Most of the children identified with CP had spastic CP.
- Brain damage leading to CP can happen before birth, during birth, within a month after birth, or during the first years of a child's life, while the brain is still developing. CP related to brain damage that occurred before or during birth is called congenital CP - majority of CP (85%–90%) is congenital. In many cases, the specific cause is not known. A small percentage of CP is caused by brain damage that occurs more than 28 days after birth - called acquired CP - usually associated with an infection (e.g. meningitis) or head injury.
- There is no cure for CP, but treatment & health-related rehabilitation therapies can improve the lives of those who have the condition. It is important to begin a treatment/needs-based therapy program as early as possible[19]. CP is the most common motor disability in childhood (CDC).
- Population-based studies from around the world report prevalence estimates of CP ranging from 1.5 to more than 4 per 1,000 live births or children of a defined age range.
- A recent study estimates prevalence of cerebral palsy in Bangladesh as 3.7/1000 children, which is 1.5 times higher than Australia or Europe[20].

3.4 CEREBRAL PALSY: IMPORTANCE OF EARLY DETECTION/DIAGNOSIS & INTERVENTION

Diagnosing CP at an early age is important for the well-being of children and their families and CP is usually diagnosed during the first or second year after birth. When a child's symptoms are mild, it is sometimes difficult to make a diagnosis until the child is a few years older[21]. Early diagnosis for CP, one of the leading causes of impairment and disability in children globally, is crucial to inform prognosis, service planning, and monitoring for associated developmental and medical disorders. With early identification, referral and diagnosis, needs-based therapy services can be implemented earlier, which might lead to better developmental outcomes for the child, and it may reduce anxiety of the parents and family [22].

3.5 SOME IMPACTS OF CEREBRAL PALSY

Cerebral palsy is one of the most common chronic disabling conditions of childhood with the possibility of tremendous impact on the affected child's capacity to carry out activities of daily living (ADL). Medical costs are estimated several times higher for children with cerebral palsy. This is most likely to increase for children with cerebral palsy who have an intellectual disability[23].

According to the Cerebral Palsy Alliance, 1 in 3 child with CP is unable to walk; 1 in 4 is unable to talk, 1 in 10 has a severe vision impairment, 3 in 4 experience pain, 1 in 4 has epilepsy, and 1 in 2 has intellectual impairment. 1 in 20 people with cerebral palsy also have some level of hearing impairment. 1 in 25 children with cerebral palsy are deaf. 1 in 3 children with cerebral palsy have hip displacement. Pain is often a result of the impairments that are associated with cerebral palsy, e.g. contractures, abnormal postures, dystonia, skin breakdown, hip subluxation, Gastro-esophageal reflux and scoliosis. Children with cerebral palsy may experience specific learning difficulties. These may include a short attention span, motor planning difficulties (organization and sequencing of movement), perceptual difficulties and language difficulties. CP often affects the language centers of the brain that control speech. In mild cases of CP, a child may have difficulty using the correct words, but in more severe cases, a child's ability to verbally express himself/herself might be seriously impeded. Speech disorders are common among those with cerebral palsy. Some children with cerebral palsy have difficulty controlling the muscles in their face, throat, neck and head. This can lead to troubles with speech, chewing and swallowing. It can also cause drooling and affect overall ability to interact and learn. All of these can impact on literacy, numeracy and other classroom skills and activities. Learning may also be affected by difficulties in fine motor and gross motor coordination and communication.

Children with Cerebral Palsy often experience a high level of dysphagia, or trouble swallowing. Dysphagia is caused by congenital, neurological or physiological abnormalities, or by anatomical obstructions or irregularities in the child's throat or esophagus. Additionally, it is necessary to improve functioning of the mouth, jaw and throat muscles (oral motor functioning) that can interfere with not only speech, but also breathing and swallowing – two issues that can pose a significant danger to a child.

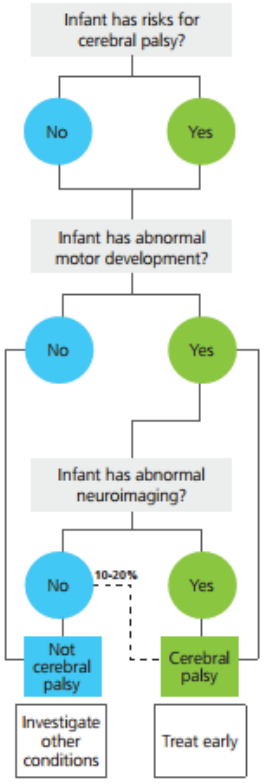
Cerebral Palsy

DIAGNOSIS AND TREATMENT

Cerebral palsy is a physical disability that affects movement and posture.

17 million
people with cerebral palsy worldwide

DIAGNOSIS



Risks for Cerebral Palsy

Risk Factor	CP Risk
Maternal Risks (thyroid, pre-eclampsia, bleeds, infection, IUGR, placental abnormalities, multiples)+/-	
Born Premature • <28 weeks • 28-31 weeks • 31-37 weeks	10.0% 5.0% 0.7%
Term Born • Encephalopathy • Healthy, no known risks	12.0% 0.1%

Assessing Motor Development

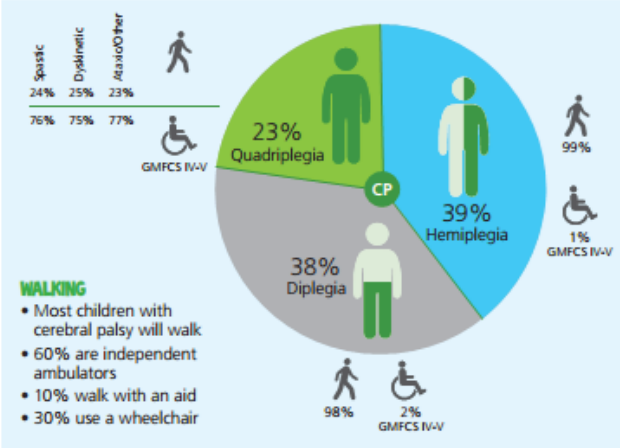
Age: <20 weeks (corrected)	Age 6-12 months
General Movements Assessment. 95% predictive.	Developmental Assessment of Young Children (DAYC). 83% predictive.
Hammersmith Infant Neurological Assessment (HINE). Helps predict severity.	Hammersmith Infant Neurological Assessment (HINE). 90% predictive.

Neuroimaging

Abnormal Neuroimaging	% of all CP
• Periventricular white matter injury	19%
• Cerebral malformation	11%
• CVA	11%
• Grey matter injury	22%
• Intracranial haemorrhage	3%
• Infection	2%
• Non-specific	19%
• Normal	13%

PROGNOSIS

Cerebral palsy can affect different parts of the body:



WALKING
- Most children with cerebral palsy will walk
- 60% are independent ambulators
- 10% walk with an aid
- 30% use a wheelchair

LIFE- LONG
Cerebral palsy is a life long disability. Disability may increase with age, and ageing may occur earlier.

SEVERITY
Predictions of severity are most accurate at 2 years of age.

PAIN, BEHAVIOUR AND SLEEP DISORDERS
in people with cerebral palsy are under-recognised. Assess and treat.

TREATMENT
Without rehabilitation and orthopaedic management, a person with cerebral palsy can deteriorate physically.

ASSOCIATED CONDITIONS AND EVIDENCE-BASED TREATMENT

CP is almost always accompanied by a number of associated conditions and these can be as disabling as the physical condition.

PAIN	INTELLECTUAL DISABILITY	NON-AMBULANT	HIP DISPLACEMENT	NON-VERBAL	EPILEPSY
3 in 4	1 in 2	1 in 3	1 in 3	1 in 4	1 in 4
Treat to prevent sleep & behavioural disorders	Poorer prognosis for ambulation, continence, academics	Independent sitting at 2yrs predicts ambulation	6-12 monthly hip surveillance using x-ray	Augment speech early	Seizures will resolve for 10-20%

BEHAVIOUR DISORDER	BLADDER INCONTINENCE	SLEEP DISORDER	BLINDNESS	NON-ORAL FEEDING	DEAFNESS
1 in 4	1 in 4	1 in 5	1 in 10	1 in 15	1 in 25
Treat early & ensure pain is managed	Conduct investigations & allow more time	Conduct investigations & ensure pain is managed	Assess early & accommodate	Assess swallow safety & monitor growth	Assess early & accommodate

World Cerebral Palsy Day worldcpday.org

Proudly supported by The Allergan Foundation

The content for this infographic was drawn from:
1.McIntyre, S., Morgan, C., Walker, K. & Novak, I. (2011). Cerebral palsy-don't delay, Developmental Disabilities Research Reviews, Volume 17, Issue 2, pages 114–129. 2.Novak, I. (2014). Evidence-based diagnosis, health care, and rehabilitation for children with cerebral palsy, Journal of Child Neurology, 22 June 2014

WORLD CEREBRAL PALSY DAY 05.OCT

3.6 CEREBRAL PALSY MANAGEMENT: MULTIDISCIPLINARY TEAM APPROACH

Early stimulation

- Visual, auditory, tactile, speech, emotion

Management of spasticity

- Physiotherapy
- Occupational therapy: better training for activities of daily living (ADL) like feeding, bathing, dressing, toilet training
- Antispasticity agents
- Splints & Braces, Orthotics

Counselling

Prevention

Anti-spasticity Drugs

- Benzodiazepam
  - Diazepam: Facilitates postsynaptic action of GABA
  - Dose: 0.2 - 0.8 mg /kg,3-4 div. doses
  - Clonazepam: 0.1 - 0.2 mg / kg,2-3 div. doses
- Tizanidine: central a-2 noradrenergic agonist
  - Dose: 6mg/day
- Gabaergic: Baclofen, 2.5mg/day"titrate up till 20-60 mg/day

<u>Management of Dyskinetic CP:</u>

- Trihexiphenidyl Hydrochloride(Artane/Pacitane):
  - 0.03 mg /kg/day1-2 div.dose
  - or
- 0.2 mg/Kg/d] 0.5] 1.0] 1.5] 2.0] 2.5 mg/Kg/d
  - in 3 div.doses on wk 1 to wk 6 respectively

(J Child Neurol 2009;24(20):176-182)

3.7 SYMPTOMS FOR PHC WORKFORCE TO SUPPORT EARLY IDENTIFICATION & REFERRAL

Symptoms of Cerebral Palsy	- Poor cry at birth/Cry after one minute - Neo-natal Convulsion - Check if movements of four limbs present (1-2 months) - Check if baby lifts chin up momentarily on prone lying within 30 seconds (1 month) - Check if baby can lift head up momentarily on ventral suspension within 30 seconds, not in line with the body (1 month) - On ventral suspension holds within 30 seconds, for a few seconds, so that its plane is in line with that of the body (2 months) - Check if baby has the ability to lift head in line with body on pull to sitting (2 month)[24] - Soft muscle, - Stiff muscle, - Feeding difficulties, Swallowing difficulties - Babies do not/cannot roll over/ lifting of head when placed on his/her stomach etc. (at about 4 months) - Delay in developmental milestones - 1 in 5 children with cerebral palsy have saliva loss (also known as dribbling, drooling) - Spasticity/ Contracture of joints - Cross leg

Symptoms of Cerebral Palsy	- Cross leg - Poor coordination of muscles - Involuntary movement - Speech problem - Intellectual delay - Epilepsy - Visual problem - Hearing and speech delay - Seizure gait
Tools for health workers	- History with chief complaints of mother/ caregivers - Observation - Checklist - (Birth history to be included into checklist) - Develop-mental Monitoring Checklist - Referral slip - Updated list of possible referral points
Actions Required	- Take history - Screen following developmental chart - Refer to the nearest facility having trained medical doctors and/or other qualified service providers for diagnosis - Provide community based support - Monitoring (Inform the patient/ parents/ caregivers about the date and time of availability of the specialist/ services (if available/where necessary)

3.8 INDICATORS TO DIAGNOSE IMPAIRMENT & DISABILITY BY TRAINED MEDICAL DOCTORS

Indicators: **Cerebral Palsy**	- Hydrocephaly/ Microcephaly, - Developmental delay, - Floppy or Spastic child - Delayed neck control, poor sitting and delay, poor standing and delay, - Development of contracture - Motor delay - Multi-focal spasticity/ Stiff muscle - Presence of primitive reflexes overtime, conversion - Abnormal reflexes/ Abnormal muscle tones/ Abnormal postures - Poor muscle control/coordination/balance, - Presence of drooling after 18 months - Swallowing problem - Gait abnormality/difficulty - Epilepsy - Tremor - For toddler, not walking, uneasy posture, type of seizure - Speech problem
Tools	- Detail birth history, ante- and post-natal history - If delivery was traumatic; if significant risk factors were encountered during pregnancy or birth, doctors may suspect CP immediately - Pre-natal history to include information on mother's pregnancy, i.e. prenatal exposure to illicit drugs, toxins, or infections; maternal diabetes; acute maternal illness; trauma; radiation exposure; prenatal care; and fetal movements, hypertension history - Examine Motor Function (Gross & Fine Motor) - Find out other associated problems - Abnormal growth charts/Developmental milestone Chart

	- Hammer for reflex test - Torch - MRI or CT scan to obtain brain image, EEG (only if needed) - Different test for associated sensory disabilities - Confirming key indicators including: the child's development milestones, growth chart standards for height and weight, How do the child's reflexes react? Whether the child is able to focus on and hear the caregivers; abnormality of posture and movement; Is the condition of the child deteriorating (non-CP) or remaining static - CP QOL (Quality of Life Questionnaire)
Actions	Check the referral info. as appropriate and as necessary take history Trained doctors to diagnose and provide service Diagnosing CP may take several steps and involve team work by the doctor, community clinic, parents/caregivers and other allied professionals. The doctor will assess to rule out non-CP cases and refer all (both CP and non-CP to appropriate services). The steps may be as following: Assess child's growth and development utilizing parents, if any concerns about the child's development are raised developmental screening test may be applied: all children to be screened for developmental delays. Provide counselling Where needed refer to specialist doctor/ physiotherapist/ occupational therapist/ speech and language therapists/ good rehabilitation services available nearby/ and also to education services/social welfare at the closest sub-district/district, and/or nationally, as necessary. For complicated cases, refer to the nearest government & NGO (GO-NGO) or other available service centres within district for disability diagnosis, services and also support the process of disability certification. *(Inform the patient/ parents/ caregivers about the date and time of availability of the specialist/ services(if available/where necessary)*

Training for medical doctors is required to cautiously use clinical tests to ensure these are for the benefit of child/adult with disabilities and are not unnecessarily economically burdensome on them

HOW TO ADDRESS HEARING & SPEECH DISABILITY AND DEAF-BLINDNESS

CHAPTER 4

4.1 DEFINITION

4.1.1 A hearing and speech impairment is a condition in which the ability to perceive sound and/or produce normal speech is affected. Persons with hearing and speech disabilities include those who are affected with long-term partial or full hearing and/or speech impairments or both (and having a hearing loss of >30dB for children (0 to 14 years) in better ear, and >40dB for adults (15 years or older) in better ear)[25], which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Note: 1. According to the Rights & Protection of Persons with Disabilities Act, 2013 a person who cannot hear sound more than 60 decibel (dB) is considered a person with hearing disability. Moreover, the Act does not differentiate the grading for children and adults, and does not take into account hearing loss in better ear. This is approved by the National Institute of ENT, Tejgaon, Dhaka. (Please refer to paragraph 4.2.1 below for WHO grading for hearing loss).

The maximum benefit to the child & adult should be considered for health & rehabilitation service delivery following the WHO global standard. However, as for issuance of certification of disability by concerned committee (refer to the Act'13), careful consideration may be required.

4.1.2 According to the Persons with Disabilities Rights and Protection Act 2013, a person with one or more of the characteristics below shall be considered as a person with speech disability. Speech and language impairment is also a communication disorder that adversely affects the person's ability to talk, pronounce, understand, and read.

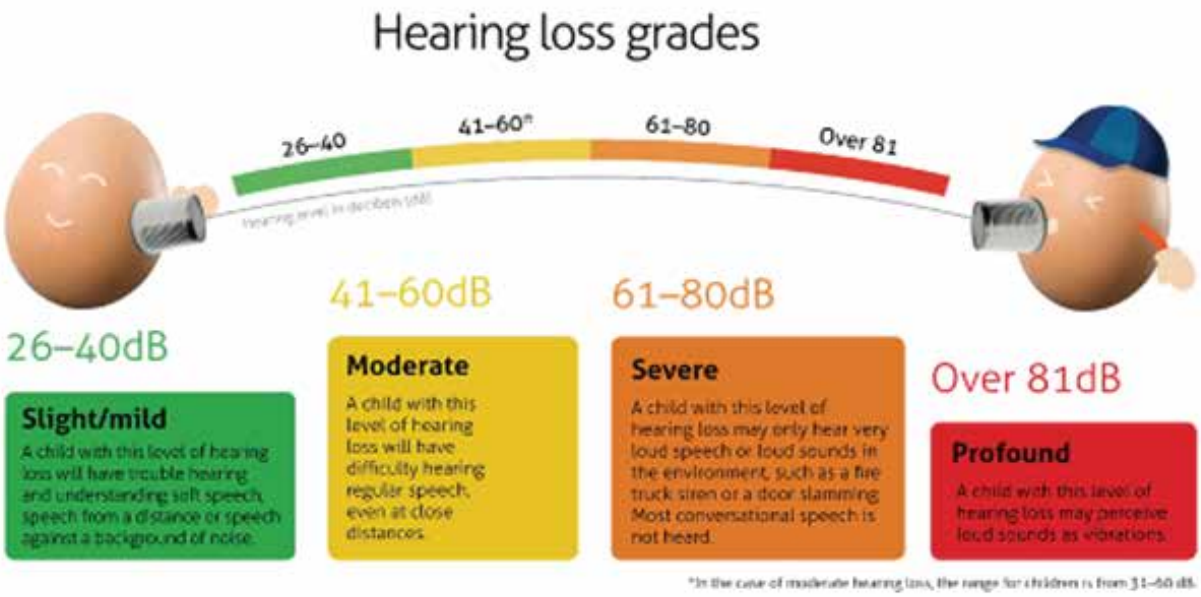
i. Not being able to speak at all (due to known and unknown causes such as, Aphasia);
ii. Limitations to arrange the sounds and sentences that are necessary for common conver sations and speak in clear pronunciation; or
iii. Problems in creating and pronouncing words due to acoustic or vocal tone or problems related to speech, birth defects, damages or limitations; or
iv. Problems/ limitations and/or interruption in processing speech; defect/damage causing interruptions in speaking i.e. stuttering.

Note: 2. Hearing & Speech Disabilities sometimes co-occur. Speech impairment can be caused by many things, such as: i) developmental disorders, ii) neurological disorders, iii) genetic syndromes, iv) hearing loss and v) illness

4.1.3 **Deaf-blindness** is described as a unique and isolating sensory disability resulting from a combination of both a hearing and a vision loss or impairment. When a person has a combination of partial or full hearing and vision loss which in interaction with various barriers may hinder his/her full & effective participation and cause difficulties with communication, access to information, learning, socialisation, development, mobility and daily life, - is considered as a person with deaf-blindness. They also include people with a progressive sight and hearing loss. Deaf-Blindness can be congenital or acquired[26]. The Act, 2013 refers to 4 types of deaf-blindness on i) basis of degree of hearing & vision loss, ii) on basis of hearing & vision loss with other disabilities, iii) on basis of problems in hearing & visual sensory processing, iv) and the element of deterioration of the hearing & vision loss.

4.2.1 According to WHO Hearing loss of >30dB in the better ear in case of children and >40dB in the better ear in adult is considered disabling. Normal hearing level is up to 25dB.

Hearing Grade Loss [27]		
Slight/ Mild	26-40dB	A patient will have trouble hearing/understanding soft speech from distance or against a background of noise
Moderate	41-60dB	A patient will have difficulty hearing regular speech even at close distance
Severe	61-80dB	A patient may only hear very loud speech or sound in the environment such as fire truck siren or a slamming of the door. Most conversational speech is not heard.
Profound	>81dB	A patient may perceive loud sounds as vibration



4.2.2 The causes of hearing loss and deafness can be congenital or acquired. Congenital causes may lead to hearing loss being present at or acquired soon after birth. Hearing loss can be caused by hereditary and non-hereditary genetic factors or by certain complications during pregnancy and childbirth, including:

1. Maternal rubella, syphilis or certain other infections during pregnancy;
2. Low birth weight;
4. Birth asphyxia (a lack of oxygen at the time of birth);
5. Inappropriate use of particular drugs during pregnancy, such as aminoglycosides, cytotoxic drugs, antimalarial drugs, and diuretics;
6. Severe jaundice in the neonatal period, which can damage the hearing nerve in a newborn infant.
7. Consanguineous marriage is one of the important causes of congenital sensorineural hearing loss.

While acquired causes include infectious diseases:

1. Infectious diseases including meningitis, measles and mumps;
2. Chronic ear infections;
3. Collection of fluid in middle ear (otitis media with effusion, OME);
4. Use of certain medicines, such as those used in the treatment of neonatal infections, malaria, drug-resistant tuberculosis, and cancers;
5. Injury to the head or ear;
6. Excessive noise, including occupational noise such as that from machinery and explosions;
7. Recreational exposure to loud sounds such as that from use of personal audio devices at high volumes and for prolonged periods of time and regular attendance at concerts, nightclubs, bars and sporting events;
8. Ageing, in particular due to degeneration and damage of sensory cells;
9. Wax or foreign bodies blocking the ear canal; and
10. Among children, chronic otitis media is the commonest cause of hearing loss.

4.3 KEY FACTS ON HEARING, SPEECH IMPAIRMENT & DISABILITY, AND DEAF-BLINDNESS

- In Bangladesh hearing impairment is the second commonest form of disability and is causing economic, social, educational and vocational problems both for the affected person and the country[28.]
- A 9.6% of population in Bangladesh was found to have some sort of disabling hearing loss (i.e. >40 dB hearing loss in adults in better ear and >30 dB hearing loss in children below 15 years in the better ear[29].
- Over 5% of the world's population – or 466 million people – has disabling hearing loss (432 million adults and 34 million children) (WHO).
- By 2050 over 900 million people (estimated one in every ten people) – will have disabling hearing loss.
- The majority of people with disabling hearing loss live in low and middle-income countries. Hearing loss may result from genetic causes, complications at birth, certain infectious diseases, chronic ear infections, the use of particular drugs, exposure to excessive noise, and ageing.
- 60% of childhood hearing loss is due to preventable causes. In children under 15 years of age, 60% of hearing loss is attributable to preventable causes. This figure is higher in low- and middle-income countries (75%) as compared to high-income countries (49%).
- 1.1 billion young people (aged between 12–35 years) are at risk of hearing loss due to exposure to noise in recreational settings.(WHO)
- At least 25% of hearing loss among babies is due to maternal infections during pregnancy, such as cytomegalovirus (CMV) infection; complications after birth; and head trauma[30].
- Approximately 15% of the world's adult population has some degree of hearing loss; 25% of them are aged above 65 years[31].
- Approximately one-third of persons over 65 years are affected by disabling hearing loss. The prevalence of disabling hearing loss in adults over 65 years is highest in South Asia, Asia Pacific and Sub-Saharan Africa [32].

4.4 HEARING, SPEECH IMPAIRMENT & DISABILITY, AND DEAF-BLINDNESS: IMPORTANCE OF EARLY DETECTION/DIAGNOSIS & INTERVENTION

4.4.1 As others, people with hearing loss benefit from early identification; use of hearing aids, and other assistive devices; captioning and sign language; and other forms of educational and social support. A large segment of hearing loss is preventable through public education, early intervention, and effective treatment according to the National Survey on Prevalence of Hearing Impairment in Bangladesh (2013). People who develop mainly profound hearing loss can learn to communicate through development of lip-reading skills, use of written or printed text, and sign language.

4.4.2 Early detection and intervention are crucial to minimizing the impact of hearing loss on a child's development and educational achievements. Orientation targeting parents/caregivers, awareness of parents/caregivers, services and screening provided by trained PHC workers, screening at pre-school, school and occupational screening for ear diseases and hearing loss can be useful ways to early identification and sub-sequent management of hearing loss.

4.4.3 Immunization programs targeting i) childhood diseases, (including measles, meningitis, rubella and mumps); ii) adolescent girls and women of reproductive age against rubella before pregnancy; iii) prevention of cytomegalovirus infections in expectant mothers through good hygiene; iv) screening for and treating syphilis and other infections in pregnant women; v) strengthening maternal and child health programmes, including promotion of safe childbirth; and vi) following healthy ear care practices are a few among other preventive measures to avoid loss of hearing.

4.4.4 Early identification and timely referral to appropriate service providers is important for infants and also adults at high risk, e.g. those with a family history of deafness or those born with low birth weight, birth asphyxia, jaundice or meningitis. This has the potential for early assessment of hearing, and ensures prompt diagnosis and appropriate management (where required through referral). Interventions to prevent, identify and address hearing loss are cost-effective and can bring great benefit to individuals.

4.4.5 Similarly for children with speech impairment early identification, diagnosis and referral means that children are more likely to get appropriate intervention and as a result can make better progress, and the longer-term impacts of impairment are minimized.

4.4.6 The early identification of children with combined vision and hearing loss is even more necessary to increase opportunities of their families to connect with early intervention personnel. This must never be for placing a "label" on a child with both vision & hearing loss but to provide them with timely early intervention and quality technical assistance (where available). It is also necessary that each child is counted and can access technical assistance. Appropriate early intervention services help maximize physical, communication, cognitive, social, and emotional development of a child with deaf-blindness[33] .

4.5 SOME IMPACTS OF HEARING & SPEECH DISABILITIES AND DEAF-BLINDNESS

4.5.1 One of the main impacts of hearing loss is on the individual's ability to communicate with others. Spoken language development is often delayed in children with unaddressed hearing loss, which can have a significantly adverse effect on the academic performance of children. Children with hearing impairment at school often have increased rates of grade failure and greater need for education assistance. Exclusion from communication significantly impact on everyday life that may cause feelings of loneliness, isolation, and frustration, for both children and adults with hearing and speech impairment/disability. Older people with hearing loss are also affected with similar problems e.g. of isolation, and require intervention.

4.5.2 The WHO estimates that unaddressed hearing loss poses an annual global cost of 750 billion international dollars[34]. This includes health sector costs (excluding the cost of hearing devices), costs of educational support, loss of productivity, and societal costs. In developing countries, children with hearing loss and deafness rarely receive any schooling. Adults with hearing loss also have a much higher unemployment rate. Among those who are employed, a higher percentage of people with hearing loss are in the lower grades of employment compared with the general workforce. Improving access to education and vocational rehabilitation services, and raising awareness especially among employers about the needs of people with hearing loss, will decrease unemployment rates for people with hearing loss.

4.6 SYMPTOMS FOR PHC WORKFORCE TO SUPPORT EARLY IDENTIFICATION & REFERRAL

Symptoms: **Hearing & Speech Disability and Deaf-Blindness (HSD)**	**Hearing Disability:** **a)** Check if the child responds to clapper bell rung softly, 15 cm from the level of ear and out of the line of vision (at birth)[35] **b)** Check if the child responds to soft rattle, 15 cm from level of ear and out of the line of vision (60-80 dB) (at birth) **c)** Check if the child does not smile/interact with others (at birth or older); **d)** Check if the child does not startle when loud sound is present/ if a child show lack of attention to sounds and it's sources; **e)** Check if the child does not speak one meaningful word when 1yr old, and does not speak at least 18 two digit words when 18 months old; **f)** Check if the child does not understand what others say (7 months – 2 yrs.); **g)** Check if the child has tendency to use sign/gestures more, instead of oral communication; **h)** Child has trouble playing/talking with other children (2-3 years) ; & wants to stay alone, and makes speech which is unclear; **i)** Delay in speech and language development; **j)** Words aren't easily understood (18 months-2 yrs.); **k)** Doesn't put words together to make sentences (1.5 – 3 yrs.); **l)** Produces speech that's unclear, even to familiar people (2-3 yrs.); **m)** Existence of ear draining/discharging fluid or pus (Discharge may be clear, mucoid, scanty or profuse, yellowish, or sometimes bloody and foul smelling); **n)** Earache and Ringing in ears and including Ear canal infection; **o)** if one doesn't respond to calls by name; Can't follow directions by oral speech; Respond inappropriately to questions/ queries; Can't differentiate similar sounds; **p)** Watch TV shows with inapt high or without volume range; Speak in loud voice etc.

Symptoms: **Hearing & Speech Disability and Deaf-Blindness (HSD)**	**Speech and Language Disability:** **a)** Crying of the newborn that does not fall within a normal pitch/loudness (birth-1 month) **b)** Spontaneous cooing 'oo' 'aa' 'ee' 'uu' and gurgling 'gghh' (2-3 months) [36] **c)** Making vowel sounds 'aa' 'uu' (4 months) **d)** Vocalizing consonants/vowel sounds e.g. ba, ma (6-8 months) **e)** May have problems to articulate appropriate sounds/ Distorted sounds can be found in their speech; **f)** May have problems with the voice quality (tone and intonation)/ - Abnormal vocal quality (rough, breathy, strained); **g)** Hoarseness in voice (dysphonia); **h)** Poor vocal volume (hypophonia) **i)** Pauses when speaking; &/or May stutter while speaking; &/or Stretches words; **j)** Problems with cognitive aspects of communication (attention, memory, problem solving, executive functions); **k)** Problems with speech (phonation, articulation, fluency, resonance); **l)** Feeding and swallowing difficulties **Deaf-blindness apart from checking the above for hearing/speech conditions, please also check following regarding vision:** **a)** Check if the baby responses to light/face (at birth)[37] **b)** Check if the if the baby regards face or e.g. woolly ball (1 month) **c)** Check if the baby can fixate and follow face (2 months) **d)** Check if the baby can fixate 1 inch cube from a distance of 30 cm (5 months) **e)** Check if the baby can watch moving adult from 3 metres (3 - 24 months) **f)** Check if the if the baby fixates a smallest homeopathy pellet/bit from 30 cm distance (9-24 months) **g)** Check if the lens is white or grey/ash **h)** Check if there is scar in the lens **i)** Check if the lens glare at night **j)** Check if s/he has squint **k)** Check if the structure of the eye is abnormal, e.g., it has droopy eyelid, eye, or bulging or protruding of one or both eyes (proptosis or exophthalmos), or disruption in the integrity of the corneal epithelium/he corneal surface scraped away/ large corneal abrasion, or the eye is very small l) If there is sign of eye injury m) If there's colour blindness (reduced ability to perceive certain colours, usually red and green) n) Check if h/she has lack of contrast sensitivity (inability to distinguishes one object from another) o) If s/he rely on touch (tactile) ways to identify things p) Problems in distinguishing facial expressions
Tools for health workers	History, with chief complaints Observation Checklist Physical examination Rattle, Whistle, Torch etc. Looks, Feel, Move Referral slip Updated list of possible referral points

Actions Required	- Take history - Screen using tools (rattle, whistle, torch light/headlight, checklist) - Refer to appropriate service points i.e. disability trained UHFPO, RMO, doctors, Consultant at UHC/ District sadar or district based medical college hospital etc. using the referral slip - Aware people using available IEC materials - Counsel patient/client as needed - Advise parents/ guardians to maintain the referral slip for the next service point(s) Where applicable, [take into account eye glasses, if one wears them)

4.7 INDICATORS TO DIAGNOSE IMPAIRMENT & DISABILITY BY TRAINED MEDICAL DOCTORS

Indicators – **Hearing & Speech Disability and Deaf-Blindness**	- Take history - Screen using tools (rattle, whistle, torch light/headlight, checklist) - Refer to appropriate service points i.e. disability trained UHFPO, RMO, doctors, Consultant at UHC/ District sadar or district based medical college hospital etc. using the referral slip - Aware people using available IEC materials - Counsel patient/client as needed - Advise parents/ guardians to maintain the referral slip for the next service point(s) Where applicable, [take into account eye glasses, if one wears them)
Tools	- Clinical, Audiological assessment (By otoscope, headlight, rattle through trained nurses or Sub-Assistant Community Medical Office -SACMO) - Free Field Audiometer/ Clinical/ Screening Audiometry/Age appropriate hearing test (BOA/VRA/OAE/ASSR/ABR) - High, medium and low frequency instrument (Assessing by Sound Level meter) - Bangla Articulation test word and sentence - Primary assessment checklist for hearing impaired children ***if Speech & Language Therapist is available the following tools can be utilized:*** - Denver articulation screening examination (DASE) - Early Language Milestone Scale-Second Edition (ELM Scale-2) - Peabody picture vocabulary test - Assessment of Link between Phonology and Articulation (ALPHA) - Kaufman Speech Praxis Test for Children (KSPT) - Dysarthria Examination Battery (Drummond) Screening of Velopharyngeal Competence
Action	- History, chief complaints (c/c) - Investigation according to patient's requirement - Clinical examination (ear, nose, throat) - Diagnose and provide service (where appropriate) - Refer to the nearest ENT Consultant/Specialist at the nearest UHC, district sadar hospitals/ medical college hospital for diagnosis/ service and certification - Where SLT is available - Refer to the nearest Speech and Language Therapist for assessment and intervention/management - Where applicable refer to other specialties e.g. to an ophthalmologist if the child/adult has vision related issues/conditions. - (Inform the patient about the date and time of availability of the specialist/services(if available/where necessary) - Also, refer to Rehabilitation, Education Services/Social Welfare at district, below and nationally, as necessary - Provide counselling - Refer to the Integrated Disability Service Centre of JPUF and/or their mobile vans - Advise individual/ parents/ guardians to maintain the referral slip for the next service point(s)

Training for medical doctors is required to cautiously use clinical tests to ensure these are for the benefit of child/adult with disabilities and are not unnecessarily economically burdensome on them

INTELLECTUAL DISABILITY (ID)

CHAPTER 5

5.1 DEFINITION

5.1.1 Intellectual disability is characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) in relation to age and in adaptive behavior, which covers a range of everyday social and practical skills. This originates before the age of 18[38]. Persons with intellectual disabilities include those who have permanent intellectual impairments and limitation in adaptive skills e.g. life skills such as grooming, dressing, safety, food handling, working, taking care of the self – safety and health, money management, cleaning, making friends, social skills, and the personal responsibility expected of their age and social group - which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

5.1.2 The group also includes person with Down Syndrome, a form of congenital condition (chromosomal disorder) characterized especially by intellectual impairment, short stature, relatively small head, upward slanting eyes usually with epicanthal folds, flattened nasal bridge, broad hands with short fingers, decreased muscle tone, and by trisomy of the human chromosome numbered 21.

Note 1. Genetic and chromosomal conditions, such as Down syndrome and Fragile X syndrome; and Fetal alcohol syndrome are some of the known causes of intellectual disabilities, therefore, these are put together under one umbrella category i.e. intellectual disability in this document.

5.2 GENERAL INFORMATION

5.2.1 Both Diagnostic and Statistical Manual of Mental Disorders (DSM–5) and American Association on Intellectual and Developmental Disabilities (AAIDD) stipulate that intellectual disability is characterized by the presence in significant deficits in "both" intellectual functioning and adaptive behavior. Intellectual functioning and adaptive behavior are two separate and distinct entities and it is necessary to establish significant deficits in each for a diagnosis of intellectual disability. Both has a complimentary role and alone are insufficient to meet the criteria. ID should only be diagnosed if there is clear evidence to suggest cognitive abilities and adaptive behavior are significantly below average and that, although the individual might make progress in learning, s/he will always be much below average. Intellectual disability cannot be cured, but can be managed.

5.2.2 A combination of established and psychometrically valid standardized assessment tools in combination with other relevant and complementary clinical evaluations and information (e.g., review of records, qualitative interviews, etc.) are used to establish deficit in intellectual functioning and adaptive behavior.

5.2.3 Examples of adaptive[39] behavior include but not limited to the following: life skills such as grooming, dressing, safety, food handling, working, money management, cleaning, making friends, social skills, and the personal responsibility expected of their age and social group. These limitations cause a child to intellectually develop slower than other children, and the children may take longer to walk, talk, and take care of themselves compared to other children. Establishing the presence of "significant sub-average" intellectual functioning and adaptive behavior

requires clinical judgment and a rigorous individualized assessment of the person's intellectual functioning and adaptive behavior. The generally accepted scientific definition of the term "significant sub-average" signifies performance which is two standard deviations below at least than the average level for the individual's peers.

5.2.4 Intellectual disability is one of the most common developmental disabilities. Causes of intellectual impairment also include deficiencies of iron and iodine, and hypo-thyroidism and as a result of the baby being deprived of oxygen during childbirth or born extremely premature. Infections like meningitis, measles may lead to intellectual disability. (American Psychiatric Association, 2013). Severe head injury, near-drowning, extreme malnutrition, infections in the brain, problems during pregnancy, exposure to toxic substances such as lead, and severe neglect or abuse can also cause it. In two-thirds of all children who have intellectual disability, the cause is unknown[40].

5.2.5 Throughout the intellectual disability determination process, clinical judgment plays a critical role. IQ tests alone cannot complete the diagnosis processes.

IQ Grades for ID (IQ tests alone are inadequate to determine ID, and should not be administered without any psychological assessment and without services		
Mild (F_{70})	IQ level 50-55 to approximately 70 Mild mental sub-normality[41]	Has the ability to communicate effectively and live relatively independently with minimal support within the community. Needs minimal help in some areas of life, with no help in most areas.
Moderate (F_{71})	IQ level 35-40 to 50-55 Moderate mental sub-normality	individuals who, with lifelong support, and positive environment will have significant relationships, can communicate, handle money, travel on public transport, make choices for themselves, and understand daily schedules.
Severe (F_{72})	IQ 20-25 to 35-40 Severe mental sub-normality	Individuals in this category suffer from a marked degree of motor impairment or other associated difficulties/deficits, indicating the presence of clinically significant damage to or mal-development of the central nervous system. Positive guidance broken down into small steps/with visualization & instant instructions can be helpful for all persons with ID.
Profound (F_{73})	IQ level below 20-25 Profound mental sub-normality	Affected individuals are severely limited in their ability to understand or comply with requests or instructions. They are almost totally dependent on those around them, require constant help, supervision and lifelong help for personal care tasks, communication, and accessing and participating in community facilities, services and activities. Most such individuals are immobile or severely restricted in mobility and capable at most of, only very rudimentary forms of nonverbal communication.
(F_{78})	Other intellectual disabilities	
(F_{79})	Unspecified Intellectual Disabilities	

5.2.6 The levels i.e. of mild to profound, are indicative of support someone might need, but the way the person with intellectual disability functions in their life often depend on other factors such as personality, their circle of support, their coping skills and other disabilities they may have. They learn and develop more slowly than average, but can learn to adapt to new situations and enjoy life independently with support.

5.2.7 Persons with intellectual disabilities have the capacity to learn, to develop, and grow. A great majority of persons with intellectual disabilities have the potential to live a productive life and participate in society, although they face challenges in learning. DSM-V places less emphasis on the degree of impairment (i.e. IQ scores) and more emphasis on the amount and type of interventions needed. A person with intellectual disability tends to have one or more of the following characteristics:

a) **Slow rate of learning:** He/she although has the ability to learn, but takes longer time than others.
b) **Thinks in a concrete way:** He/she has difficulty with abstract thinking
c) **Difficulties generalizing:** Depending on the level of disability he/she often cannot take knowledge learned in one situation and apply it to another.
d) **Needs to be taught how to make choices:** He/she has difficulty weighing pros and cons, and applying past experiences to present decision-making.
e) **Challenges in setting goals and problem solving:** He/she depending on the level of intellectual disability would need help to figure out problems and determine steps required to reach goals. Tasks that many people learn without instruction may need to be structured/broken down into small steps for them to learn.
f) **Memory problems:** Any training needs to include lots of opportunities for practice and repetition.
g) **Short attention span:** He/she may have trouble sticking with an activity or focusing attention for long periods of time.
h) **Expressive language:** He/she has difficulty conveying ideas and feelings to other people.

Note 2: Sometimes intellectual disability is referred to as developmental disability, although Developmental Disabilities are actually an umbrella term which includes severe chronic disabilities that can be cognitive or physical or both. Some developmental disabilities are largely physical, for example, cerebral palsy or epilepsy. Some individuals may have conditions that include a physical and intellectual disability, for example Down syndrome or fetal alcohol syndrome. Intellectual and other developmental disabilities often co-occur.

5.2.8 Clinically ID is classified by the following degrees of intellectual functioning:

• Borderline	• Mild	• Moderate	• Severe	• Profound

5.2.9 Signs[42] and symptoms of ID (used to be referred to as mental retardation) include: Rolling over, sitting up, crawling, or walking late; Talking late or having trouble with talking; Slow to master things like potty training, dressing, and feeding himself or herself; Difficulty remembering things; Inability to connect actions with consequences etc. Sometimes, individuals with Intellectual Disability may have speech that could be difficult to understand and some might not even develop speech. Children with an intellectual disability exhibit delays in language development. Children and adults with an intellectual disability may need assistance with, following and understanding directions, using and understanding spoken and written language, learning new information, understanding detailed information, completing tasks/documents. People with intellectual disability may need to learn other means of communication, such as signing, use of pictures and communication aids to help them achieve their communication potential.

5.2.10 Important steps[43] in the clinical assessment of a child with ID include: Suspicion of ID is often prompted by parent interview and/or direct observation of the child, which needs to be confirmed with norm-referenced testing for IQ and adaptive functioning by trained professionals. Treatable diagnoses that might mimic ID, e.g. severe auditory or visual impairment or neurologic disorders must be ruled out. Identification of the etiology, if possible, through medical history (for 3 generations) and/or physical exam (e.g., a large head circumference may indicate fragile X syndrome or distinctive facial features might suggest Cornelia de Lange syndrome). Determining the severity of ID, with psychometric and adaptive function testing can be helpful in prognosis for independent living.

5.2.11 Additional factors must be taken into account, e.g. the community environment typical of the individual's peers and culture. Linguistic diversity and cultural differences and in the way people communicate, move, and behave should be taken into consideration for assessment. Assessments must also consider that limitations in individuals often coexist with strengths, and that a person's level of life functioning will improve if appropriate personalized supports are provided over a sustained period. In order to determine whether an individual has intellectual disability. Professionals must follow many-sided evaluations and consider individualized support plans[44].

5.3 KEY FACTS ON INTELLECTUAL DISABILITY

a) Some of the most common known causes of intellectual disability include Fetal alcohol syndrome; genetic and chromosomal conditions, such as Down syndrome and fragile X syndrome; and certain infections during pregnancy[45].

b) Low birth weight, premature birth, multiple birth, and infections during pregnancy are associated with an increased risk for many developmental disabilities[46].

c) There are three major criteria for intellectual disability: significant limitations in intellectual functioning, significant limitations in adaptive behaviour, and onset before the age of 18[47].

d) The prevalence of intellectual disability across the world is around 1%. And the prevalence is almost two times more in low and middle income countries compared to high income countries [48].

5.4 INTELLECTUAL DISABILITY: IMPORTANCE OF EARLY DETECTION/DIAGNOSIS & INTERVENTION

5.4.1 Young children at-risk for or those who have been identified with intellectual and/or developmental disabilities need access to high-quality, affordable developmental services in natural environments. Services should build on the strengths of the child and family, address their needs, be responsive to their culture and personal priorities, and delivered through evidence-based practices.

5.4.2 Early identification and intervention is important for providing early childhood services and supports in natural environment. This is to ensure maximum benefit e.g. increased community inclusion during early childhood and across the life span. Early intervention and provision of services to children at-risk is a sound developmental and fiscal investment[49]. While early identification and early diagnosis is important, care should be taken to prevent stigmatization and labelling.

5.5 SOME IMPACTS OF INTELLECTUAL DISABILITY

5.5.1 People with intellectual disability, one of the most marginalized groups in our society, have extremely limited access to education, employment, and financial resources; they often may not receive the same level of attention, health care as other members of family or society. They are particularly vulnerable to a range of chronic health problems including: sensory problems (e.g. problems with vision, hearing and dental), poor nutrition, constipation, thyroid problems, gastro-esophageal reflux disease (GERD) and helicobacter pylori, obesity, osteoporosis, epilepsy, cardiovascular disease, Type 1 and Type 2 diabetes, some types of cancers (particularly stomach and gall-bladder), mental health problems, addictions, and ageing problems.

5.5.2 Five key determinants of health inequalities affect people with intellectual disabilities, which according to Emerson (2011) are: (1). Greater risk of exposure to social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness, (2). Increased risk of health problems associated with specific genetic, biological, and environmental causes of intellectual disabilities, (3). Communication difficulties and reduced health literacy, (4). Personal health risks and behaviours such as poor diet and lack of exercise, and (5). Deficiencies relating to access to healthcare provision. Study indicate higher incidence of Alzheimer disease among people with Down syndrome as compared against general population; while people with intellectual impairments (unrelated to Down syndrome) have higher rates of dementia[50]. People with intellectual disability have a higher prevalence of physical health problems but often experience disparities in accessing health care[51]. The prevalence of sexual abuse against people with disabilities has been shown to be higher, especially for institutionalized men and women with intellectual disabilities[52].

5.6 SYMPTOMS FOR PHC WORKFORCE TO SUPPORT EARLY IDENTIFICATION & REFERRAL

Symptoms - Intellectual Disability	- Check if the infant response to face, voice, touch (at birth) - Check if the baby brightens to face, voice, touch (1 month) - Check if the baby has social smiles present (3 months) - Check if the baby looks at rattle s/he is holding and plays with it for several moments (4-5 months) - Check if the baby follows falling ball within sight (7-8 months) - Check if the baby plays imitative games immediately after demonstration (e.g. rattling a spoon in a cup (9 months) - Check if the baby retrieves ball by string with attention (10 months) - Check if the baby finds toy under cup (12-13 months) - Check if the baby response correctly to 'where is mummy' (14-15 months - Check if the baby has good eye contact (3-24 months) - Physical appearance (unusually large head, a thin and shiny scalp with easily visible veins, a bulging or tense fontanelle (the soft spot on top of a baby's head, downward looking eyes, and other symptoms e.g. poor feeding, irritability, vomiting, sleepiness, muscle stiffness and spasms in baby's lower limbs - Headaches, neck pain, feeling sick, being sick – this may be worse in the morning, Sleepiness, can progress to a coma, changes in your mental state, e.g. confusion, blurred vision or double vision, difficulty walking, inability to control bladder (urinary incontinence) and, in some cases, bowel [54] - Baby is born with a small head or the head stops growing after birth[55] - Floppiness, small nose and flat nasal bridge, small mouth with a tongue that may stick out, eyes that slant upwards and outwards, a flat back of the head, broad hands with short fingers their palm may have only one crease across it below-average weight and length at birth etc.[57].

	- Slow to master ADLS (e.g. things like potty training, dressing, and feeding himself or herself) - Difficulty remembering things (add by yrs.) - The consequences to actions - Poor problem-solving skills or logical thinking - Behavior problems such as explosive outbursts (minor to major) - Cannot demonstrate age appropriate behavior - Not oriented with time, space, persons) - Matching problem, Time, place, person disorientation (for dementia/aged, sometimes for severe ID –for children) - No or Late response to instruction - Learning difficulties in both child and adults
Tools for health workers	- History with chief complaints of mother/ caregivers - Observation - Checklist - Flip chart (IEC) - Physical and Cognitive Developmental Milestones chart - Learning difficulty questionnaire - Referral slip - Updated list of possible referral points
Actions Required	- Listen to mothers'/ caretakers' complains/ (& patients' complains) - Take history and use tools to do preliminary screening - Assess - Refer to nearest appropriate service points at UHC/District using the referral slip - Aware people using available IEC materials - Counsel parents/ guardians as needed. - Advise parents/guardians to maintain the referral slip for the next service point(s)

5.7 INDICATORS TO DIAGNOSE IMPAIRMENT & DISABILITY BY MEDICAL DOCTORS

Indicator - Intellectual Disability	a. Delay in reaching developmental milestones e.g. gross/fine motor skill) b. Inability to connect actions with consequences (add by yrs.) c. Trouble comprehending accepted social behaviors & participation (e.g. playing, with peer etc.) &/or understanding d. Limitation in perception e. Hyper-active/Hypo f. Deficits in intellectual functioning—"reasoning, problem solving, planning, abstract thinking, memory, judgment, academic learning, and learning from experience"—confirmed by clinical evaluation and individualized standard IQ testing by psychologist g. Presence of abnormal textures, hyper- or hypo pigmentation, eczema, Wood's lamp findings, hemangiomata and syndromic features h. Congenital hyperthyroidism & Hypo, chromosomal abnormality, hydrocephalus, autism, epilepsy i. Malnutrition j. Down syndrome (Flatter faces, especially the nose, may have short fingers, short neck, small head, low muscle tone, eyes shaped like almonds (shaped in a manner not typical for their ethnic group) k. Microcephalus (brain's growth is decreased because of conditions that can be identified: chromo somal anomaly such as Down syndrome, congenital infections with organisms such as virus rubella, metabolic disorders, bacterial meningitis, or lack of oxygen early in life; exposure to radiation or chemicals producing a small head size (thus, small brain) l. Hydrocephalies in infants, eyes fixed downward, seizures, vomiting or nausea, excessive sleepiness, trouble staying awake/waking up poor feeding, low muscle tone and strength, high-pitched cries, personality changes, changes in facial structure, crossed eyes, headaches, muscle spasm, delayed growth, trouble eating, irritability, loss of coordination, loss of bladder control, larger than normal head

	m. Learning disabilities n. Dyslexia (a learning difficulty affecting primarily the skills involved in accurate and fluent word reading and spelling) o. Deficits in adaptive functioning e.g. skills necessary for day-to-day life, such as being able to communicate effectively, interact with others, and take care of oneself p. Fragile X-syndrome: (Physical features may include large ears, long face, soft skin and large testicles (called "macroorchidism") in post-pubertal males. Connective tissue problems may include ear infections, flat feet, high arched palate, double-jointed fingers and hyper-flexible joint) q. Problem with attention skills, Concentration span, Restlessness, r. Impulsive, Distraction, Repetitious, s. Usually, gets along with people, often with sensory problem)
Tools	• Case history for parents (Weight (Infant/Child/ Head Injury)) • Family History with chief complaints of mother/ caregivers (look for metabolic diseases, parental consanguinity, relatives with autistic features, multiple miscarriages, or unexplained infant/ childhood deaths & sex of the affected relative, if any), Case history for parents • Pregnancy or perinatal history • Pay sensitive attention to parental concerns & Thoughtful inquiry about parental observations[57] • Observation of a wide variety of the child's behaviors, Observation[58] • Examine/Assessment (clinical)/assess of specific developmental attainments • Growth Parameters: Ht | Wt | OFC [occipital frontal circumference] for deviations from typical growth chart • Hearing and vision and language testing is important for identifying any other associate impairments. This is also necessary to rule out sensory impairment as a cause of the delay • Cognitive, (Physical, Speech) developmental milestone (CDD Poster) • Mid-upper arm circumference • Specific test (e.g. IQ, Mini Mental test –MMSE (separate for Child & Adult), Perceptual) for probable case of ID (not for certification) by trained professional • Norm-referenced testing for IQ and adaptive functioning conducted by trained doctor or by psychologists (Confirmation by clinical evaluation and individualized standard IQ testing at National Institute of Mental Health (NIMH), Institute of Paediatric Neuro-disorder & Autism (IPNA), Nasirulla Clinical psychological unit, DU) • Blood/ Urine/ Imaging tests to look for structural problems in the brain, or Electroencephalogram (EEG) to look for evidence of seizures; Test for growth hormone/other hormonal tests/MRI/ Ultra-sonogram/CT scan (only if necessary)* • Cerebrospinal Spinal Fluid (CSF) analysis (only if necessary)*
Actions Required	• Check the referral info. noted by the trained health workers/with chief complaints • Trained doctor to diagnose and provide service and/or refer to the nearest GO-NGO or other available service centre within district or other place for service/ to support disability certification • Review (if required)/ refer for tests (e.g. MMSE etc.) as necessary by concerned professional/ Refer to appropriate nearest service and diagnosis points in public and other sector (Shishu Bikash Kendra (SBK)/ NINS/ IPNA, BPF, CRP, SWID Bangladesh etc.) (Inform the patient about the date and time of availability of the specialist/ services (if available/where necessary) • **Any male child with intellectual disability should be ruled out for Fragile-X syndrome** • Provide counselling • Advise parents/ guardians to maintain the referral slip for the next service point(s) • Also, refer to Rehabilitation, Education Services/Social Welfare at district, below and nationally, as necessary

**Training for medical doctors is required to cautiously use clinical tests to ensure these are for the benefit of child/adult with disabilities and are not unnecessarily economically burdensome on them*

MENTAL ILLNESS LEADING TO DISABILITY

CHAPTER 6

6.1 DEFINITION

6.1.1 A person has psychosocial/mental disability if his/her daily life is significantly impeded/affected due to prolonged psychological problems caused by e.g. schizophrenia or other similar psychiatric conditions such as major depressive disorder, bipolar disorder, dementia, and drug, and if they do not have sufficient access to supports and services, and face barriers including attitudinal barriers from fellow beings/systems and cultures they belong to and that affect their daily living.

Note 1: This understanding is consistent with the WHO International Classification of Disability, Functioning and Health (ICF).

Note 2: Some suggestions were brought forward by resource persons in connection to the definition of 'mental or psycho-social disabilities' as given in the Act. Thus certain curable illnesses e.g. clinical depression, post-traumatic stress, problems associated with anxiety and phobia were taken out of the list of illness that may lead to mental or psycho-social disability from the above definition in this document to avoid stigmatization.

Under no circumstance it is expected to compromise the health and health-related rehabilitation care necessary for the concerned child/adult at risk of impairment & disabilities. However, as for issuance of certification of disability by concerned committee (in reference to the Act), careful consideration may be required.

6.2 GENERAL INFORMATION

A mental illness is a syndrome characterized by clinically significant disturbances in cognition, emotion or behaviour that causes significant distress or disability in social, occupational and other important activities. Mental disability (also referred as psycho-social or psychological disability or psychiatric disability) comprises a broad range of problems/conditions, with different symptoms, which are generally characterized by some combination of abnormal thoughts, emotions, behaviour and relationships with others. (Most of these disorders can be successfully treated). Person suffering from more severe mental disability, such as schizophrenia, may have a less favorable chance of leading an ordinary life.

Signs and symptoms of Mental illness leading to disability may include:

- Abnormal thinking, perceptions, emotions, behaviour and relationships with others.
- Prolonged depression (sadness or irritability),
- Feelings of extreme highs and lows,
- Undue suspiciousness,
- Social withdrawal,
- Physical harm, Headaches and stomachaches
- Dramatic changes in eating or sleeping habits,
- Violence and aggression,
- Strange thoughts (delusions),
- Odd behaviour, -
- Substance abuse and suicidal ideation

6.3 KEY FACTS ON MENTAL ILLNESS LEADING TO DISABILITY

6.3.1 About 16.05% of the adult population in Bangladesh is suffering from mental disorders and the prevalence was higher in women than in men (19% vs 12.9%)[59]. A study done by the National Institute of Mental Health, Dhaka and World Health Organization, Bangladesh in 2009 indicates a prevalence of 18.4% mental disorder in children in Bangladesh.

6.3.2 Mental disorders are highly prevalent medical conditions and also highly disabling. 'Measured by years lived with disability and by premature death in disability adjusted life years (DALYs), psychiatric and neurological conditions accounted for over 13% of the global disease burden in the year 2001[60 & 61].

6.3.3 Worldwide, estimated rates of lifetime prevalence of mental disorders among adults ranges from 12.2% to 48.6% and 12-month; prevalence rates ranges from 8.4% to 29.1% according to community-based epidemiological studies. Worldwide, mental illness stands four out of ten common causes of disease although it is often given less priority on policy making and intervention particularly in developing countries like Bangladesh.

6.3.4 An estimated 15 million people or about 10% of Bangladesh population suffer with this disorder or different mental illness[62]. Globally, 450 million people suffer from a mental or behavioural or neuro-psychiatric disorder.

6.4 MENTAL/ PSYCHO-SOCIAL DISABILITY: IMPORTANCE OF EARLY DETECTION/DIAGNOSIS & INTERVENTION

Many psychiatric conditions have their root in the early stages of life. Many people first present signs of their chronic illness early on. Therefore, it is a window of opportunity for treatment of mental illness and management of mental or psychiatric disabilities early on. Intervening early can interrupt the negative course of some mental illnesses and in some cases, may lessen long-term disability. Recent developments on the brain reveals that the longer the periods of maladaptive and dysfunctional thoughts and behaviour it is more difficult to influence the capacity for recovery due to cumulative effects [63].

6.5 SOME IMPACTS OF MENTAL/ PSYCHO-SOCIAL DISABILITY

6.5.1 Mental illness leading to disability is perhaps one of the least understood categories of disabilities. There is a thin line between mental illness/ mental disorder and psycho-social or mental disability. Psycho-social or mental disability is one of the least understood disabilities. But there is no question that people with this disability face numerous barriers in obtaining equal opportunities, which cause social exclusion. These barriers may be environmental, in-accessibility, legal, institutional and attitudinal. Bangladesh faces numerous challenges as there is hardly any community based mental health facilities in the country. In addition there is scarcity of skilled workforce, inadequate financial resource allocation, lack of public awareness and social stigma in regard to mental illness[64] and/or disorder some of which may lead to disability.

For people with mental illness/disorder, social exclusion is often the hardest barrier to overcome and is usually associated with rejection, feelings of shame and fear. Mental health is largely misunderstood and highly stigmatized in most countries including in Bangladesh.

6.5.2 Lack of adequate understanding, knowledge and experiences on the issue makes the situation more complicated and perhaps much less prioritized. Persons with mental disorders often suffer a wide range of human rights violations and social stigma.

6.5.3 People with severe mental illness are less likely to access general health care. According to the American Journal of Psychiatry and Neuroscience, a lack of proper diagnosis, inadequate and/or improper laboratory tests, inadequate training of behavioural specialists, length of time spent without seeking care, combined with stigma, fear and shame and stigma are some of the key obstacles for people with behavioural disorder to seek mental health care.

6.5.4 Mental disorder is not covered in social insurance schemes and no facility provides follow-up care in the community according to a study. There is hardly any day treatment mental[65] health facilities in the country, and systematically-collected data on mental disorders are scarce. A review of secondary data made in Bangladesh[66] puts the reported prevalence of mental disorders from 6.5 to 31.0% among adults and from 13.4 to 22.9% among children. Negative attitude towards individual with mental disability is high, and treatment of those affected is hardly a priority in health care delivery. Mental health services are concentrated around a limited number of tertiary care hospitals in big cities and absent in primary care in Bangladesh. Awareness and promotional campaign on mental health is very limited. According to WHO between 76% and 85% of people with mental disorders in low- and middle-income countries, receive no[67] treatment for their disorder, which stands at between 35% and 50% in high-income countries. While, there is issues regarding the quality of some of these services, additionally, people with mental illness also do not necessarily get the required social support and care. According to Woodward (n.d.), nearly 65% of psychiatrically referred population had some sort of communication disorder (Love and Thompson, 1988)[68]. A high profile study in 1996 (Emerson and Enderby) found the prevalence of communication disorders in a mental health service to be 75%[69]. Within a mental health population, 32% of those assessed demonstrated overt signs of dysphagia: 35% in an inpatient unit, 27% attending the day hospital and 31% attending long-term care settings (Regan et al, 2006)[70].

6.6 SYMPTOMS FOR PHC WORKFORCE TO SUPPORT EARLY IDENTIFICATION & REFERRAL

Symptoms - **Mental/ Psycho-Social Disability**	a. Headaches and non-specific body aches, unexplained prolonged body symptoms b. Sleep disturbances c. Prolonged depression (morbid sadness or irritability) d. Feelings of extreme highs and lows/ Mood changes e. Social withdrawal f. Anger, aggressiveness, physical or verbal abuse (with or without provocation) g. Strange thoughts (delusions) h. Significant behavior changes i. Difficulty concentrating j. Significant weight loss or weight gain k. Substance abuse, smoking l. Irrelevant speech/undue suspiciousness

Tools for health workers	- History from client/ patient and parent/ caregiver/ family member - Observation from guardian/caregiver/parents/health workers - Checklist - Referral slip
Actions Required	- Take history using tools/questionnaire to do preliminary screening - Refer to appropriate service points at Upazila Health Complex (UHC)/District using the referral slip - Aware people using available IEC materials - Counsel parents/guardians as needed. - Advise parents/guardians to maintain the referral slip for the next service point

6.7 INDICATORS TO DIAGNOSE IMPAIRMENT & DISABILITY BY MEDICAL DOCTORS

Indicators - Mental/ Psycho-Social Disability	**Major Mental Illness:** psychotic disorder, mood disorder, dementia **a. Psychotic disorder:** Undue suspiciousness, Self-muttering, Self-laughing, Violence, Aggression, Suicidal wish or attempts, Strange thoughts (Delusions - false beliefs) Hallucinations, (may hear voices or see, taste or smell things which do not exist), Disorganized speech, Disorganized or catatonic behaviour, apathy, aloneness, Social Withdrawal. **b. Mood disorder:** Experience very high or low moods, Over activity, Unusual happiness, Talkativeness, Inflated self-esteem, Decreased need for sleep, Excessive expenditure (manic episodes), Excessive sadness, Decreased interest in any activity, poor appetite or overeating, suicidal thought/attempts, Hopelessness, Pessimistic thought, Forgetfulness, Low libido (depressive episodes). **c. Dementia:** Forgetfulness (recent memory), Lost from home, Wandering, Confabulation
Tools	- History and Mental State Examination (MSE) by trained personnel - Diagnostic and Statistical Manual of Mental Disorders (DSM V) - or - International Classification of Disease, Tenth Edition (ICD 10) by trained personnel[71] - Pathology*: CBC, Bl. RBS, S.GGPT, S. Creatinine, Urine R/E - Thyroid function test - Thyroid stimulating hormone (TSH), - CT Scan of Brain, - MRI of Brain - Drug test*: urine for cannabinoid, opiates, amphetamine, Benzodiazepines
Action	- Check the referral info. noted by the health workers with chief complaints (if available) - Take history as necessary - Trained doctors to diagnose and provide services where possible; and/or refer to the nearest GO-NGO or other available service centre within district or other place. - Provide services as appropriate and/or refer to the nearest GO-NGO or other available service centre within district or other place to support disability certification. - Provide counselling - (Inform the patient about the date and time of availability of the specialist/ services where necessary) - Draw attention of the Civil Surgeon- CS (if the subject is here for disability certificate) - Also, refer to Rehabilitation, Education Services/Social Welfare at district, below and nationally, as necessary - Advise parent/Guardian to preserve referral/test result etc.

**Training for medical doctors is required to cautiously use clinical tests to ensure these are for the benefit of child/adult with disabilities and are not unnecessarily economically burdensome on them*

PHYSICAL DISABILITY

CHAPTER 7

7.1 DEFINITION

Physical impairment is a physical condition affecting a person's mobility, physical capacity, stamina or dexterity. It is the long-term loss of part of one's body's physical function, which involves difficulties with walking and mobility, sitting and standing, use of one's hands and arms, breathing, control of e.g. bladder, muscle, sleeping, tremor, seizures and chronic tiredness - which in interaction with various barriers may hinder the full and effective participation of a person in society on an equal basis with others.

7.2 GENERAL INFORMATION

7.2.1 Physical impairment can be genetic or acquired. This can be caused by something that happened before or during birth or later in life through an illness or injury and accidents. A physical disability may be observable, such as loss of a limb, or less palpable/tangible, for example, epilepsy or stroke. Physical impairment is diverse although it can be divided into several categories[72]: Musculo Skeletal Disability, Neuro Physical and Cardio-Pulmonary Impairment. The 1st group concerns physical impairment caused by muscular or bony irregularities, diseases or degeneration; and this category covers i.e. Loss or Irregularities of Limbs, Osteogenesis Imperfecta, and Muscular Dystrophy. The second group i.e. Neuro Physical Impairment signifies impairments causing inabilities to perform controlled movements of affected body parts due to diseases, degeneration or disorder of the nervous system. And this category covers/caused by Spina Bifida, Poliomyelitis, Stroke, Head Injury and Spinal Cord Injury and even cerebral Palsy (discussed independently in the Act 2013 and this Guideline). Spinal Cord Injury can result in Paraplegia or Tetraplegia. The third group covers impairments in aerobic capacity, cardio-vascular fitness and stamina, e.g. chronic obstructive pulmonary disease.

7.2.2 Causes of Physical impairment include: infectious disease, congenital conditions or malformations, developmental or chronic health problems, amputation and accidents.

7.3 KEY FACTS ON PHYSICAL DISABILITY

7.3.1 Physical disability is varied; it is a mistake to treat all people with physical or any disabilities s if they have the same condition. The causes of physical disabilities are also diverse. Some physical disabilities are the result of injury (and belong to acquired group) while others may be congenital conditions. Not every circumstance of physical disability has a known cause. Physical disability can be congenital or acquired.

a. Congenital: Cerebral Palsy[iii], Developmental delay, congenital talipes equinovarus (CTEV) or clubfoot, Limb absence, (U/L, L/l, Part of the limb), Radial Club Hand, Cleft Leap, Cleft Palate, Hydrocephalus, Microcephalus[iv], Torticollis, Polydactyl, Part of Hand absent, Spina Bifida, Spina Congenital Coxa Verus, Valgus, Congenital Hip Dislocation, Congenital Pseudo e or Limb Length Discrepancy. Orthosis, Osteogenesis Imperfecta, Motor Neuron Disease, Duchenne muscular dystrophy (DMD) a genetic disorder characterized by progressive muscle degeneration and weakness, Marco dactyl etc.

[iii] It is dealt separately as an independent disability.

[iv] Both Hydrocephalus and Microcephalus are dealt under intellectual disabilities.

b. Acquired: Traumatic/Non-Traumatic: Brachial Plexus Injury, Spinal Cord Injury(Traumatic/ Non- Traumatic), Head Injuries, Acquired brain injury (ABI) and stroke, Poliomyelitis, Arthritis, Meningitis, Parkinson's, Respiratory (lung) disorders such as COPD, Limb length discrepancy, Tumor, Injury of U/l, L/L, Amputation, If limb is amputed, dead or deadly or functionless, Guillain-Barré syndrome (GBS), Multiple Sclerosis, Chronic Osteomyelitis, Volkman Ischemic Contracture, Arthritis, Degenerative or other problem in spine, Post traumatic Gangrene, Tuberculosis (TB), Women's urinary incontinence/Pelvic floor muscle problem (post-partum or in elderly women)/Uterine prolapse &/or vagina fistula (post-surgical) etc.

Following are some of the most common physical disabilities seen:

a) Acquired Brain Injury (ABI): Acquired brain injury may be the result of head injuries, concussions, stroke, infections in the brain, exposure to poisonous or toxic substances, and the lack of oxygen. ABI may result in a number of different physical disabilities plus other problems. As the brain is the central functioning unit for the body, those with ABI may suffer from problems with e.g. a varieties of their senses, and/or cognitive reasoning and memory, and/or depression, and/or anger or aggressiveness, and more. The severity of the Physical disabilities and/or theirs symptoms correlates to the severity of the brain injury. Possible physical disabilities associated with this include but not limited to loss of use of the limbs, paralysis, difficulty walking, and difficulty speaking[73].

b) Amputation: Amputation is the process in which a body part is removed or severed from the body. It may be the consequence of a medical intervention or a surgical procedure, or it may occur during a traumatic incident/accident. Sometimes an amputation may result from a congenital condition or disorder, e.g. someone may be born missing one or both hand etc. Those coping with amputations need to learn to accommodate for the various physical disabilities they face. In some cases, an amputee overcomes various challenges by overcompensating for it in other areas. For instance, someone who loses their arms may use their legs and feet to perform tasks often performed with the hands. In some cases, prosthetic devices can assist a person who is affected with amputation.

c) Cerebral Palsy: CP has various causes, and it can result in many physical disabilities and often with other associated disabilities. Given the incidence and multifaceted nature of CP, and the varieties of disabilities it can result in, this has been dealt as a separate condition leading to disability both in the Rights and Protection of Persons with Disability Act 2013 and the document **'Defining Disability: A Guideline for Medical Doctors and Primary Health Care Workforce'**.

d) Muscular Dystrophy: it is a physical disability that affects the musculoskeletal system of the human body. There are several forms of Muscular dystrophy (MD) including Becker (BMD), Limb-Girdle (LGMD), Duchenne (DMD), Emery-Dreyfus (EDMD), Facioscapulohumeral (FSHD, FSH), Congenital (CMD), Distal (DD), Myotonic (MMD), and Oculopharyngeal (OPMD). MD affects muscle cells and reduces strength causing them to become weakened or to waste away. More cases of MD affect boys more than girls. It has no known cure, but there are therapies that can help improve or maintain muscle tone. It may cause numerous physical disabilities and it is necessary that those who are having this condition receive the best care possible.

e) Parkinson's disease: It's a degenerative disease and a progressive disorder that targets the central nervous system leading to extreme physical disabilities. The cause of Parkinson's disease remains unknown, but it has been shown that the source comes from the death of dopamine making cells located within the brain. Some symptoms include difficulty walking and with coordination, trouble speaking and tremors. No two cases of the disease are the same, and the degree of disability varies. Parkinson's affected people need to receive a course of treatment tailored to his or her individual needs. It has no cure, but treatments may lessen the severity of symptoms[74].

f) Spinal Cord Injury (SCI): As a result of the damage to the spinal cord resulting from trauma (e.g. a car crash) or from disease or degeneration (e.g. cancer) an individual may acquire physical disability. WHO estimates an annual global incidence of 40 to 80 cases per million population. Up to 90% of these cases are due to traumatic causes, though the proportion of non-traumatic spinal cord injury appears to be growing. Symptoms depend on the severity of injury and its location on the spinal cord, and it may include partial or complete loss of sensory function or motor control of arms, legs and/or body. The most severe spinal cord injury affects the systems that regulate bowel or bladder control, breathing, heart rate and blood pressure. Most people with spinal cord injury experience chronic pain. Every year, around the world, between 250 000 and 500 000 people suffer a spinal cord injury (SCI) and the majority of spinal cord injuries are due to preventable causes such as road traffic crashes, falls or violence[75].

g) Stroke: The types and degrees of disability following a stroke are dependent on the area of the brain that is damaged. Usually, stroke leads to paralysis or problems controlling movement. A small percentage of stroke patients experience a loss of vision and/or speech difficulties following a stroke. It can be one of the major causes of disability among older people. Its prevalence in the population may increase because of enhanced survival and a growing elderly population. Estimating and appropriate management/health-related rehabilitation services for a person with impairment and disability following stroke should be a high priority[76].

h) Chronic Pain, low back pain may eventually cause impairment &/or disability[77].

i) Congenital Anomaly (e.g. Club Feet): Clubfoot is a birth defect with one or both feet rotated inwards and downwards. The affected foot, calf and leg may be smaller than the other. In about half of those affected, both feet are involved. Approximately one infant in every 1,000 live births may have clubfoot, which makes it one of the commonest congenital foot deformities. About a half of those affected may have it in both their foot. Most cases of clubfoot can be successfully treated if early identification is ensured. Even nonsurgical methods that may include a combination of stretching, casting, and bracing can also successfully manage clubfoot if early intervention and referral is ensured. Treatment usually begins shortly after birth[78].

j) Arthritic Condition Arthritis can also lead to impairment and/or disability, if the condition significantly limits one's regular movements, senses, or activities, which in interaction with environmental, cultural, attitudinal factors may create disabling situation[79].

7.4 PHYSICAL DISABILITY: IMPORTANCE OF EARLY DETECTION/DIAGNOSIS & INTERVENTION

7.4.1 Delays in identification and diagnosis of impairment &/or disability in other word means a child or adult with impairment remain unattended for. And this situation can lead to disability or secondary disabilities. For example, a child with club foot if identified, diagnosed early on, and receive early intervention sometimes, may not reach to a disabling conditions. The Article 26, Habilitation and Rehabilitation, of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) calls for: "… appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life"[80]. It further calls on countries to organize, strengthen, and extend comprehensive rehabilitation services and programmes, as early as possible, based on multidisciplinary assessment of individual needs and strengths, and including the provision of assistive devices and technologies.

7.4.2 A timely intervention and 'health-related rehabilitation can have the following broad outcomes:■prevention of the loss of function ■slowing the rate of loss of function ■improvement or restoration of function ■ compensation for lost function ■ maintenance of current function'[81] for the person at risk or who has an impairment or disability.

7.4.3 Early diagnosis can prevent the onset of disease-induced disability, for example for people with leprosy, or people infected with vector-borne parasitic disease like Lymphatic filariasis (LF). Early identification and intervention including treatment for some disease can significantly improve even life expectancy and quality of life e.g. for children suffering from a type of muscular dystrophy, which causes progressive weakness in the skeletal muscles, and most children having this i.e. Duchenne Muscular Dystrophy (DMD) require a wheelchair by age 11. But early diagnosis of DMD and other impairment/disabling conditions is often delayed until the disease/condition is well under way[82].

7.5 SOME IMPACTS OF PHYSICAL DISABILITY

7.5.1 Physical disabilities are among the most common and diverse disabilities. Individuals with physical disability in general experience increased barriers to obtain e.g. health care due to physical or environmental inaccessibility, costs of health care and transportation/ communication, lack of appropriate services, and inadequate skills and knowledge of health workers[83]. According to CBM Children with physical disabilities encounter marginalization and remain excluded from education and, eventually, a future in employment in low income countries; and that they are three times more likely to die in childhood than their non-disabled peers. According to the WHO people with a spinal cord injury one of the leading causes of physical disabilities are two to five times more likely to die prematurely than people without a spinal cord injury. People with spinal cord injury have one of the worst survival rates in low- and middle-income countries. Furthermore, spinal cord injury is associated with lower rates of school enrollment and economic participation, and it carries substantial individual and societal costs.

7.5.2 Children and adults with physical impairments face technical barriers due to the inaccessible design or location of facilities including difficulties collecting or carrying water, using washroom doors, or hand pumps to manipulate. Long, uneven or slippery paths, poor lighting or steps into latrines can all impede access for people with disabilities. Any access to specialist health care and rehabilitation services alongside making general health more care accessible to them can decrease burden on the individual and his/her family. With cross-sectorial referral this can even result in the child/adult's access to education, health care, gaining skills and employment and finally social inclusion. Individuals with a physical impairment may have associate difficulties e.g.

with speech due to difficulties to coordinating the muscles of the body involved in speech e.g., breathing muscles, vocal cords/voice box, tongue and lips. Some individuals with a physical impairment may have the weakness around the head, neck or torso and have affected speech production. Their ability to eat and drink may be hampered. Physical impairment such as cleft lip and palate may be associated with difficulties, e.g. early feeding problems (especially with cleft palate), problems with speech development, dental problems, especially when cleft lip extends to the upper gum area, recurrent middle ear infections and hearing problems. Some children with orofacial clefts may have issues with self-esteem if they are concerned with visible differences between themselves and other children[84] .

7.6 SYMPTOMS FOR PHC WORKFORCE TO SUPPORT EARLY IDENTIFICATION & REFERRAL

Symptoms - Physical Disability	a. Movements of four limbs present (1-2 months) b. Partial or full absence of Hand/ Leg c. Partial/Full Weakness of body part and spine, and trauma, injury to body part that hampers daily activity and living d. Any type of physical inactivity/problems/ mal-function/ decreased functioning e. Contracture development of limb spasticity f. Has problem with balance due to neurological cause/Difficulty or delay to stand, sit, walk etc. g. Congenital physical disability/problem, e.g. Cleft Lip, Cleft Palate, Club Foot etc. h. Sudden/gradual paresis affecting in one or both side of the body/ i. Lack of mobility due to Stroke/ Paralysis (partial/full) j. Progressive physical disability k. Spinal cord injury l. Chronic pain/malfunction of spine joints or body parts m. Irreversible breathlessness/ Wheeze/ Breathing difficulties n. Women's urinary incontinence/Pelvic floor muscle problem (post-partum or in elderly women)/Uterine prolapse &/or vagina fistula (post-surgical) o. Bladder dysfunction
Tools for health workers	- History (ante/during & post-natal) - Observation - Checklist - Development milestone (motor dev) - Physical examination, - Looks, Feel, Move - Blood pressure/ pulse - Post-medical history (PMH) (e.g. existence of diabetes) - Referral slip - Updated list of possible referral points - Note dropping or leakage of urine/ faeces, minimum prolapse of uterus
Actions Required	- Take history - Observes and screen - Refer to appropriate service points at UHC/ District using the referral slip - Aware people using available IEC materials - Counsel parents/guardians as needed. - Advise parents/ guardians to maintain the referral slip for the next service point - Provide counselling

7.7 INDICATORS TO DIAGNOSE IMPAIRMENT & DISABILITY BY MEDICAL DOCTORS

Symptoms - Physical Disability	a. Limb deficiency/ impairment b. Difficulty in postural control, functional limitation, transitional movement (e.g. sit to stand or vice versa) c. Difficulty in standing or walking without support d. Difficulty in performing activities of daily living (ADL) e. Developmental Delay f. Muscle weakness, stiffness/wasting g. Difficulty in social activity h. Bowel-bladder function impairment i. COPD, Respiratory Distress/other cardio-pulmonary problem (irreversible conditions) j. Disabling pain syndrome (spine/joint/arthritis) k. Progressive Physical & functional disability (M&D) l. Degenerative Physical problems m. Post-partum pelvic floor complications (muscle weakness, pain/back pain) n. Stress or urge incontinence, bladder impairments, fistula, minimum uterine prolapse (grade 1 or 2) o. Neurological bladder dysfunction
Tools for health workers	- History - Observation - Physical/ functional examination (including neuro-muscular examination) - FIM (functional impairment for adult) - WeeFIM (for children) - X-ray - Electroencephalogram (EEG), - Magnetic resonance imaging (MRI), - CT Scan, Ultra-sonography (Child's brain, for adults muscular/joint, abdomen) (only if necessary) - EMG & Nerve Conduction Velocity testing (NCV) - Ultra-sonography (Child's brain, for adults muscular/joint, abdomen) - Respirometer - Quality of life questionnaire
Actions Required	- Check the referral info. noted by the health workers with chief complaints and as necessary take history - Diagnose - Provide services as appropriate and/or refer to the nearest GO-NGO or other available service centre within district or other place - Also, refer to Rehabilitation, Education Services/Social Welfare at district, below and nationally, as necessary - Provide counselling - (Inform the patient about the date and time of availability of the specialist/ services(if available/where necessary) - Advise individual/ parent/guardian to preserve the referral info. for the next service points (if needed)

**Training for medical doctors is required to cautiously use clinical tests to ensure these are for the benefit of child/adult with disabilities and are not unnecessarily economically burdensome on them*

VISUAL DISABILITY

CHAPTER 8

8.1 DEFINITION

8.1.1 An impairment is when a disease affects the structure or functions of a person's body. A vision impairment covers the visual system (structure) and the functions of vision. Persons with visual disabilities include those who have long-term partial or full vision loss and who have visual acuity worse than 6/60 to 3/60 or no perception of light in the better eye - which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. This understanding is consistent with the WHO International Classification of Disability, Functioning and Health (ICF).

Note: The Act, 2013 also includes vision loss in one eye as a disabling condition, which will also need to be considered for certification of disability.

8.2 GENERAL INFORMATION

8.1.2 There are many signs of vision loss, including finding it difficult or impossible to read or write using sighted materials, or recognize currency when selling goods or purchasing, drive a rickshaw or car/bus, stitching or recognizing faces etc. It may be difficult to manage glare. Blindness doesn't necessarily cause total darkness. Many people who are considered blind can still see some light or shadows, but cannot see anything clearly. Only about 15% individuals with eye disorders are totally blind, while about 85% have some remaining sight[85]. A sudden loss of peripheral vision, sudden loss of central vision, a sudden blurring of one's vision, a sudden appearance of spots within one's field of vision are all signs and/or symptoms of visual impairment and demand examination as soon as possible. A sudden or gradual loss of vision could potentially be permanent, especially if not treated quickly or sometimes it is untreatable. A flood of spots in one's field of vision; a sensation that a dark curtain has settled across one's field of view, sudden eye pain, red eyes, nausea, vomiting, double vision, double images, sudden blurry vision in eye, a narrowing of one's field of view, cloudy and blurred eyesight, a disk or circle of light seen around lights at night, loss of bright color vision, blind spots in one's field of view, irritated sensation, frequent flashes of light, and swelling are all signs of visual impairment and need attention.

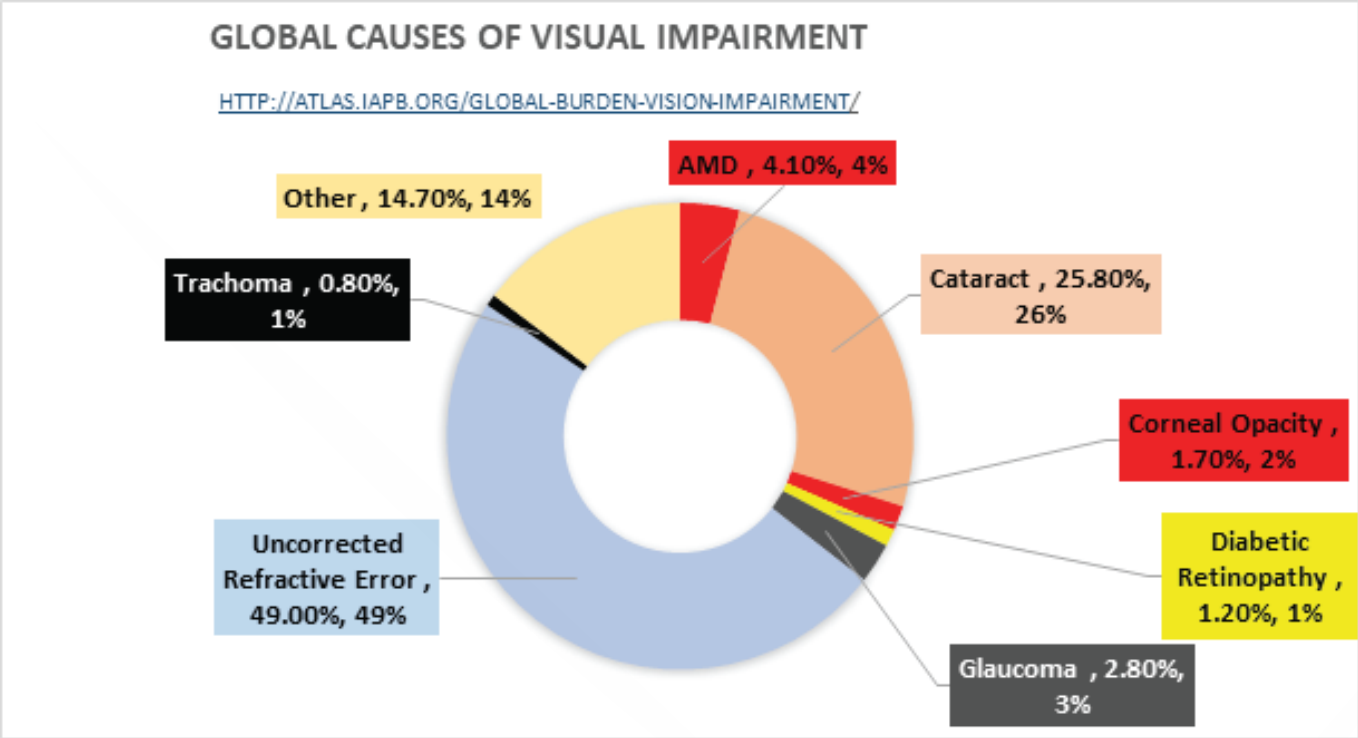
8.2.2 The World Health Organization (WHO) defines impaired vision in five categories:

- Low vision 1 is a best corrected visual acuity of 6/70 or 20/70.
- Low vision 2 starts at 6/60 or 20/200.
- Blindness 3 is below 3/60 or 20/400.
- Blindness 4 is worse than 1/60 or 5/300
- Blindness 5 is no light perception at all.
- A visual field between 5° and 10° (compared with a normal visual field of about 120°) goes into category 3; less than 5° into category 4, even if the tiny spot of central vision is perfect[86].

8.2.3 Low Vision: Not all eye care professionals agree with an exclusively numerical (or visual acuity) description of low vision. Following describes low vision more functionally: Low vision is uncorrectable vision loss that interferes with daily activities and cannot be corrected with regular glasses, contact lenses, medicine, or surgery. It is perhaps better defined in terms of function, rather than [numerical] test results. (Massof and Lidoff). Person with low vision needs different kind of eye examination that uses different and more detailed tests to determine what you can and cannot see [87]&[88].

8.3 KEY FACTS ON VISUAL IMPAIRMENT & DISABILITY[89]

- An estimated 253 million people live with vision impairment: 36 million are blind and 217 million have moderate to severe vision impairment.
- 81% of people who are blind or have moderate or severe vision impairment are aged 50 years and above.
- Globally, chronic eye diseases are the main cause of vision loss. Uncorrected refractive errors and then un-operated cataract are the top two causes of vision impairment. Un-operated cataract remains the leading cause of blindness in low- and middle-income countries.
- The prevalence of infectious eye diseases, such as trachoma and onchocerciasis, have reduced significantly over the last 25 years.
- Over 80% of all vision impairment can be prevented or cured[90].
- 89% of visually impaired people live in low and middle income countries, (IAPB Vision Atlas)[91].
- 55% of visually impaired people are women, (ref: IAPB Vision Atlas).



8.4 IMPORTANCE OF EARLY DETECTION/DIAGNOSIS & INTERVENTION OF VISUAL DISABILITY

8.4.1 The control of childhood blindness is a high priority in the WHO VISION 2020—The Right to Sight programme and the national eye care programme of Bangladesh. Early identification, diagnosis and referral is essential to lessen potential disability and/or improve quality of life of the infant/child/adult with visual impairment. For example, Retinopathy of Prematurity (ROP) is a potentially blinding eye disorder that primarily affects premature infants. Incidence of ROP in developed countries is 10–27%, depending on degree of prematurity and birth weight. Different studies from India, reports incidence of ROP to be at 24–47% among high risk preterm infant populations. Routine screening programs e.g. of preterm babies are not in place for ROP in South Asian countries including in Bangladesh. Long term morbidity of ROP has a spectrum ranging from myopia to blindness[92].

8.4.2 Similarly, cataract is a significant cause of visual impairment for both children and older population and it has the potential to be a disabling condition if remains without timely surgical intervention. Early diagnosis and prompt surgical intervention for cataract is critical to prevent irreversible amblyopia[93] or partial or complete loss of vision in the affected eye.

8.4.3 Early identification, diagnosis and referral thus is of utmost importance to address impairment, prevent further deterioration and disability, and improve quality of life.

8.5 SOME IMPACTS OF VISUAL DISABILITY

8.5.1 People with visual disability often face different barriers and have lower rates of education and/or employment than people without impairments due to un-inclusive education and vocational education system. They face economic & social barrier and a lack of health and rehabilitative services/support, particularly in low and middle-income countries such as Bangladesh. Primary education is free in Bangladesh for all children and yet children with disabilities including children with visual disabilities are among the least represented at school. Lack of transport to reach school, absence of vision and hearing based pedagogy are among some of the important barriers to education of children with visual disabilities[94].

8.5.2 When it comes to health and well-being, vision loss may affect one's quality of life (QOL), independence, and mobility and has been linked to falls, injury, and worsened status in domains spanning mental health, cognition, social function, employment, and educational attainment. Thus the health consequences associated with vision loss extend well beyond the eye and visual system[95]. Peer-reviewed studies have documented a relationship between vision impairment and falls (Crews et al., 2016a; Lord, 2006). A study commissioned by Prevent Blindness indicates the direct medical expenses, other direct expenses, loss of productivity, and other indirect costs for visual disorders across all age groups were approximately $139 billion dollars (in 2013) (Wittenborn and Rein, 2013). The direct costs for the under-40 population reaching $14.5 billion dollars (Wittenborn et al., 2013).

8.5.3 Depression and anxiety are common health problems in visually impaired older adults, whose loss of vision is caused mainly by age related disease such as age related macular degeneration and glaucoma. Studies reveal that older adults with vision impairment have a higher prevalence of depression than those without[96]. Vision impairment increases the risk of falls, particularly for older people[97] increasing the cost of vision impairment to other areas of the health system. Some studies indicate high rates of fractures in people with vision impairment compared to those without. Older drivers with cataracts pose a higher risk of being in a crash than those without[98].

8.5.4 For children severe and early impairments are likely to affect the language development of affected children[99]. Children with vision impairment are less likely to enroll in school and/or achieve the same level of educational attainment as their peers due to barriers and limitation in education system and services. Vision is particularly important for communication as half of all communication is non-verbal (e.g. gestures or facial expressions). Communication difficulties of children with Visual impairment and disability is often underestimated, more so in developing countries such as Bangladesh where sub-specialists and support services on speech and language therapy is difficult to find across the country.

8.5.5 Fifty percent of those who have visual disability in impoverished countries report a loss of social standing and decision-making authority, and 80% of women with visual disability note a loss of authority within their families. “Poverty and blindness are believed to be intimately linked, with poverty predisposing to blindness, and blindness exacerbating poverty by limiting employment opportunities, or by incurring treatment cost[100]. For those who live in poverty, blindness or poor vision can tremendously impact on quality of life. Some literature indicate that almost 90% of individuals affected with vision loss/poor vision may not have work[101]. The lack of economic development is a factor that aggravates the prevalence of visual impairment[102].

8.6 SYMPTOMS FOR PHC WORKFORCE TO SUPPORT EARLY IDENTIFICATION & REFERRAL

Symptoms - Visual Disability	a. Baby Responses to light/face (at birth) b. Regards face or e.g. woolly ball (1 month) c. Fixates and follows face (2 months) d. Fixates 1 inch cube from a distance of 30 cm (5 months) e. Watches moving adult from 3 metres (3 - 24 months) f. Fixates a smallest homeopathy pellet/bit from 30 cm distance (9-24 months) - (Source: RNDA, BPF) g. If s/he has problem seeing) – [take into account eye glasses, if one wears them] h. If the lens is white or grey/ash i. If there is scar in the lens j. If the lens glare at night k. If s/he has squint l. If the structure of the eye is abnormal, e.g., it has droopy eyelid, eye, or bulging or protruding of one or both eyes (proptosis or exophthalmos), or disruption in the integrity of the corneal epithelium/he corneal surface scraped away/ large corneal abrasion, or the eye is very small (microphthalmia) m. Sign of eye injury n. Colour Blindness (reduced ability to perceive certain colours, usually red and green) o. Lack of contrast sensitivity (inability to distinguishes one object from another) p. Rely on touch (tactile) ways to identify things q. Problems in distinguishing facial expressions
Tools for health workers	Torch Light Vision Chart Relevant Flip chart/ other IEC Material Referral Slip Information on Referral Point
Actions Required	- Screen using available tools (vision chart, torch light); - Take history and Refer to appropriate service points at UHC/District using the referral slip; - Also, refer all with VD i.e. to nearest UHC (to trained Residence Medical Officer-RMO or Upazila Health & Family Planning Officer-UHFPO) and/or district sadar hospital for verification for disabiliy even if they’re with the following conditions: - A visual impairment that adversely affects someone even after his/her vision is corrected to the extent possible. - Someone lacks light perception (total blind in both eyes) e.g. for disability verification/ confirmation, referral for possible certification and to rehabilitation, education, social welfare services - Refer others with eye/vision problem for service - Aware/educate people using the IEC materials - Counsel patient/client as needed - Advise parents/guardians to maintain the referral slip for the next service point(s)

8.7 INDICATORS TO DIAGNOSE VISUAL IMPAIRMENT & DISABILITY BY MEDICAL DOCTORS

<table>
<tr><td>Indicators for Visual Impairment/ Disability</td><td>
a. Distance Visual Impairment
<table>
<tr><td>Level</td><td>Visual acuity</td></tr>
<tr><td>Mild</td><td>6/12 but equal or better than 6/18</td></tr>
<tr><td>Moderate</td><td>Worse than 6/18</td></tr>
<tr><td>Severe</td><td>Worse than 6/60</td></tr>
<tr><td>Blindness</td><td>Worse than 3/60, 1/60; or no light perception</td></tr>
</table>
b. Near vision impairment

Level: Near
Acuity: Worse than N6 or N6 at 40cm” with existing correction.
Level: Blindness
Visual acuity: Worse than 3/60, 1/60; or no light perception
</td></tr>
<tr><td>Tools for health workers</td><td>Torch light, Magnifying loop, Vision chart
Pinhole (Slit lamp where community vision centre is established)
Ophthalmoscope, Retinoscope, Trial set, Slit lamp, Volk lens</td></tr>
<tr><td>Actions Required</td><td>- Diagnose and provide service (where appropriate)
- Refer to the nearest ophthalmologist/ Paediatric ophthalmologist at district sadar hospitals Medical college hospital for diagnosis/ service and certification
- Refer to appropriate health & rehabilitation/education services
- if child/adult has trouble seeing even after correction of vision to the extent possible;
- if child/adult is with Moderate Low Vision (20/70-20/160 and condition that cannot be corrected);
- the individual’s vison is (from 20/200-20/400 and is legally blind with severe low vision or from 20/400-20/1000 with profound visual impairment, and is very close to total blindness) for confirmation/possible certification and referral to rehabilitation/education;
- if the individual is totally blind (lacks light perception) for confirmation/possible certification and referral to rehabilitation/education/social welfare;
- Inform the date and time of availability of the ophthalmologist/services (where necessary/if info. available
- Provide counselling and referral slip
- Advise parents/guardians to maintain the referral slip for the next service point(s)</td></tr>
</table>

OTHER PROFESSIONS THAT CAN SUPPORT TO DIAGNOSE DISABILITIES, & APPROACHES

CHAPTER 9

A MULTI-SECTOR APPROACH IS MORE BENEFITTING IN SUPPORTING A CHILD/ADULT WITH DISABILITIES, COMPLETELY. FOLLOWING INCLUDES A LIST OF OTHER PROFESSIONALS WHO CAN SUPPORT A DISABILITY TRAINED PHC DOCTOR:

CEREBRAL PALSY	HEARING, SPEECH DISABILITY & DEAF-BLINDNESS	INTELLECTUAL DISABILITY
- Neuro-Developmental Paediatrician - Physiotherapists (PT) - Child psychologist - Occupational therapist (OT) - Trained Physicians - Prosthetist &/or Orthotist (P&O) - Speech-language Therapist (SLT) - Physical medicine department - Orthopedician - Dentist (for associated problems) - Ophthalmologists/ Paediatric ophthalmologist (for associated impairment &/or disability) - Rehabilitation, social & education specialist services [v] - Trained other PHC workforces including medical doctors with relevant training	- ENT Consultants/ Specialist - Speech & language therapists - Audiologist - Ophthalmologists (for associated blindness) - Occupational Therapists (OT) - Psychologist (for associated/suspected other impairment &/or disability) - Rehabilitation, social & education specialist services (see footnote) - Trained other PHC workforces including medical doctors with relevant training	- Child Neurologist - Psychiatrist - Psychologist - OT (for functional/ADL) - Paediatric ophthalmologist/ophthalmologists (if with visual impairment) - Counsellor - Communication specialist - Rehabilitation, social & education specialist services (see footnote) - Trained other PHC workforces including medical doctors with relevant training - PT (if with associated physical problem etc.) - Speech & language therapists (if with associated speech related problem)

PSYCHOSOCIAL OR MENTAL DISABILITY	PHYSICAL DISABILITY	VISUAL DISABILITY
- Psychiatrist - Trained Medical Officers - Clinical Psychologist - OT (e.g. for basic life skill training etc.) - Trained Psychiatric nurse - Trained PHC workforce on mental health - Rehabilitation, social & education specialist services (see footnote) - Trained Counsellor	- Neuro - medicine professional (to check if with associate impairment) - Physical Medicine Dept. at tertiary facilities - Physiotherapist - Surgeon/Orthopaedician - Prosthetists & Orthotists - Plastic surgeon - Occupational Therapist - Paediatrician - Rehabilitation, social & education specialist services (see footnote) - Trained other PHC workforces including medical doctors with relevant training	- Eye Consultants/ Ophthalmologists at UHC and District Sadar Hospitals - Paediatric ophthalmologists - Optometrist (where required & available for optical and non-optical services) - Trained other PHC workforces including medical doctors with relevant training - Trained ophthalmic nurses/ Trained SACMO - Rehabilitation, social & education specialist services (see footnote)

Note: Please refer to other professionals if associated impairment/disability is present in the child/adult with disability(ies).

[v]All Rehabilitation & Education services must be always with trained Social Workers & trained Teachers/Special educators, special needs teachers with ability to take care/educate children/youth with disabilities, located at inclusive setting/ schools (preferably) or special and/or integrated schools.

LIST OF SOME REFERRAL POINTS/ORGANISATIONS/ INSTITUTES

CHAPTER 10

A MULTI-SECTOR APPROACH IS MORE BENEFITTING IN SUPPORTING A CHILD/ADULT WITH DISABILITIES, COMPLETELY. FOLLOWING INCLUDES A LIST OF OTHER PROFESSIONALS WHO CAN SUPPORT A DISABILITY TRAINED PHC DOCTOR:

CEREBRAL PALSY	HEARING, SPEECH DISABILITY & DEAF-BLINDNESS	INTELLECTUAL DISABILITY
1. Medical colleges with Shishu Bikash Kendra (SBK), physical medicine and paediatric department 2. National Institute of Neurosciences & Hospital (NINS) 3. Institute of Paediatric Neuro-disorder & Autism (IPNA), BSMMU 4. Centre for the Rehabilitation of the Paralyzed (CRP), Savar[vi] 5. Bangladesh Protibondhi Foundation (BPF), Mirpur, Dhaka[vii] 6. Centre for Disability in Development (CDD), Savar 7. Disabled Rehabilitation and Research Association (DRRA) 8. Integrated disability service centre (IDSC) and mobile vans of Janiya Protibondhi Unnayan Foundation (JPUF), Ministry of Social Welfare 9. Nearest good quality rehabilitation/physiotherapy centre/services	1. UHC, District Sadar, and Medical Colleges & Hospitals with ENT Dept. 2. National Institute of ENT 3. IDSC, JPUF in different districts 4. CDD, Savar 5. CRP 6. SAHIC, Mohakhali, Dhaka 7. HiCARE School in Dhaka and Banaripara, Barishal 8. Specialized Hospital in private sector with ENT services 9. NGOs and private organizations with quality ENT services 10. Special schools operating under DSS &/or JPUF under the MoSW	1. Medical colleges with and Paed. Dept. & SBK 2. IPNA 3. Agrabad Ma o Shishu Hospital, Chattagram 4. CRP 5. BPF 6. Society for the Welfare of the Intellectually Disabled (SWID) Bangladesh 7. DRRA school at Badda, Dhaka 8. IDSC, Special School at JPUF, Mirpur, Dhaka 9. Proyash school, Bangladesh Army
PSYCHOSOCIAL OR MENTAL DISABILITY	**PHYSICAL DISABILITY**	**VISUAL DISABILITY**
1. Pabna Mental Health Hospital 2. National Institute of Mental Health, Sher-e-Bangla Nagar, Dhaka 3. Psychiatric Department of Govt. Medical Colleges & Hospitals 4. Department of Psychiatry, BSMMU 5. Department of Psychiatry, Combined Military Hospital (CMH) 6. Psychiatric Department of Private Medical College (e.g. National Medical College, Uttara Medical College, Enam Medical College, Dr. Sirajul Islam Medical College & Hospital, Dhaka Community Medical College, Khwaja Yunus Ali Medical College located in Sirajganj, Ragib-Rabeya Medical College Road, Pathantula, Sylhet, University of Science & Technology Chittagong (USTC) at Chattagram, Bajitpur Medical College at Kishoreganj) 7. Nasirullah Psychotherapy unit of Dhaka University 8. CRP Gonokbari, Savar Nabinagar (Mental Health Day Care Centre) 9. Protibondhi Nagorik Shongsthaner Parishad, (for advocacy)	1. UHC, Sadar/General hospital, Medical Colleges & Hospitals physical medicine specialists &/or Dept.of Orthopaedics, & Plastic Surgery services 2. Physical Medicine Dept. at BSMMU 3. Chattagram, Rajshahi,& Barishal Medical College Satellite clinic for spinal cord injury 4. CRP 5. CDD 6. IDSC, JPUF 7. DRRA (Dhaka , Satkhira & Manikganj) 8. Specialized Hospital, nearest rehab/ physiotherapy centre 9. Proyash school[viii] 10. BRAC Limb and Brace Centre (BLBC)	1. UHC, Sadar/General hospital, Medical Colleges & Hospitals with ophthalmologists/Eye Dept. 2. National Institute of Ophthalmology & Hospital 3. Dept. of Ophthalmology, BSMMU 4. Nearest BNSB Eye Hospitals in e.g. Mirpur, Dhaka; Mymensingh, Khulna, Dinajpur, Moulvibazar 5. Ispahani Islamia Eye Institute and Hospital[ix] 6. CEITC, Pahartoli, Chattagram 7. OSB Hospital 8. Tertiary hospitals with paediatric ophthalmic services 9. Eye units of BIRDEM and associate diabetic Hospitals 10. Bangladesh Jatiya Andha Kallyan Somiti (BJAKS) Hospital, Alekharchar, Cumilla 11. Dhaka Progressive Lions Hospital, Narshingdi 12. Kumudini Hospital, Tangail 13. VARD Eye Hospital,Sylhet & Sunamganj 14. Bangladesh Lions Hospital, Dhaka 15. Reputed Private eye Hospital 16. Current partner hospitals of Sightsavers, ORBIS, Fred Hollows Foundation, CBM, Helen Keller International 17. Special schools under DSS &/or JPUF, MoSW 18. Baptist Mission, BERDO, Salvation Army, ABC & other NGOs for education &/or social rehabilitation etc. and BVIPS for advocacy

[vi]CRP has branches at Mirpur (Dhaka) Chattagram, Moulvibazar, Barisal, Rajshahi, Pabna, Sylhet, Mymensingh with some services.
[vii]BPF has branches with some services at Savar, Malibag (Dhaka), Narshingdi, Dhamrai, Kishoreganj, and Faridpur.
[viii]Proyash has services in Jashore, Bogura, Chittagong, Rangpur, Savar, Cumilla, Sylhet and Ghatail area.
[ix]IIEIH main hospital at Farmgate, Dhaka; has branch hospital with some services at Jamalpur, Barishal & Naogaon.

REFERRAL POINTS/ORGANISATIONS/INSTITUTES

	CP	HSD	ID	MD	PD	VD
UHC with respective consultants with respective specialties		✓			✓	✓
District sadar/general hospital with respective Consultants		✓			✓	✓
Shishu Bikash Kendra (SBK) located at Bangladesh Shishu Hospital and certain tertiary Medical College Hospitals in the public sector	✓		✓			
All medical colleges with e.g. paediatric dept., physical medicine dept., neuro-dev. dept., eye dept., ENT dept., psychiatric dept. etc. and Respective Dept. of Bangabandhu Sheikh Mujib Medical University (BSMMU), Shahbag Dhaka and other specialized hospitals	✓	✓	✓	✓	✓	✓
National Institute of Neurosciences & Hospital (NINS), Sher-E-Bangla Nagar, Agargaon,Dhaka	✓		✓			
IPNA at Bangabandhu Sheikh Mujib Medical University (BSMMU), Shahbag, Dhaka	✓		✓			
National Institute of ENT, Tejgaon, Dhaka		✓				
Agrabad Ma o Shishu Hospital, Chattagram			✓			
Pabna Mental Health Hospital, Hemayetpur, Pabna				✓		
National Institute of Mental Health (NIMH), Sher-e-Bangla Nagar, Dhaka				✓		
Department of Psychiatry, Surgery, Ophthalmology, ENT etc. at the Combined Military Hospital (CMH)		✓		✓	✓	✓
National Institute of Ophthalmology & Hospital (NIOH), Sher-E-Bangla Nagar Dhaka						✓
Chattagram, Rajshahi, Barishal Medical College Satellite clinic for spinal cord injury					✓	
Psychiatry Department of Private Medical College (e.g. 1) National Medical College, 2) Uttara Medical College, 3) Enam Medical College, 4) Dr. Sirajul Islam Medical College & Hospital, 5) Dhaka Community Medical College, 6) Khwaja Yunus Ali Medical College located in Sirajganj, 7) Ragib-Rabeya Medical College Road, Pathantula, Sylhet, 8) University of Science & Technology Chittagong (USTC) at Chattagram, 9) Bajitpur Medical College at Kishoreganj)				✓		
Tertiary centres with Paediatric Ophthalmological services (including. at NIOH in Dhaka, CEITC in Chattagram, IIEIH at Farmgate, Dhaka, Bangladesh Eye Hospital in Dhaka etc)						✓
Centre for the Rehabilitation of the Paralyzed (CRP), Head Office at Savar, Dhaka (see detail services by centre and contact/address in annex)	✓	✓	✓		✓	
CRP Gonokbari, Savar Nabinagar (Mental Health Day Care Centre				✓		
Nasirullah Psychotherapy unit of Dhaka University				✓		
Bangladesh Protibondhi Foundation located at Mirpur, Dhaka (Head Office), and they have limited s ervices on certain disabilities in their Savar (Dhaka), Narshingdi, Dhamrai, Kishoreganj, and Faridpur branches and Kallyani School for children with N, Dhaka	✓		✓			
Centre for Disability in Development (CDD), Savar, Bangladesh	✓	✓			✓	
DRRA, Shyamoly, Dhaka (contact for information on services) and DRRA school at Badda, Dhaka for children with NDD; DRRA projects at Manikganj and Satkhira districts	✓		✓		✓	
Nearest reputed rehabilitation & physiotherapy centre, reputed hearing care centre etc. (pvt.) and reputed specialized hospitals	✓				✓	
Janiya Protibondhi Unnayan Foundation (JPUF), Ministry of Social Welfare (MoSW), Bangladesh's 103 Protibondhi Seba O Sahajya Kendra (also known as integrated disability service centre) & mobile van services in certain districts (*before referring, first check if the nearest centre has concerned services*)		✓				✓
Society for Assistance to Hearing Impaired Children (SAHIC), Mohakhali, Dhaka and Chattagram		✓				
HiCARE School in Dhaka and Banaripara, Barishal		✓				
Society for the Welfare of the Intellectually Disabled (SWID) Bangladesh			✓			

- Nearest BNSB Eye Hospitals in e.g. Mirpur, Dhaka; Mymensingh, Khulna, Dinajpur, Moulvibazar - Ispahani Islamia Eye Institute and Hospital (IIEIH), Farmgate, Dhaka; Jamalpur & Naogaon - Chittagong Eye Infirmary and Training Complex (CEITC), Pahartoli, Chattagram - OSB Eye Hospital Hospital, Mirpur-1, Dhaka - Eye units of BIRDEM and associate diabetic hospitals - Bangladesh Jatiya Andha Kallyan Somiti Hospital (BJAKS), Cumilla - Dhaka Progressive Lions Hospital, Narshingdi - Eye Unit of Kumudini Hospital, Mirzapur, Tangail - VARD Eye Hospital in Balaganj, Sylhet and Sunamganj - Bangladesh Lions Hospital, Dhaka - Current partner hospitals of Sightsavers, ORBIS International, Fred Hollows Foundation, CBM, Hellen Keller International - Reputed eye hospital in the private sector						✓
BRAC Limb and Brace Centre (BLBC)					✓	
Educational & other Support						
Special School of JPUF & DSS, MoSW for Children with ID, VD, H&SD and autism in selected places						
Prayash, Special need School, Dhaka Cantonment (special education & some services)						
Inclusive schools with trained teachers for children with PD, HSD, VD & other disabilities, Integrated Education Program for children with VD of DSS & Assistance for Blind Children-ABC, and Special Schools (refer Dept. of Social Services, Blind Education and Rehabilitation Development Organisation- BERDO and Salvation Army school for children with VD						
Protibondhi Nagorik Shongsthaner Parishad (PNSP) & Bangladesh Visually Impaired Peoples Society (BVIPS) (only for social rehabilitation/advocacy)						

HEALTH/MEDICAL/ REHABILITATION PRACTITIONER'S ETHICS

CHAPTER 11

HEALTH/MEDICAL/REHABILITATION PRACTITIONER'S ETHICS[103]

Medical doctors and allied health workforces[x] need to apply and/or practice minimum health/-medical/services ethics while the come across/deal with a child and/or adult with disabilities of different genders, and/or their parents/care givers/family members/guardians.

Principles and approaches to be followed include:

Respect for Persons/Autonomy:

- Acknowledge a person's right to make informed choices[104].
- Capable patients with disabilities must be provided with full, relevant, and truthful infor mation about recommended treatments/therapies/services/referrals.
- They must be informed of reasonable alternatives, including expected benefits, potential risks, and the results of refusing treatment altogether.
- Practitioners who respect their clients' autonomy, ensure accuracy in information given, in advance of services offered.
- Practitioners must seek freely given and adequately informed consent, and emphasize the value of voluntary participation.

Justice:

- It refers to the fair and impartial treatment of all clients and the provision of adequate services and treating others equitably.
- This is about treating all including those with impairment and/or disabilities equitably, distributing benefits/burdens fairly, and respecting their human rights and dignity.
- Practitioners have a duty to provide health care, counselling, referral to other services including rehabilitative, psychotherapy services etc. (where applicable).
- Services must be accessible and appropriate to the needs of potential clients.

Nonmaleficence (do no harm):

- Practitioners must not harm the patient including those with impairment and/or disabilities.
- The Principle of Beneficence and the Principle of Non-Maleficence will frequently be applied together.
- The result of these considerations will determine what is in the patient's best interests.

Beneficence (do good):

- Health care providers need to be of a benefit to the patient, and they need to take positive steps to prevent and to remove harm[105] from the patient including those with impairment and/or disabilities.
- The best interests of the service recipient/patient should be considered.
- The relevant harms to be prevented or removed include pain and suffering, disease, disability, and death.
- The relevant good to be promoted include well-being, health, proper functioning, and life.
- It is essential that the doctor and team need to work strictly within their limits of competence and provide services on the basis of adequate training or experience.

---

[x] include health volunteers, the whole range of primary health care (PHC) workforce, nurses, paramedics, specialist doctors, and other auxiliary health & rehabilitation professionals e.g. physiotherapists, occupational therapists, speech & language therapists in public and other sectors.

- While applying the principle, it is necessary to determine if the proposed medical treatment/services/therapy will prevent or remove harm, or promote good for the patient, and contribute to improve the quality of life, and if these are accessible/affordable to the service recipient.
- The principle must be applied even when working with clients whose capacity for autonomy is diminished because of immaturity, lack of understanding, extreme distress, serious disturbance or other significant personal constraints.

Principle of Respect for Dignity:

- The Principle of Respect for Dignity is meant to apply to everyone involved in the medical/health/therapy/service encounter'.
- All people despite their social, economic and educational status, impairment &/ or disability, gender, age, ethnicity, faith and profession deserve to be treated with respect and dignity.
- Respect for persons and respect for their dignity applies even to those who are not capable of making their own decisions and even if medical decision is not taken.
- Respect for people's dignity includes respect for their emotions, relationships, reasonable goals, privacy, and bodily integrity.

Communications:

- When dealing with a person with disability (child or adult), use "people first" language to respect that people with disabilities aren't defined by their disability, they are people first, disability second.
- The doctor and team must not refer them as 'disabled', 'handicapped' 'confined to wheel chair' etc.[106].
- They must speak directly to people with disabilities and with age-appropriate language-not to the people who may be accompanying them.

Maintain the privacy:

- Confidentiality is one of the core duties of medical practice.
- A patient's personal health information must be protected; where required the patient's consent to release the information will be necessary.

Provide Counselling: The trained doctor needs to be effective in counselling. S/he should have excellent communication skills; acceptance; empathy; problem-solving skills; and multicultural competency. The purpose of counselling is to support the child/adult with disability and their parents/caregivers/family members/guardians identify their strengths, and enhance their development by talking openly and spontaneously to someone impartial and knowledgeable. One of the main objectives of counselling is to bring about a voluntary positive change in the client.

THE WAY FORWARD

CHAPTER 12

THE WAY FORWARD

The document has the following key recommendations to mainstream disabilities within a specific time-frame to enable Bangladesh meet its SDG commitments and to move towards disability inclusive health care:

- Review/agree on minimum quality standards i.e. develop operational guideline and protocol for health and related rehabilitation professionals and services in Bangladesh.
- Where needed, field test & roll out agreed tools to be used by PHC workforces & trained doctors.
- Establish functional referral points involving public sector & NSA (includes NGOs& private service providers); consider a cross-sectoral approach.
- Consider a consortium approach to improve the effectiveness of training to optimize quality, resources (including human resources), and avoid duplication.
- Pilot, and then take the learning to roll out across the country.
- Strengthen monitoring & supervision of disability services; and include disability indicators in HMIS/ District Health Information System (DHIS2).
- Consider licensing & monitoring options for allied workforces e.g. PT, OT, SLT & other providers to streamline services.
- Review existing Human Resources structure within public health sector to create needs-based positions of PT, OT, SLT &counsellors etc. at relevant levels of health & reha bilitation facilities in Bangladesh.
- Introduce a rehabilitation service and referral protocol for individual,public and private service providers.

APPENDIX-1: LIST OF WORKSHOP PARTICIPANTS

1. Professor (Dr) Abul Kalam Azad, Director General, DGHS
2. Professor (Dr) Nasima Sultana, ADG (Admin), DGHS
3. Professor (Dr) AHM Enayet Hussain, ADG (Planning & Development), DGHS
4. Dr Ashish Kumar Saha, Director, MIS, DGHS
5. Dr Nur Mohammad, LD, NCDC, DGHS
6. Dr Khwaza Abdul Gafur, Director (Finance), DGHS
7. Dr A B M Majharul Islam, Director, Admin, DGHS
8. Dr Khaleda Islam, Director, PHC, DGHS
9. Dr Narayan Saha, Professor, Head of Paediatric Neurology, National Institute of Neurosciences & Hospital, Dhaka
10. Dr Monowara Sultana, Director & LD, Alternative Medical Care, DGHS
11. Professor (Dr) Mahmudul Hassan, Director, NIENT, Dhaka
12. Prof. Basana Rani Muhuri, Chittagong Medical College
13. Prof. Dr. Faruq Alam, Director & Professor, NIMH, Dhaka
14. Dr. Manash Ranjan Chakraborty, Professor, NIENT, Dhaka
15. Prof. (Dr) MA Mohit Kamal, Professor, NIMH, Dhaka
16. Prof (Dr.) Mahadeb Chandra Mandal, NIMH, Dhaka
17. Dr. Mekhala Sarker, Associate Prof., (Psychiatry), NIMH, Dhaka
18. Dr Nahid Ferdaausi, Associate Professor, NIOH, Dhaka
19. Dr. Md. Zonaid Rahim, Associate Prof, NIENT, Dhaka
20. Dr. Molla Ershadul Haque, NITOR, Dhaka
21. Dr Farzana Rahman, Asst. Professor, NIMH, Dhaka
22. Dr Arun Kanti Biswas, DD, CDC, DGHS
23. Dr Dilruba Sultana, DD (PM-1), DGHS
24. Dr Mahmuda Begum, Asst. Director, PHC, DGHS
25. Dr Md Rizwanul Karim, Programme Manager, NCDC, DGHS
26. Dr MasudRexaKabir, PM, CBHC, DGHS
27. Dr Raihan e Zannat, PM, NCDC, DGHS
28. Dr Abdul Alim, DPM 1, NCDC, DGHS
29. Mr Md Abdul Aziz, Deputy Chief AD & Training, Bureau of Health Education, DGHS
30. Dr. Abdul Khair, AD PHC, DGHS
31. Md. Rafiqul Hyder, AD PHC, DGHS
32. Dr Shahnewaz Parvez, DPM, NCDC, DGHS
33. Dr Md Rajib Al Amin, DPM-5, NCDC, DGHS
34. Dr Sarowar Uddin Milon, DPM-6, NCDC, DGHS
35. Dr SM Mustafizur Rahman, DPM, NCDC, DGHS
36. Dr Maruf Ahmed Khan, DPM-3, NCDC, DGHS
37. Ms Esrat Alam, CSLT, JPUF, MoSW
38. Dr Md Ehsanul Karim Civil Surgeon, Dhaka
39. Dr Md Khurshid Alam, Civil Surgeon, Manikganj
40. Dr ANM Ehtesham Kabir, FP, NBCH Cell, NNHP & IMCI, DGHS
41. Mr Sk. Md. Faisal Hossain, Capacity Building Officer, CDD
42. Mr Nasirul Islam, CRP, Vice Principal, President, Bangladesh Physiotherapy Association (BPA)
43. Mr Md. Habibur Rahman, Assistant Professor, BHPF
44. Dr Abu Faisal Md. Ariful Islam
45. Ms Hasina Mamtaz, NC-Mental Health, WHO
46. Ms. Mahmuda Alim, Sightsavers
47. Mr Shafiqul Islam, Handicap International, Bangladesh
48. Mr Shafiqul Islam, Asst. Coordinator, CDD
49. Mr Md Musherraf Hossain Mazumder, Advocate, Appellate Division, Bangladesh Supreme Court
50. Mr Debesh Das, Assistant Director, DRRA
51. Mr. Julker Nayan, Asst. Prof. & Head of OT, CRP; President, BOTA
52. Dr Md. Shahidul Islam, BRAC
53. Dr SM Shahidullah, Kumudini Hospital
54. Dr. Chowdhury Rehnuma Tabassum, MO,IPNA, BSMMU
55. Ms Rifat Shahpar Khan, Creative Pathways
56. Ms Farida Yesmin, Executive Director, DRRA
57. Dr Tara KeSawar, World Health Organization (WHO)
58. Ms. Yukee Yosh, JICA
59. Mr. Asim Dio, CBM, Dhaka
60. Dr. Saidur Rahman Mashreky, CIPRB
61. Ms Sharmin Hasnat, Sr SLT & acting Head, SLT, CRP, Savar
62. Mr. Md. Sazzad Hossain, CRP & SSLT
63. Ms. Uzzala Banik, Joint Secretary, BVIPS
64. Mr Kazi Md. Arman Hossain, Press Secretary, BPA
65. Mr Fida Al-Shams, Founder Member, SSLT
66. Ms Forida Yesmin, Psychologist, SWID Bangladesh
65. Mr Rofiqul Islam, SPO, Sightesavers
66. Mr Mohammad Alauddin, Director of Program, Orbis International
67. Dr Khairul Al-Mamun, DRRA
68. Dr Ajanta Rani Saha, Joint Secretary, SWID Bangladesh
69. Ms Nusrat Jahan Sonia, In-Charge, Dept.of Physiotherapy, CRP-Mirpur
70. Mr Sazzad Kabir, Development Manager, CDD
71. Dr. Kamran al Baset, CIPRB
72. Mahmudul Hassan, Assistant Director, SWID
73. Ms Hasiba Hasan Joya, SDSL
74. Nahidul Islam, Ass. Coordinator, PNSP
75. Mr Hiren Pandit, Manager, Adovacay and Networking, DRRA
76. Mr Jamal Uddin, DRRA
77. Ms Swapna Reza, Head of Advocacy, MSS Ms. Israt Laila, PO, ADD International
78. Ms Moon Moon Hossain, Partnership Analyst, BRAC
79. Ms Rehana Akhter, SAHIC
80. Ms Nayan Sultana, HiCARE
81. Sabrina Sultana, President, B-SCAN
82. Ms Sultana Razia, In-Charge & Sr Paediatric Occupational Therapist, CRP
83. Nazmun Nahar, ADD International
84. Ms. Zakia Haque, Creative Pathways
85. Ms Monju Ara Khatun, Creative Pathways
86. Ms, Sanjida Islam, Creative Pathways
87. Dr. Ashequr Rahman, The Dental Office
88. Ms Jabunnahar Begum Panna, Principal, Kallyani School, BPF
89. Mr. Karuna Kishore Chakraborty, Manager, DRRA
90. Ms Razia Sultana, Project Coordinator OT-DC-MH,CRP, Ganakbari
91. Md. Arab Ali Sarker, SAHIC
92. Md. Goalm Mostafa, project Manager, HI
93. Mr Golam Kibria, OT, DRRA
94. Ms Shahnaz Sultana, Asst Head of Programme, CRP
95. Ms Zulekha Begum, HiCARE
96. Mr Syed Shakawat Hossain, OT, Manikganj, DRRA
97. Mr Sk Khaliduzzaman, Project Coordinator, DRRA
98. Mr Md Abul Hossain, DRRA, Satkhira
100. Mr SubimolBarua, DRRA, Chattagram
101. Ms Lipika Mondol, Satkhira
102. Mr Khalid Hassan Munna, Volunteer, DRRA
103. Ms Shahnaz Parvin, DRRA
104. Mr Syed Mahbubul Alam
105. Mr Mohhammad Hassan Rahman
106. Mr Sayeduzzaman
107. Mr Md. Nizam Uddin
108. Ms Khadiza Howlader
109. Mr Juboraj Faisal Nagorik, News Room editor
110. Mr Ariful Islam, Independent, Narshingdi

REFERENCES

[1]WHO| World Report on Disability 2011; World Health Organization and the World Bank; (www.who.int/disabilities/world_report/2011/report.pdf)
[2]BBS, Household Income and Expenditure Survey (HIES) of Bangladesh (2010), Bangladesh Bureau of Statistics, Ministry of Planning
[3]Nossal Institute for Global Health, Centre for Eye Research Australia and ICDDR'B| Rapid Assessment of Disability; in 2010; https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-015-2202-7, cited in May 2018.
[4]Population estimates as of Sunday, June 10, 2018, based on the latest United Nations estimates; http://www.worldometers.info/world-population/bangladesh-population/, cited on June 11, 2018.
[5]BDHS, UNIGCME –UN Inter-agency-group for Child Mortality estimation, 2013; UN Inter Agency Group for Child Mortality Estimation–Report'17
[6]UNICEF| Situation Analysis on Children with Disabilities in BANGLADESH 2014, UNICEF
[7]UNCRPD, Article-25 Health, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-25-health.html, cited on April 2, 2018
[8]Rights and Protection of Persons with Disabilities Act,2013
[9]IDDC, UN, IDA| Disability Indicators SDG Advocacy Toolkit, https://www.iddcconsortium.net/sites/default/files/resources-tools/files/disability_indicators_advocacy_toolkit.pdf, cited on July 1, 2018
[10]Health Information Systems Programme (HISP); http://www.mn.uio.no/ifi/english/research/networks/hisp/, cited in May 2018.
[11]United Nations Convention on the Rights of Persons with Disability (UNCRPD)
[12]WHO, Towards a Common Language for Functioning, Disability and Health ICF, 2002, www.who.int/classifications/icf/icfbeginnersguide.pdf and International Classification of Functioning, Disability and Health (ICF), www.who.int.Classifications; cited on April 10, 2018.
[13]Understanding and Interpreting Disability as Measured using the WG Short Set of Questions; Washington Group on Disability Statistics (WG), April 20, 2009; https://www.cdc.gov/nchs/data/washington_group/meeting8/interpreting_disability.pdf, cited in May 2018.
[14] Cerebral Palsy Alliance, https://www.cerebralpalsy.org.au/about-conditions/cerebral-palsy/, cited on June 7, 2018; and http://rm-healthy.com/10-signs-cerebral-palsy/10/, cited in May - June 2018
[15]Cerebral Palsy; https://healthand.com/au/topic/general-report/cerebral-palsy, cited on May 30, 2018
[16]Centre for Disease Control & Prevention– CDC,https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html, cited on May 29, 2018
[17]CDC page on CP, https://www.cdc.gov/ncbddd/cp/data.html, cited on May 29, 2018
[18]What is Cerebral palsy?, Cerebral palsy alliance; https://www.cerebralpalsy.org.au/about-conditions/cerebral-palsy/ cited on May 29, 2018
[19]https://www.cdc.gov/ncbddd/cp/facts.html, cited on May 29, 2018
[20]Khandaker et al. BMC Neurology (2015), Bangladesh Cerebral Palsy Register (BCPR): a pilot study to develop a national cerebral palsy (CP) register with surveillance of children for CP, https://link.springer.com/content/pdf/10.1186%2Fs12883-015-0427-9.pdf, cited on May 29, 2018
[21]Early Intervention and the Importance of Early Identification of Cerebral Palsy, https://www.physio-pedia.com/Early_Intervention_and_the_Importance_of_Early_Identification_of_Cerebral_Palsy, cited on June 11, 2018; Mainstreaming health service gap and availability study 2015 by DRRA & CBM; Health surveillance tools of Ministry of Social Welfare (MoSW)
[22]Centre for Disease Control & Prevention; https://www.cdc.gov/ncbddd/cp/diagnosis.html; and Screening and Diagnosis_Cerebral Palsy_NCBDDD_CDC-https://www.cdc.gov/ncbddd/cp/diagnosis.html, cited on May 29, 2018.
[23]Cerebral Palsy Alliance; https://research.cerebralpalsy.org.au/what-is-cerebral-palsy/how-cerebral-palsy-affects-people/, cited in May - June 2018
[24]BPF, Rapid Neurodevelopmental Assessment of Children (RNDA), 2nd Edition 2016
[25]Deafness and hearing loss, Fact sheet (Updated March 2018); http://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss, (updated March 15, 2018) cited on April 15, 2018
[26]Australian Deafblind Council (ADBC) 2004, cited on June 11, 2018 & https://www.sense.org.uk/get-support/information-and-advice/conditions/deafblindness/, cited on July 1, 2018
[27]Grades of hearing impairment, http://www.who.int/pbd/deafness/hearing_impairment_grades/en/, cited on April 15, 2018
[28]WHO/SEARO/Country Office for Bangladesh and Ministry of Health and Family Welfare (BSMMU); National Survey on Prevalence of Hearing Impairment in Bangladesh 2013; http://www.searo.who.int/bangladesh/publications/national_survey/en/, cited on May 25, 2018
[29]ibid
[30]https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html, cited on May 29, 2018
[31]Millions of people in the world have hearing loss that can be treated or prevented, http://www.who.int/pbd/deafness/news/Millionslivewithhearingloss.pdf
[32]WHO| Mortality and Burden of Diseases and Prevention of Blindness and Deafness, 2012, page 2, cited on May 28, 2018. http://www.who.int/pbd/deafness/WHO_GE_HL.pdf and WHO global estimates on prevalence of hearing loss (2012), http://www.who.int/pbd/deafness/WHO_GE_HL.pdf, cited in May and on June 11, 2018.
[33]Peggy Malloy, Kathleen Stremel Thomas, Mark Schalock, Steven Davies, Barbara Purvis, Tom Udell, June 2009, http://documents.nationaldb.org/products/EI-deaf-blind-infants.pdf, cited on June 17, 2018 and http://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss, cited on May 7, 2018
[34]http://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss, cited on May 7, 2018
[35]BPF, RNDA, Second Edition 2016, p.g. 30
[36]ibid
[37]Ibid
[38]American Psychiatric Association, 2013; p.33; and American Association on Intellectual and Developmental Disability; https://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability#.Wss1mS5ubIU; and Schalock et al., 2010, p.1; American Psychiatric Association, 2000), cited on May 29, 2018
[39]American Psychiatric Association, 2013; Schalock et al., 2010; Tassé & Grover, 2013; American Psychiatric Association, 2013; Schalock et al., 2010; and American Association on Intellectual & Developmental Disabilities, https://aaidd.org/intellectual-disability/definition#.Wx7_uO6FPIU; cited on May 29, 2018.
[40]What causes intellectual disability?, https://www.webmd.com/parenting/baby/intellectual-disability-mental-retardation#2-4, cited on June 11, 2018.
[41]WHO| ICD 10 Codes for Intellectual Disabilities, https://icd10coded.com/cm/ch5/F70-F79/, cited on 29/05/2018, and Healthy Place, https://ww-

w.healthyplace.com/neurodevelopmental-disorders/intellectual-disability/mild-moderate-severe-intellectual-disability-differences, cited in May 2018 and on June 11, 2018; and American Association on Mental Retardation (AAMR); http://www.onestops.info/article.php?article_id=54, cited on 29/05/2018.

[42]NICHCY Disability Fact Sheet #8 January 2011http://www.parentcenterhub.org/wp-content/uploads/repo_items/fs8.pdf, cited in April - May 2018.

[43]https://www.medicalhomeportal.org/diagnoses-and-conditions/intellectual-disability, cited on June 11, 2018.

[44]https://aaidd.org/intellectual-disability/definition#.Wx8LLu6FPIU, cited on May 27, 2018.

[45]CDC, https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html, cited on June 11, 2018.

[46]Ibid, American association on Intellectual and Developmental Disability,

[47]http://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability#.WwzmK-6FPIU, cited in May 2018

[48]Prevalence of intellectual disability: A meta-analysis of population-based studies, cited on May 27, 2018

[49]https://aaidd.org/news-policy/policy/position-statements/early-intervention#.Wx8jUe6FPIU, cited on June 11, 2018.

[50]Australian Institute of Health and Welfare; Disability and ageing: Australian population patterns and implications. Canberra, 2000.

[51]Equality treatment: closing the gap: a formal investigation into the physical health inequalities experiences by people with learning disabilities and/or mental health problems. London, Disability Rights Commission, 2006, http://www.oalib.com/references/10916206, cited June 11, 2018.

[52]http://www.who.int/disabilities/world_report/2011/chapter3.pdf, cited on June 6, 2018 and Hague G, Thaira RK, Magowan P. Disabled women and domestic violence: making the links. Bristol, Women's Aid Federation of England, 2007; 41. and McCarthy M. Sexuality and women with learning disabilities. London, Jessica Kingsley Publishers, 1999.

[53]Hydrocephalus-symptoms, https://www.nhs.uk/conditions/hydrocephalus/symptoms/cited on May 29, 2018.

[54]ibid

[55]Microcephaly, http://www.who.int/news-room/fact-sheets/detail/microcephaly, cited on May 29, 2018.

[56]https://www.nhs.uk/conditions/downs-syndrome/characteristics/, cited on May 29, 2018.

[57]Ibid

[58]https://cme.ucsd.edu/ddhealth/courses/earlyidentification.html, cited on June 11, 2018.

[59]National Mental Health Survey in 2003-2005, Bangladesh.

[60]World Health Organization. The world health report 2002: reducing risks, promoting healthy life. Geneva: World Health Organization; 2002. Available from http://www.who.int/whr/2002 and WHO International Consortium in Psychiatric Epidemiology. Cross- national comparisons of the prevalences and correlates of mental disorders. Bulletin of the World Health Organization 2000; 78:413-25, cited in May – June 2018.

[61]The treatment gap in mental health care, www.who.int/bulletin/volumes/82/11/en/858.pdf, cited in May 2018.

[62]American Journal of Psychiatry and Neuroscience, Volume 3, Issue 4, July 2015, Pages: 57-62, http://article.sciencepublishinggroup.com/html/10.11648.j.ajpn.20150304.11.html, cited in May 2018

[63]http://www.thomsoncdc.com/our-services/psychology/importance-early-detection-mental-health-issues/, cited on June 11, 2018.

[64]Anwar Islam, Tuhin Biswas. Mental Health and the Health System in Bangladesh: Situation Analysis of a Neglected Domain. American Journal of Psychiatry and Neuroscience. Vol. 3, No. 4, 2015, pp. 57-62. doi: 10.11648/j.ajpn.20150304.11.

[65]WHO-AIMS Report on Mental Health System in Bangladesh, 2007, WHO and MoHFW; www.who.int/mental_health/bangladesh_who_aims_report.pdf

[66]Mohammad, Helal Uddin Ahmed, Waziul Alam Chowdhury,Louis Wilhelmus Niessen, and Dewan Shamsul Alam; Mental disorders in Bangladesh: a systematic review; https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4149198

[67]Mental disorders, Fact sheet, Updated April 2018, http://www.who.int/mediacentre/factsheets/fs396/en, cited on May 28, 2018.

[68]https://anzmh.asn.au/conference/pp/Woodward.pdf, cited on June 11, 2018.

[69]ibid

[70]International Statistical Classification of Diseases and Related Health Problems 10th Revision, apps.who.int/classifications/icd10/browse/2016/en and pps.who.int/classifications/icd10/browse/2016/en#/V, cited in April 2018.

[71]ibid

[72]HANDICAPS WELFARE ASSOCIATION; http://hwa.org.sg/news/general-information-on-physical-disabilities/,cited in June 2018.

[73]Disabledtravellers.com, http://www.executiveclasstravelers.com/1/types-of-disabilities.htm, cited-May28, 2018.

[74]ibid

[75]Fact Sheet on Spinal Cord Injury, http://www.who.int/en/news-room/fact-sheets/detail/spinal-cord-injury, cited on May 29, 2018.

[76]https://www.ncbi.nlm.nih.gov/pubmed/8171101, cited on July 1, 2018.

[77]https://www.webmd.com/back-pain/news/20140325/low-back-pain-leading-cause-of-disability-worldwide-study#1, cited on July 1, 2018.

[78]https://orthoinfo.aaos.org/en/diseases--conditions/clubfoot/, cited on July 1, 2018.

[79]https://www.healthline.com/health/arthritis-disability, cited on July 1, 2018.

[80]Chapter four, The World Report, http://www.who.int/disabilities/world_report/2011/chapter4.pdf, cited on April - May 2018.

[81]The World Report, 2011, cited on April - May 2018

[82]European medical group, https://www.europeanmedical-group.com/omnipresent/preventing-disabilities-in-children-caused-by-leprosy/ and Understanding the community impact of lymphatic filariasis: a review of the sociocultural literature, http://www.who.int/bulletin/volumes/85/6/06-031047/en/, and Early Intervention And Treatment Immensely Benefits Muscular Dystrophy, https://www.medindia.net/news/Early-Intervention-And-Treatment-Immensely-Benefits-Muscular-Dystrophy-53178-1.htm, cited on June 11, 2018.

[83]WHO, Disability and health, Fact sheet, Reviewed January 2018; http://www.who.int/mediacentre/factsheets/fs352/en/, cited in May 2018.

[84]Birth defects, Facts about Cleft Lip and Cleft Palate, https://www.cdc.gov/ncbddd/birthdefects/cleftlip.html, cited on June 11, 2018.

[85]Vision Aware; http://www.visionaware.org/info/your-eye-condition/eye-health/low-vision/low-vision-terms-and-descriptions/1235, cited May 28, 2018.

[86]ibid

[87]https://medical-dictionary.thefreedictionary.com/Visual+Impairment

[88]Vision Aware, The Low Vision Examination, http://www.visionaware.org/info/your-eye-condition/-

eye-health/low-vision/low-vision-examination/1235, cited May 28, 2018.
[89]Blindness & Vision impairment; Key Facts (Updated October 11, 2017); http://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment, cited in Apr.2018.
[90]Vision impairment and blindness; Fact Sheet (Updated October 2017); http://www.who.int/mediacentre/factsheets/fs282/en/, cited on April 27, 2018.
[91]http://atlas.iapb.org/global-burden-vision-impairment/, cited on April 27, 2018.
[92]A. S. M. Nawshad Uddin Ahmed,a,b Humaira Muslima,c Kazi Shabbir Anwar,d Naila Z. Khan,c M. A. K. Azad Chowdhury,a Samir K. Saha,e and Gary L. Darmstadt. Retinopathy of Prematurity in Bangladeshi Neonates; and Charan R, Dogra MR, Gupta A, et al. The incidence of retinopathy of prematurity in a neonatal care unit. Indian J Ophthalmol 1995;43:123–6. 28. Aggarwal R, Agarwal R, Deorari AK, et al. Retinopathy of prematurity. Indian J Pediatr 2002; 69:83–6. 29. Varughese S, Jain S, Gupta N, et al. Magnitude of the problem of retinopathy of prematurity. Experience in a large maternity unit with a medium size level-3 nursery. Indian J Ophthalmol 2001;49:187–8.
[93]Pediatric cataract: challenges and future directions, by Anagha Medsinge and Ken K Nischal, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4293928/ cited on June 12, 2018.
[94]Revathy Rugmini, Regional Representative Asia, Leonard Cheshire Disability and Abdus Salam, Chief Executive, Gana Unnayan Kendra. Inclusive Education in Bangladesh: a policy brief
[95]Making Eye Health a Population Health Imperative: Vision for Tomorrow; https://www.ncbi.nlm.nih.gov/books/NBK402367/, cited on May 29, 2018.
[96]van der Aa HPA, van Rens GHMB, Comijs HC, Margrain TH, Gallindo-Garre F, Twisk JWR, et al. Stepped care for depression and anxiety in visually impaired older adults: multicentre randomized controlled trial. Bmj. 2015:h6127-h; WHO World report on vision 'DRAFT FOR CONSULTATION' cited in May 2018.
[97]Swenor KS LM, Varadaraj V, Ramulu PY. Ageing with visual impairment: The value of vision function and the impact on quality of life of older people. 2017, and WHO World report on vision 'DRAFT FOR CONSULTATION' cited in May 2018.
[98]Owsley C, Stalvey BT, Wells J, Sloane ME, McGwin G, Jr. Visual risk factors for crash involvement in older drivers with cataract. Arch Ophthalmol. 2001;119(6):881-7, and Visual risk factors for crash involvement in older drivers with cataract. Arch Ophthalmol. 2001;119(6):881-7) and WHO World report on vision 'DRAFT FOR CONSULTATION' cited in May 2018.
[99]Visual Impairment: Its Effect on Cognitive Development and Behaviour, http://www.intellectualdisability.info/physical-health/articles/visual-impairment-its-effect-on-cognitive-development-and-behaviour, cited in May 2018.
[100]Kuper, H., et. al. "Does Cataract Surgery Alleviate Poverty? Evidence from a Multi-Centre Intervention Study Conducted in Kenya, the Philippines and Bangladesh." PloS Medicine. 5.11 (2010); Unite for Sight http://www.uniteforsight.org/community-eye-health-course/module1
[101]Module 12: Poverty and Blindness, Unite for Sight, http://www.uniteforsight.org/community-eye-health-course/module13, cited in May 2018.
[102]Socio economic aspects of blindness and visual impairment, http://www.who.int/blindness/economy/en/, cited on June 11, 2018.
[103]The Underlying Principles of Ethical Patient Care http://thepafp.org/website/wp-content/uploads/2017/05/Principles-of-Ethical-Patient-care-2008.pdf and https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4276576/, cited in April - May 2018
[104]https://www.nwabr.org/sites/default/files/Principles.pdf, and Abide by the Declaration of Helsinki World Medical Association Declaration of Helsinki Ethical Principles for Medical Research Involving Human cited in Apr.-May 2018
[105]University of Washington School of Medicine; Ethics in Medicine; https://depts.washington.edu/bioethx/topics/confiden.html and http://www.med.cmu.ac.th/secret/meded/AOMJAI/web_module%2010/Ethics%20in%20Medicine.pdf, cited in Apr.- May 2018
[106]http://www.personcare.net/dos-and-donts-of-disability-etiquette, cited in May 28, 2018; and https://physiotherapy.ca/cpa-code-ethics and APTA, Code of Ethics for the Physical Therapist, www.apta.org/uploadedFiles/APTAorg/About_Us/Policies/HOD/Ethics/CodeofEthics.pdf, cited-Jun.11,2018.

PHOTO CREDIT:

- DRRA
- SIGHTSAVERS/Kiron
- CSID/Rifat Shahpar Khan
- Rifat Shahpar Khan
- DRRA
- DRRA
- Rifat Shahpar Khan
- SIGHTSAVERS