NATIONAL CLINICAL GUIDELINES

THE EARLY IDENTIFICATION, DIAGNOSIS, MANAGEMENT, AND PREVENTION OF CHILDHOOD DISABILITIES

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المبادئ الإرشادية السريرية لدولة قطر
NATIONAL CLINICAL GUIDELINES FOR QATAR

وزارة الصحـــــة العامـــــة
Ministry of Public Health
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Abbreviations

The abbreviations used in this guideline are as follows:

AABR	Automated Auditory Brainstem Response
ADHD	Attention Deficit Hyperactivity Disorder
AIMS	The Alberta Infant Motor Scale
ANSD	Auditory Neuropathy Spectrum Disorder
ASD	Autism Spectrum Disorder
ASQ	Ages and Stages Questionnaire
BAHA	Bone Anchored Hearing Aid
BICROS	Bilateral Contralateral Routing of the Signal
BMI	Body Mass Index
BTE	Behind-The-Ear
CA-PHAB	Children's Abbreviated Profile of Hearing Aid Benefit
COSI-C	Client Oriented Scale of Improvement for Children
CROS	Contralateral Routing of the Signal
CT	Computed Tomography
CMV	Cytomegalovirus
cCMV	Congenital Cytomegalovirus
DLD	Developmental Language Disorder
DSL	Desired Sensation Level
ECG	Electrocardiogram

EEG	Electroencephalogram
EMG	Electromyography
ERG	Electroretinogram
GAD	Generalised Anxiety Disorder
GDD	Global Developmental Delay
GMA	General Movement Assessment
IDD	Intellectual and Developmental Disabilities
IQ	Intelligence Quotient
IT-MAIS	Infant-Toddler Meaningful Auditory Integration Scale
M-CHAT	Modified Checklist for Autism in Toddlers
MRI	Magnetic Resonance Imaging
MRSA	Methicillin-Resistant *Staphylococcus aureus*
NAL	National Acoustic Laboratories
NAL-NL2	NAL Nonlinear Fitting Procedure, Version 2
NICU	Neonatal Intensive Care Unit
NPEDHL	The Qatar National Programme for Early Detection of Hearing Loss
OAE	Otoacoustic Emission
OCD	Obsessive Compulsive Disorder
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
PHCC	Primary Health Care Corporation
PRL	Preferred Retinal Loci
PTA	Pure Tone Average
REAR	Real-Ear Aided Response
RECD	Real Ear to Coupler Difference
SOGS	Schedule of Growing Skills
TORCH	Toxoplasmosis, Other, Rubella, Cytomegalovirus, and Herpes Infections
UML	Unified Modelling Language
UTI	Urinary Tract Infection
VEMP	The Vestibular Evoked Myogenic Potential
VEP	Visual Evoked Potential
vHIT	The Video Head Impulse Test

View Pathway

Table of Contents

View Pathway

1 Information about this Guideline

1.1 Objective and Purpose of the Guideline

The purpose of this guideline is to provide a framework for early detection, investigation, diagnosis, and prevention of disabilities in children from birth to 18 years of age. The objective is to guide the appropriate management of patients presenting to provider organisations in Qatar. It is intended that the guideline will be used by all healthcare professionals in provider settings that manage children.

1.2 Scope of the Guideline

This guideline covers the following aspects of care:

- Prevention of, and screening for, disabilities in early childhood.
- Assessment, diagnosis, and referral of children with impairments in vision, hearing, intellectual ability, physical ability, and mental health.
- Principles of Specialist Management.

1.3 Editorial Approach

This guideline document has been developed and issued by the Ministry of Public Health of Qatar (MOPH), through a process which aligns with international best practice in guideline development and localisation. The guideline will be reviewed on a regular basis and updated to incorporate comments and feedback from stakeholders across Qatar.

The editorial methodology, used to develop this guideline, has involved the following critical steps:

- Extensive literature search for well-reputed, published evidence relating to the topic.
- Critical appraisal of the literature.
- Development of a draft summary guideline.
- Review of the summary guideline with a Guideline Development Group, comprised of practising healthcare professionals, subject matter experts and patient representatives, from across Qatar.
- Independent review of the guideline by the National Clinical Guidelines & Pathways Committee, appointed by the MOPH, from amongst stakeholder organisations across Qatar.

Whilst the MOPH has sponsored the development of the guideline, the MOPH has not influenced the specific recommendations made within it.

1.4 Sources of Evidence

The professional literature published in the English language has been systematically queried using specially developed, customised, and tested search strings. Search strategies are developed to allow efficient yet comprehensive analysis of relevant publications for a given topic and to maximise retrieval of articles with certain desired characteristics pertinent to a guideline.

For each guideline, all retrieved publications have been individually reviewed by a clinical editor and assessed in terms of quality, utility, and relevance. Preference is given to publications that:

1. Are designed with rigorous scientific methodology.
2. Are published in higher-quality journals.
3. Address an aspect of specific importance to the guideline in question.

Further information about the literature search and appraisal process is included in the appendix.

1.5 Evidence Grading and Recommendations

Recommendations made within this guideline are supported by evidence from the medical literature and where possible the most authoritative sources have been used in the development of this guideline. In order to provide insight into the evidence basis for each recommendation, the following evidence hierarchy has been used to grade the level of authoritativeness of the evidence used, where recommendations have been made within this guideline.

Where the recommendations of international guidelines have been adopted, the evidence grading is assigned to the underlying evidence used by the international guideline. Where more than one source has been cited, the evidence grading relates to the highest level of evidence cited:

- **Level 1 (L1):**
  - Meta-analyses.
  - Randomised controlled trials with meta-analysis.
  - Randomised controlled trials.
  - Systematic reviews.

- **Level 2 (L2):**
  - Observational studies, examples include:
    - Cohort studies with statistical adjustment for potential confounders.
    - Cohort studies without adjustment.
    - Case series with historical or literature controls.
    - Uncontrolled case series.
  - Statements in published articles or textbooks.

- **Level 3 (L3):**
  - Expert opinion.
  - Unpublished data, examples include:
    - Large database analyses.
    - Written protocols or outcomes reports from large practices.

In order to give additional insight into the reasoning underlying certain recommendations and the strength of recommendation, the following recommendation grading has been used, where recommendations are made:

- **Recommendation Grade A (RGA):** Evidence demonstrates at least moderate certainty of at least moderate net benefit.
- **Recommendation Grade B (RGB):** Evidence is insufficient, conflicting, or poor and demonstrates an incomplete assessment of net benefit vs harm; additional research is recommended.
- **Recommendation Grade C (RGC):** Evidence demonstrates potential harm that outweighs benefit; additional research is recommended.
- **Recommendation of the GDG (R-GDG):** Recommended best practice based on the clinical experience of the Guideline Development Group members.

1.6 Guideline Development Group members

The following table lists members of the Guideline Development Group (GDG) nominated by their respective organisations and the Clinical Governance Group. The GDG members have reviewed and provided feedback on the draft guideline relating to the topic. Each member has completed a declaration of conflicts of interest, which has been reviewed and retained by the MOPH.

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Ms Eman Yousef A A Al-Mulla	Chief of Speech Therapy Department	Hamad Medical Corporation
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Guideline Development Group Members		
Name	**Title**	**Organisation**
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1.7 National Clinical Guidelines & Pathways Committee members

The following table lists members of the National Clinical Guidelines & Pathways Committee (NCGPC), appointed by the MOPH. The NCGPC members have reviewed and provided their feedback and approval of the guideline document. Each member has completed a declaration of conflicts of interest, which has been reviewed and retained by the MOPH.

National Clinical Guidelines & Pathways Committee (NCGPC) Members		
Name	**Title**	**Organisation**
Ms Huda Amer Al-Katheeri	Chair of the NCGPC, Director of Strategic Planning & Performance Department	Ministry of Public Health
Shk Dr Mohammed Hamad J. Al Thani	Co-Chair of the NCGPC, Director of Public Health	Ministry of Public Health
Dr Hani Ben Hassen Al Kilani	Senior Consultant, Executive Director for Corporate Clinical Policy and Guidelines	Hamad Medical Corporation
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Dr Ghassan Youseph Hommos	Senior Consultant Endocrinology	Al Emadi Hospital
Dr Egon Toft	VP and Dean	College of Medicine, Qatar University

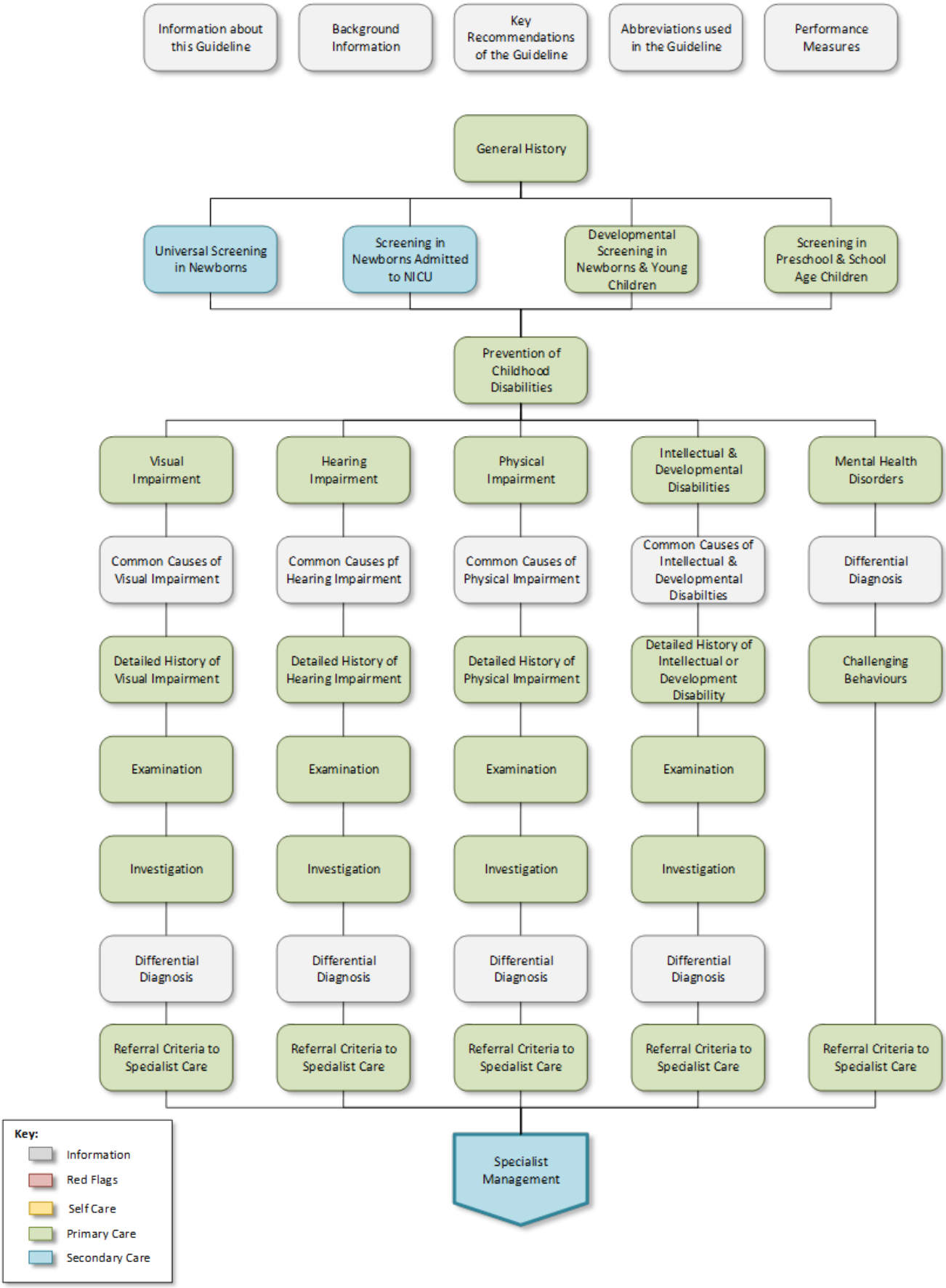
1.8 Responsibilities of Healthcare Professionals

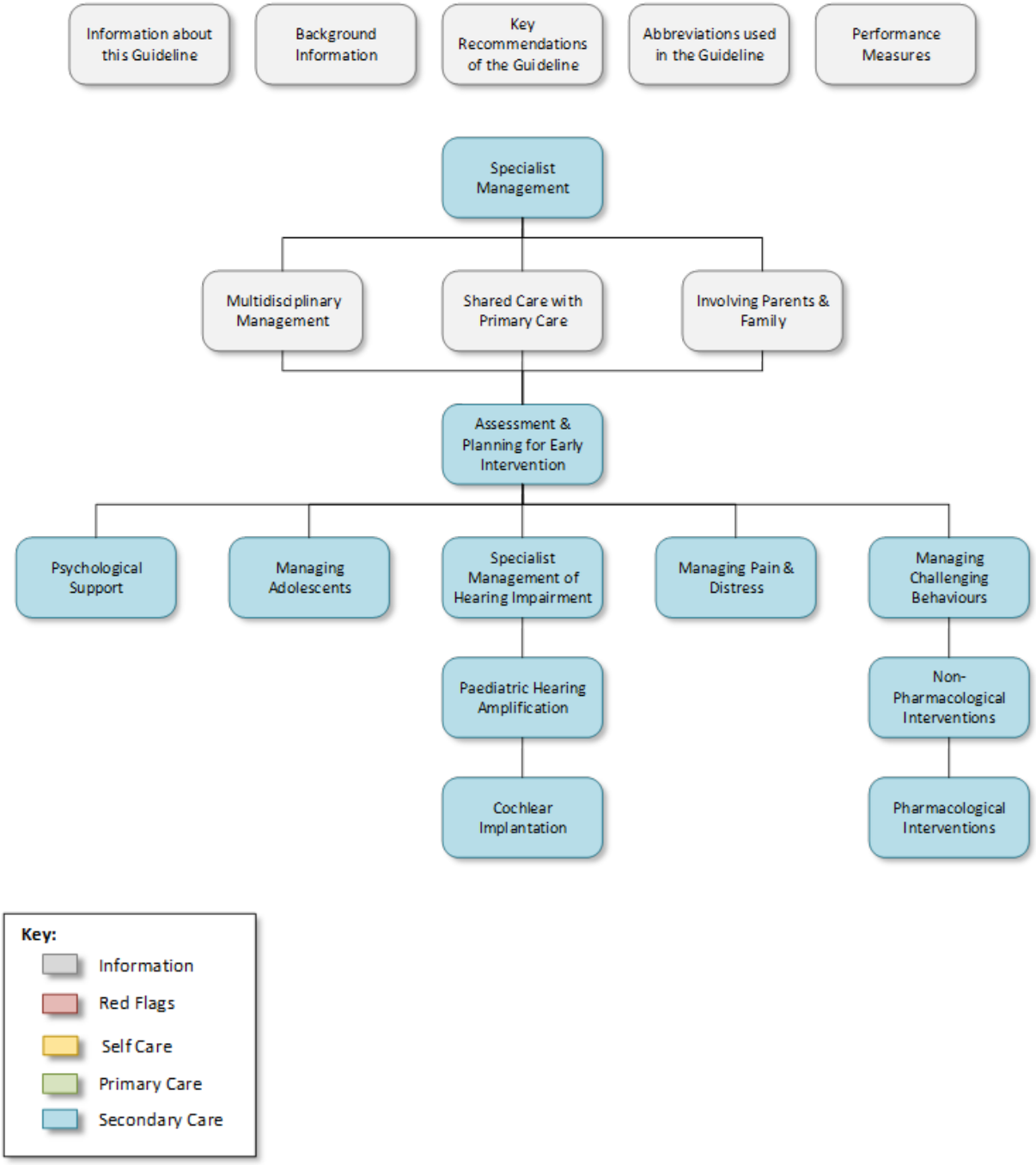
This guideline has been issued by the MOPH to define how care should be provided in Qatar. It is based upon a comprehensive assessment of the evidence as well as its applicability to the national context of Qatar. Healthcare professionals are expected to take this guidance into account when exercising their clinical judgement in the care of patients presenting to them.

The guidance does not override individual professional responsibility to take decisions which are appropriate to the circumstances of the patient concerned. Such decisions should be made in consultation with the patient, their guardians, or carers and should consider the individual risks and benefits of any intervention that is contemplated in the patient's care.

2 Early Identification, Diagnosis & Management Pathway

Click on a box below to see the relevant page of the Pathway.




Information about this Guideline
Background Information
Key Recommendations of the Guideline
Abbreviations used in the Guideline
Performance Measures
Specialist Management
Multidisciplinary Management
Shared Care with Primary Care
Involving Parents & Family
Assessment & Planning for Early Intervention
Psychological Support
Managing Adolescents
Specialist Management of Hearing Impairment
Managing Pain & Distress
Managing Challenging Behaviours
Paediatric Hearing Amplification
Non-Pharmacological Interventions
Cochlear Implantation
Pharmacological Interventions
Key:
Information
Red Flags
Self Care
Primary Care
Secondary Care

3 Key Recommendations of the Guideline

The key recommendations of this guideline are:

General History (*Section 5*):

- A detailed history should be obtained from[1–6] [**L1**]:
    - The child (if they are able).
    - Parent or caregiver.
    - Teachers.
    - Other health care providers (e.g. therapists, rehabilitation counsellors).
    - Other persons who might provide information helpful.
- A detailed health history of the impairment should be collected in addition to the general history.

Screening for Early Disabilities (*Section 6*):

- All infants should undergo universal screening in the first days of life, before discharge from the hospital after birth[7,8].
- The standard Well-Baby Services Package in Primary Health Care Corporation includes screening checks and developmental surveillance/assessment at 2, 4, 6, 9, 12, 18, 30 months and preschool age (4 years)[9]:
    - If the child passes the screening tests:
        - The child should be discharged with parental education to report if the child develops any warning signs.
    - If a developmental problem is suspected:
        - Refer to the corresponding section of this guideline for appropriate assessment.
        - Consider referral to a specialist assessment.
- All newborns admitted to NICU with gestational age less than 32 weeks and birth weight less than 1500 g must be screened for *Retinopathy of Prematurity* through fundus examination with a well-dilated pupil [**R-GDG**].
- All newborns admitted to NICU for more than 48 hours must undergo the first stage of screening for hearing loss prior to discharge [**R-GDG**]. Screening should take place as close to discharge as possible.
- Every newborn should be screened for hearing loss maximum by 3 months and provided rehabilitation or enrolment in early intervention by 6 months of age[10].
- All children should undergo a vision and hearing test at or around the time of school entry[11].
- Developmental milestones in children with impairments should be evaluated across various domains[9,12]. Failure to achieve certain milestones by the requisite age, is a developmental warning sign or red flag.
- Consider screening for cerebral palsy using the *General Movement Assessment* (GMA) based on criteria in *Section 6.3*.
- Screening for Autism Spectrum Disorder is covered in the NCG on The Diagnosis and Management of Autism Spectrum Disorder by MOPH[13].

Visual Impairment (*Section 7*):

- There are many various causes of visual impairment and blindness[14–17].
- A detailed health history of the impairment is required.
- Visual and hearing impairments are often associated with one another[1].
- A full ophthalmological examination may require more than one visit or one visit with many short breaks as children may tire easily[5].
    - The basic examination should include[2] [**L1, RGA**]:
        - Clinical examination of the craniofacial region, including eyes and skull.
        - Confirmation of visual developmental milestones.

        - Qualitative and quantitative vision testing[5,17].
    - Additional examinations may be required[18].
- Further investigations should be considered accordingly to the findings of initial assessment and examination. These may include:
    - Magnetic resonance imaging (MRI) or computed tomography (CT) scans[5].
    - Visual evoked potentials (VEP) and retinal dystrophy electroretinogram (ERG)[17] [**L2**].
    - Genetic testing[16] [**L2**].
- Refer the child to an ophthalmologist, if at least one of the following is present[3,9,19] [**L1, RGA**]:
    - Structural abnormalities of the eye.
    - Abnormal pupillary reflex (white or asymmetric).
    - Abnormal red reflex.
    - Asymmetric corneal light reflex.
    - No response to bright light.
    - Nystagmus.
    - Monocular visual acuity is ≤6/9 at age 3-6 years.
    - Substantial difference in acuity between the eyes.
    - Key visual developmental milestones are not achieved.
    - Regression in visual milestones is observed.
    - History of prematurity.
    - Family history of retinoblastoma, inherited eye disease, or developmental delay.
- Specialist Management of Hearing impairment comprises of [**R-GDG**]:
    - Medication.
    - Surgical intervention.
    - Hearing assistive devices.
    - Auditory-verbal therapy.

Hearing Impairment (*Section 8*):

- Common causes of early hearing impairments include[7,20–22]:
    - Genetic factors.
    - Acquired factors.
- Common causes of late-onset hearing impairment in children, include[7]:
    - CMV infection.
    - Genetic syndromes associated with progressive hearing loss.
    - Neurodegenerative disorders.
    - Trauma.
    - Bacterial meningitis in the neonatal period and thereafter.
- Detailed history and thorough examination are important for the correct diagnosis and management [22].
- An examination using appropriate equipment calibrated every 6 months, should be used[23] [**L1**]. The hearing examination should be conducted in a quiet environment[12] [**L1, RGA**].
    - It is not recommended to diagnose hearing loss in an infant through observation alone[21] [**L2,RGC**].
    - Screening approaches using unconditioned behavioral responses (e.g. eye shift after sound presentation, responding to hand clapping) are not recommended due to their low sensitivity[12] [**L1, RGC**].
- Children with increased risk of congenital hearing loss should be examined with both AABR and OAEs[7,24] [**L1, RGA**].
- Children in a low-risk category should be screened with OAE and AABR at 2 months of age with the first vaccination at the health center [**R-GDG**].
- Patients should be referred to a specialist and receive a full audiological assessment if at least one of the following is present[9,12,21,25]:
    - Confirmed hearing loss of any degree.

  - Failed auditory screening/testing.
  - Family history of congenital hearing loss.
  - Parental or caregiver concern about potential hearing loss.
  - Child identified as being high risk for hearing impairment.
  - History of recurrent or persistent otitis media with effusion with flat tympanogram for >3 months.
  - Confirmed middle ear dysfunction.
  - Regression or failure to achieve key speech-language developmental milestones.
  - Malignancy is suspected.
  - Surgical intervention is considered.
- Criteria and age limitations for paediatric hearing amplification (hearing amplification devices and cochlear implant) are listed in *Section 8.7*.

Physical Impairment (*Section 9*):

- There are various causes of physical impairments[19,26–34].
- A detailed health history of the impairment and physical examination are required.
- When diagnosis is not possible following the examination and clinical evaluation:
  - Consider investigations and laboratory testing.
    - GMA.
    - MRI (preferred over CT scans[31]).
    - CT scan (if MRI is not available or contraindicated).
    - Cranial ultrasound scan (in a young infant).
    - EEG[30,35].
  - If the diagnosis remains unclear, consider further investigations.
- Patients should be referred to a general paediatrician, if at least one of the following is present[9,19,36,37]:
  - Age < 14 years.
  - Delay or regression in motor milestones.
  - Failure to thrive.
  - Presence of non-physical impairments (e.g. hearing, visual or intellectual).
  - Clinical suspicion of physical impairment.
  - Parent, carer, or health care provider suspects a physical impairment.
- Patients should be referred to paediatric rehabilitation if they have a motor impairment that interferes with function[38].

Intellectual and Developmental Disabilities (*Section 10*):

- There are various causes of developmental disabilities[39,40].
- A detailed health history of the impairment onset during childhood is required.
- A detailed developmental history is required.
- The basic examination for intellectual and developmental impairments should include:
  - General physical examination.
  - Evaluation of intellectual and adaptive functioning through neuropsychological testing.
  - Evaluation of motor development skills.
  - Evaluation of communication skills[40].
  - Observation of general behaviour (e.g. oddities in behaviour, attention span, presence of drooling)[5,6].
  - Mental status examination.
- An appropriate standardised test of intellectual aptitude should be selected for children. Consider [41,42]:
  - The *Wechsler Preschool and Primary Scale of Intelligence, Third Edition* (age range 2 years 6 month-6 years old).

  - The *Wechsler Intelligence Scale for Children, Fourth Edition* (school children).
  - The *Wechsler Adult Intelligence Scale, Third Edition* (for adolescents ≥16 years old.)
  - *Stanford Binet Intelligence Scales, Fifth Edition* (age range 2 to 85+ years).
- Consider the following options if any of the above diagnoses are suspected or when neurological examination is abnormal[35,39,40]:
  - MRI (preferred over CT scans[4]).
  - CT scans.
  - If diagnosis is not clear, consider other tests according to the clinical presentation:
- Patients should be referred to a developmental paediatrician if at least one of the following is present[4,39,40]:
  - A genetic or metabolic disorder is suspected.
  - Diagnosis of GDD.
  - Delay in achieving developmental milestones.
  - Regression in milestones.
  - Identification of learning difficulties in school-age children.
  - Parental, carer, or health care provider suspects any kind of intellectual impairment.
  - Other impairments (hearing, visual or physical) are present.

Mental Health Disorders (*Section 11*):

- Appropriate screening for mental and behavioural problems should be performed in all patients with disabilities to evaluate and assess mental health disorders, challenging behaviours, suicidal thoughts and self-harm attempts, which are frequent in such patients[4,6,19,26,40,43].
- Patients should be referred to a specialist if at least one of the following is present[43–45]:
  - Repeated negative contents of play.
  - Signs of disinhibition.
  - Persistent exposure to harmful influences (e.g. neglect, traumatising environment).
  - Persistent negative mood for ≥2 weeks.
  - Persistent hyperkinetic behaviour.
  - Aggression.
  - Severe affective symptoms.
  - Suicidal thoughts or attempts.

Specialist Management (*Section 12*):

- Care to children with impairments, especially those with complex needs, should be provided by an MDT professional, using an interdisciplinary approach[1,2,19], which has been individualised to the needs of the patient. The management may require consultation with or referral for additional treatment, therapy, or rehabilitation[1,2,6,19].
- Accurate assessment is required to obtain useful and accurate information about a child's skills and functioning and about the surrounding environment. It is required to assist parents, health-care providers, and other individuals involved in providing care to the child to better understand, plan for and support the development and inclusion of the child with a disability [47].
- Children with impairments and/or disability frequently require an interdisciplinary assessment and care (see *Section 12.1*) [1,2,19], and the collaboration within and among Primary and Secondary Care settings as well as among professionals within one unit is crucial especially when treating children with complex care needs [48].
- Children with impairments are more likely to be bullied and experience abuse[40,49–51] and, therefore, require recognition of psychological problems and psychological support[19] [**L1, RGA**]:
  - Signs of abuse and neglects should always be recorded and assessed[47].
  - Symptoms of depression should not be overlooked in individuals with intellectual and language impairments when other behavioural problems are prominent[39].
  - Challenging behaviours should be managed[47] according to *Section 13.6* and the respective guidelines.

- Psychological interventions should be personalised. They should be developed, planned and implemented in collaboration with patients and their parents or caregivers[50] [**L1, RGA**].
- Assessing the presence and degree of pain, discomfort, distress, and sleep disturbances should be carried out at every visit[19] [**L1, RGA**].
- Parents or carers should be provided with clear and up-to-date information in simple language on an ongoing basis[6,19,39] [**L1, RGA**]. They may also require counselling and support on how to address the child's needs[47,52].
- A family assessment should be conducted to determine the resources, concerns, and priorities of the family [12].
- When required, parents or carers should be provided with an individualised parental skills training[40,44,53,54] [**L1, RGA**].

Managing Challenging Behaviour (*Section 12.6*):

- If challenging behaviours are present, the following treatment options may be considered[39,40,53] [**L1, RGA**]:
    - First-line: non-pharmacological management with behavioural therapy [39,40,53] [**L1, RGA**]:
        - Cognitive behavioural therapy.
        - Applied behavioural analysis.
        - Functional behavioural analysis.
        - Behavioural planning.
        - Other approaches.
    - Second-line: pharmacological management with psychotropic medications (see *Section 13.6.2*).
        - It should only be prescribed and monitored by a developmental paediatrician or psychiatrist working as part of an MDT [**R-GDG**] and in accordance with the respective guidelines.

Managing Adolescents (*Section 12.7*):

- Patients and their parents or carers should be provided with information about the following topics tailored to their individual needs[19,47,55–58]:
    - Menstruation, including:
        - Consequences of suppressing menarche.
        - Mood alterations.
        - Premenstrual behavioural changes.
        - Changes in symptoms (e.g. changes in the seizure pattern).
        - Heavy menses and pain management.
        - Assistance in managing menses.
    - Fertility and contraception.
    - Sex and sexuality.
    - Parenting.
    - Risks of sexual abuse and violence.
    - Protection measures and how to report abuse.

Prevention of Disabilities in Early Childhood (*Section 13*):

- Anticipatory guidance specific to the age of the patient should be provided at every well-child visit [**R-GDG**].
- Early identification and proper further management of these health conditions helps to prevent disability or reverse the damage caused by the impairment to some extent[6,18].
- The best available strategy to prevent disability in children is the avoidance of modifiable risk factors (i.e. family issues and environmental control), including but not limiting to:

  - Dietary recommendations.
  - General prophylaxis.
  - Immunisation.
  - Infections.
  - Following safety regulations, wearing a seat belt for children and using a car seat for infants and booster seat for toddlers.
- Non-modifiable risk factors include genetics, ethnicity, gender and other parameters that are out of control.
- Education of population in general on impairments and disability, their causes, prevention, and identification is highly desired[59] [**L1**].

Key Considerations for Patient Preferences (*Section 15*):

- It is important for healthcare professionals to develop an understanding of the patient as an individual and the unique way in which each person experiences a condition and its impact on their life [**R-GDG**].
- Patients should be treated with respect, kindness, dignity, courtesy and honesty. Patient's choice should be respected and used [**R-GDG**].
- The environment should be conducive to discussion and that the patient's privacy is respected, particularly when discussing sensitive, personal issues [**R-GDG**].
- Patient's right to confidentiality should be respected [**R-GDG**].
- Patients should be involved in decision making about their own care or their dependent's care [**R-GDG**].
- Individuals not directly involved in the delivery of care should first be introduced to the patient before starting consultations or meetings, and let the patient decide if they want them to stay [**R-GDG**].
- Obtaining and documenting informed consent from patients, in accordance with MOPH policy and guidance is required [**R-GDG**].
- Disclose errors when they occur and show empathy to patients [**R-GDG**].
- Always try to improve communication including using pictures, symbols or involving an interpreter or family members (only if an interpreter is unavailable) [**R-GDG**].
- Medical jargon should be avoided. Confirm understanding by asking questions c.
- Continuity of care is very important and should be provided by clear and timely sharing of patient information between healthcare professionals [**R-GDG**].

4 Background Information

4.1 Definition and Classifications

- **An Impairment** is defined as any loss or abnormality in an anatomical structure or physiological or psychological limitation[26,60,61].

- **A Disability** is defined as a limitation or lack (resulting from an impairment) of opportunities to perform an activity in the manner or within the range considered normal for a human being[26,60]. It is defined by the interaction between health conditions and environmental and personal factors[47,61].

- **International Classification of Functioning, Disability and Health (ICF)** is a classification that provides a unified and standard language and framework for the description of health and health-related states[60].
    - Based on ICF: Children and Youth Version (ICF-CY), disability can occur at three levels[47,61]:
        - Impairment in body function or structure (e.g. a cataract which affects sensing of form, shape, and size of visual stimuli).
        - Limitation in activity (e.g. inability to read or move around).
        - Restriction in participation (e.g. exclusion from school).

- **Developmental Disabilities** are a group of conditions due to an impairment in physical, learning, language, or behaviour areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime[62].

- **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[63].

- **A Handicap** indicates a patient's disadvantaged position in society, resulting from an impairment and/or disability[26,60]. This terminology is now obsolete [**R-GDG**].

- **Early Childhood** is the period from prenatal development to eight years old[64]. It represents a crucial phase of growth, development, and life-long learning, which makes this phase critical in ensuring the child reaches maximal potential alongside his/her disability[47].

- **Early Childhood Development** is a generic term that refers to a child's cognitive, social, emotional and physical development[47].

- **Developmental Milestone** is a stage in the neuromuscular, mental, or social maturation of an infant or a young child, generally marked by the attainment of a capacity or skill[9].

- **Developmental Delay** refers to children who experience significant variation in the achievement of expected milestones for their actual or adjusted age[47]. Developmental delays can be classified as mild, moderate or severe.

- **Global Developmental Delay** (GDD) is a significant delay occurring in several developmental domains (gross or fine motor skills, speech and language, cognition, personal-social and activities of daily living)[4,65]. It may be diagnosed in pre-school children and is highly associated with intellectual impairments (see *Section 10.5* for details)[4].

- **Developmental Surveillance** is a flexible, continuous process whereby knowledgeable professionals perform skilled observations of children during the provision of health care[66,67]. It includes a monitoring and discussion of any potential delay or concern with development[67,68].

4.1.1 Visual Impairment

Visual acuity is a measure of the ability to see fine detail and the main criterion used for classification of visual impairments[1]. Deterioration in visual acuity leads to **Visual Impairment**, which is a functional limitation of the eye(s) or visual system[2] with vision acuity worse than 6/18[3,69].

The WHO classifies vision impairment as[69,70]:

- Distance vision impairment (see *Table 7.1.5* for details):
  - Mild impairment or normal vision.
  - Moderate impairment.
  - Severe impairment.
  - Blindness.
- Near vision impairment.

Based on the visual field affected, visual impairments are classified as[2]:

- Reduced visual acuity.
- Central visual field defects.
- Peripheral visual field defects.
- Reduced contrast sensitivity and glare sensitivity.

4.1.2 Hearing Impairment

Hearing Impairment is a diminished sensitivity to sound ranging from subjectively barely appreciable disturbances to total deafness and including neural hearing loss (e.g. auditory neuropathy spectrum disorder (ANSD)) [20,25,71]. Disabling hearing loss in children refers to hearing loss greater than 30 dB in the better hearing ear[72].

Hearing impairment is classified as [73]:

- Slight.
- Mild.
- Moderate.
- Moderately severe.
- Severe.
- Profound.

Based on the structures affected, hearing loss is divided into:

- Conductive[20–22]:
  - Disruption of the mechanical transmission of sound waves through the external and middle ear to the cochlea[21,22].
  - Patients perceive diminished sounds[22].
- Sensorineural[20–22]:
  - Failure to transduce vibrations to neural impulses effectively within the cochlea[21]; or
  - Failure to transmit impulses after the cochlea, down the vestibulocochlear nerve[21].
  - Patients perceive diminished and distorted sounds[22].
- Mixed[21,22]:
  - Combination of the conductive and sensorineural types.
  - Usually occurs due to damage throughout the middle ear and the inner ear.

- Central[20,21]:
    - Defects in the brainstem or higher processing centres of the brain.

4.1.3 Physical Disability

Physical Disability is a medically diagnosed, acquired or congenital, chronic physical impairment, that may adversely affect physical, social, or academic functioning of the child and may result in the need for adaptive skills, environmental modification, special education and related services[74].

Some common causes of physical disability include[26,75]:

- Orthopaedic disorders:
    - Loss or deformity of limbs.
    - Osteogenesis imperfecta.
    - Metabolic bone disease.
- Neuromuscular disorders:
    - Cerebral palsy.
    - Spina bifida.
    - Head injury.
    - Muscular dystrophy.
    - Spinal cord injury.
- Cardiovascular disorders (e.g. stroke, congenital heart defects).
- Pulmonary disorders that limit activity.

4.1.4 Intellectual and Developmental Disabilities

Intellectual and developmental disabilities (IDD) are disorders that are usually present at birth and that negatively affect the trajectory of the individual's physical, intellectual, and/or emotional development [76].

- Intellectual and other developmental disabilities often co-occur. In the present NCG, the term IDD is used for situations in which intellectual disability and other disabilities are present (e.g., Down syndrome, behaviour disorders, brain injury, etc.).
- Developmental disabilities that do not impact intellectual functioning and adaptive behaviour are listed in the respective sections.

Intellectual Impairment is a neurodevelopmental condition with onset during development and leading to limitations in intellectual functioning and adaptive behaviour[4,39,40,77]:

- Intellectual functioning is the ability to understand reality and interact with it[39]. It is manifested through a set of capabilities, behaviours, thoughts, and emotions[39].
- Adaptive behaviour comprises 3 domains[39,40]:
    - *Conceptual Domain*: language, knowledge, memory, ability to understand time, etc.
    - *Social Domain:* empathy, social judgment, rule-following ability, self-esteem, etc.
    - *Practical Domain:* self-care, organisation, daily living skills, using tools, etc.

Based on the intelligence quotient (IQ) scores, intellectual impairments are classified as[69]:

- Mild.
- Moderate.
- Severe.
- Profound.

4.1.5 Speech and Language Impairment

Developmental Language Disorder (DLD) is characterised by the absence of speech in children despite their normal non-verbal IQ, no primary physical disabilities, neurological disorder, or mental illness [78]:

- A *Speech or Language Delay*:
  - Implies that the child is developing speech or language in the correct sequence but at a slower rate than expected[79].
- A *Speech or Language Disorder*:
  - Suggests that the child's speech or language ability is qualitatively different from typical development[79]:
    - *Speech disorder* is a deficit that may cause speech to sound abnormal or prevent it altogether[80].
    - *Language disorder* is a condition that interfere with the ability to understand the code, to produce the code, or both[80].

Screening instruments are not able to accurately distinguish between the two conditions and the distinction between them is complicated, especially in terms of perspectives and long-term predictions Therefore, the terms "*speech and language delay'*, "*speech and language disorder"*, "*speech and language impairment"*, and "*speech and language disability",* are often used interchangeably[79].

4.2 Prevalence

In 2010, 1964 children and young people <19 years old with difficulties were registered at various disabled centres in Qatar, which composed approximately 25% of disabled individuals in the country[81,82]. The number of registered children increased to >5800 in 2016[83] and to >9600 in 2018[81].

Internationally, among children younger than 6 years, 1% to 6% have amblyopia or its risk factors (strabismus, anisometropia, or both), which, if left untreated, could lead to amblyopia[39]. In the US, the prevalence of amblyopia, strabismus, and anisometropia ranges from 1% to 6% among children younger than 6 years[39].

The causes of visual impairment in the UK, classified anatomically are, 'cerebral' (40%), retinal (24%) and optic nerve (23%), with some variation according to the severity of the VI[1]. Hearing loss affects approximately 0.5 to 1% of children in the US[2225].

4.3 Risk Factors

Risk factors for impairments and early disability in children include but are not limited to[4,5,7,18,21,39,40,59,84–86]:

- Preconception risks:
  - History of stillbirths or miscarriages.
  - Assisted reproduction.
  - Genetic abnormalities.
  - Maternal exposure to certain medications.
  - Maternal stress.
  - Obesity.
  - Diabetes.
  - Low socioeconomic status of the family.
  - Low levels of parental education.
  - Consanguinity and positive family history.

    - Advanced maternal age.
- Pregnancy risks:
    - Multiple gestations.
    - Maternal thyroid disease, hypertension, asthma.
    - Maternal diabetes and obesity.
    - Preeclampsia.
    - Developmental anomalies.
    - Infections, e.g. TORCH syndrome (Toxoplasmosis; Other: syphilis, varicella-zoster, parvovirus B19; Rubella; Cytomegalovirus; and Herpes infections).
    - Intrauterine growth restriction.
    - Placental abnormalities (e.g. abruption or umbilical cord prolapse).
    - Substance abuse (alcohol).
    - Radiation.
    - Teratogenic medications (valproic acid, phenytoin, etc.).
- Perinatal birth risks:
    - Acute intrapartum hypoxia ischemia.
    - Birth asphyxia.
    - Seizures.
    - Hypoglycaemia.
    - Jaundice.
    - Infection.
    - Low birth weight.
    - Trauma or injury.
    - Prematurity.
- Post-neonatal risks:
    - Infections.
    - Exposure to ototoxic medications.
    - Congenital brain malformations.
    - Surgical complications.
    - Accidental and non-accidental brain injury occurring before age 24 months.
    - Mechanical ventilation (for at least 5 days).
    - Presence of other impairments.
    - Trauma or injury.
    - Chemotherapy.

Infants in the well-baby nursery with diagnoses of craniofacial anomalies, family history of hearing loss, and diagnosis of intrauterine infection comprise a special high-risk category [**R-GDG**].

4.4 Associated Conditions

Different types of impairments are often associated with one another in children:

- Visual and hearing impairments are often present together[1].
- Hearing loss is usually associated with linguistic and developmental problems[22].
- Spina bifida and hydrocephalus are usually associated[27,28].
- Autism Spectrum Disorder (ASD), seizures, and neuromuscular physical impairments are frequently associated with intellectual impairments and mental health problems[28,87,88].

Children with disability have poorer overall health[88] and certain health problems are more common among them. These include[21,27,88–90]:

- Asthma.
- Arthritis.

- Cancer.
- Chronic pain.
- Dental caries.
- Diabetes.
- Eczema.
- Fatigue (including chronic fatigue syndrome).
- Respiratory infections.
- Gastrointestinal problems (e.g. gastrointestinal reflux, impaired motility, and constipation).
- Heart diseases.
- Mental health diseases.
- Migraine headaches.
- Musculoskeletal disorders (e.g. contracture, scoliosis, back pain, joint injuries).
- Overweight and obesity.
- Pressure sores or ulcers.
- Seizures.
- Sleep disturbance.
- Skin allergies.
- Urinary tract infections (UTIs).
- Failure to thrive.

Additionally, children with disabilities may have difficulty swallowing, chewing or sucking, and difficulty achieving bladder and bowel continence[90].

4.5 Barriers to Early Diagnosis

The major barriers to the early diagnosis of an impairment are[1,18,59,80]:

- Long waiting time for specialist assessment [**R-GDG**], lack of consultation time or lack of access to appropriate services.
- Complexity of the diagnostic process:
    - Lack of definitive bio marker for the condition [**R-GDG**].
    - Complex metabolic syndromes affecting different body systems.
    - Limitations in certain body functions can mask other problems and, therefore, can remain unrecognised for long periods.
- Psychosocial aspects:
    - Patient's and/or family's fear of the diagnosis.
    - Fear of serious and frequently unmodifiable disease.
- Societal stigma and lack of acceptance.
- Lack of social awareness.
- Lack of proper screening tools.

5 General History

A detailed history should be obtained from[1–6] [**L1**]:

- The child (if they are able).
- Parent or caregiver.
- Teachers.
- Other health care providers (e.g. therapists, rehabilitation counsellors).
- Other persons who might provide information helpful.

Important points to elicit, include but are not limited to:

- General health review[1,5,84]**:**
  - Nature and duration of the presenting problem.
  - Whether key developmental milestones are being achieved.
  - Any regression in milestones.
  - Injuries, accidents, trauma.
  - Presence of seizures and details of seizure control.
  - Infectious illness (e.g. meningitis).
  - Immunisation.
  - Dietary history and preferences.
  - Sleep pattern.
  - Bowel habits (e.g. constipation or incontinence).
  - Psychological problems.
  - Parent or caregiver observations, worries, and concerns and expectations.
  - Other disabling conditions.
  - Long term conditions.
  - Attendance of physiotherapy, occupational therapy, speech and language pathology or speech therapy.
- Maternal prenatal history:
  - Medical aspects (e.g. infections and medications).
  - Travel history (i.e. visits to countries with endemic infections such as Zika virus causing microcephaly).
- Pregnancy and birth history[3,5,9,22,84]**:**
  - Presence of risk factors for disability (see *Section 4.3*).
  - Gestational age.
  - Mode of delivery.
  - Admission to neonatal intensive care unit (NICU).
  - Birth weight and head circumference (if available).
- Detailed developmental history [**R-GDG**]:
  - Gross motor.
  - Fine motor.
  - Speech and language.
  - Social and self-care skills.
- Medication history[2,5,22]**:**
  - Number and list of medications (especially drugs with interactions).
  - Medication allergies.
  - Compliance of medications.
- Ethnicity[84].
- Family history[1,2,84]:
  - Consanguinity.
  - Siblings or other relatives with similar conditions or disabilities.
- Social history[2]:
  - Living arrangements.
  - Family interactions.

    - Educational concerns.
    - Concordance with treatments, including attendance at physiotherapy and occupational therapy appointments.
- Assessment of needs[2]:
    - Needs as stated by the patient.
    - Needs as determined by the history.
    - Needs as identified by family or caregiver.
    - Needs as identified by teacher.
    - Aids and devices (wheelchair, braces, crutches, prosthesis, etc).

A detailed health history of the impairment should be collected in addition to the general history (see additional details in the corresponding sections of this guideline).

6 Screening

Children with disabilities are a particular vulnerable group. Early detection of child development delays and/or impairments is crucial, as the first 3 years of a child's life are a critical period for development. Early screening leads to more successful long-term outcomes. If not identified as early as possible, these conditions can threaten the development of the child and may have lifelong consequences [**R-GDG**].

6.1 Universal Screening in Newborns

All infants should undergo universal screening in the first days of life, before discharge from the hospital after birth[7,8]:

- Children who fail in-hospital screening should be referred for a repeat testing between 2 and 8 weeks[7] (but not later than 3 months of age[21]) after discharge[7,12,21].
- Infants from the high-risk category (see *Section 4.3*) and with newborn-detectable risks (e.g. preterm infants, infants with birth defects) should undergo full screening[7,21,25].

According to amendments in the revised guidelines for National Programme for Early Detection of Hearing Loss (NPEDHL) in state of Qatar[10], screening and detection of hearing loss in every new-born babies by 3 months and rehabilitation or enrolment in early intervention by 6 months of age.

The audiological screening protocols for NICU and high-risk babies differ from those for well-baby nurseries [**R-GDG**]. Hearing screening protocol for well babies of low-risk category involves two stages [**R-GDG**]:

- First stage with two screening technology evoked otoacoustic missions test (OAEs) and automated auditory brainstem response (AABR) test methodology at 2 months of age with the first vaccination at the health centre.
- The second stage is at 4-6 years of age during preschool screening.

6.2 Screening in Newborns Admitted to NICU

Retinopathy of Prematurity:

- All newborns admitted to NICU with gestational age less than 32 weeks and birth weight less than 1500 g must be screened for retinopathy of prematurity through fundus examination with a well-dilated pupil [**R-GDG**].

Hearing Impairment:

- All newborns admitted to NICU for more than 48 hours must undergo the first stage of screening for hearing loss prior to discharge.
- Screening should take place as close to discharge as possible [**R-GDG**].
- In NICU:
    - Screening by a two technology, 4-stage protocol: At birth, 2 months, 1 year of age, and preschool screening at 4-6 years[23].
    - Screening is recommended with both evoked otoacoustic emissions (OAEs) and automated auditory brainstem response (AABR) [91].
    - For infants who do not pass automated ABR testing in the NICU, referral should be made for high quality hospital rescreening and, when indicated, comprehensive evaluation including ABR [**R-GDG**].
    - For rescreening, a complete screening on both ears is recommended, even if only 1 ear failed the initial screening [92].

- A repeat full hearing screening before discharge is recommended for all infants readmitted in the first month of life if there are conditions associated with potential hearing loss (e.g. hyperbilirubinemia)[92].
- Screening is not recommended in infants with congenital aural atresia in one or both ears or with visible pinna/ear canal deformity or severe malformation.
    - These babies should be referred for diagnostic audiological evaluation immediately upon discharge[92].

6.3 Developmental Screening in Newborns and Young Children

The standard Well-Baby Services Package includes screening checks at 2, 4, 6, 9, 12, 18, 30 months and preschool age (4 years)[9]:

Child Health Notebook:

- Healthcare providers in Qatar, are expected to be familiar with the *Child Health Notebook,* as the standard patient-held record for documentation and communication of screenings from birth to 4-6 years of age.
- The notebook guides parents and providers on the timing of interval screening, developmental milestones, and general health [**R-GDG**].
- All providers conducting well-baby screening (including those in the private sector), should ensure accurate completion of the *Child Health Notebook* [**R-GDG**].

Developmental screening will catch delays earlier, making treatment more effective [**R-GDG**]:

- If the child passes the screening tests:
    - The child should be discharged with parental education to report if the child develops any warning signs.
- If a developmental problem is suspected:
    - Refer to the corresponding section of this guideline for appropriate assessment.
    - Consider referral to a paediatric specialist.

All infants who have one or more of the following conditions should be screened for cerebral palsy using the GMA [93,94] [**L1**]:

- Grade 3 or 4 intraventricular haemorrhage.
- Significant post haemorrhagic hydrocephalus.
- Periventricular leukomalacia.
- Abnormal brain magnetic resonance imaging (MRI).
- Significant neurological concern from the NICU team.
- Hypoxic-ischemic encephalopathy stage 2 or 3.

6.4 Screening in Preschool Age and School Age Children

All children should undergo a vision and hearing test at or around the time of school entry[11]. Any anomalies (e.g. amblyopia) detected by the nurse require prompt evaluation by a specialist [**R-GDG**].

Developmental milestones in children with impairments should be evaluated across various domains[9,12]. Failure to achieve expected milestones by the requisite age, is a developmental warning sign or red flag.

7 Visual Impairment

7.1 Common Causes

There are many different causes of visual impairment and blindness[14–17]:

- Genetic, including:
  - Congenital cataracts.
  - Infantile glaucoma.
  - Retinal degeneration.
  - Optic atrophy.
  - Retinal dystrophy (e.g. Kearn-Sayre disease, Bardet Biedl, and Usher syndromes).
  - Neurological and metabolic disorders (e.g. Batten disease).
  - Albinism.
  - Chromosomal abnormality (e.g. Down syndrome).
- Birth injuries, including:
  - Birth asphyxia.
  - Cerebral palsy.
  - Premature birth.
- Nutritional deficiencies (e.g. vitamin A).
- Infections, including:
  - Ophthalmia neonatorum.
  - Measles.
  - Trachoma.
- Accidental injury (e.g. corneal opacity).
- Non-accidental injury (e.g. shaken baby syndrome) [**R-GDG**].
- Other causes (e.g. retinoblastoma, strabismus, uncorrected refractive error, amblyopia, nystagmus).

7.2 Detailed History

In addition to general history in *Section 5*, enquire specifically about the following[2,3,95]:

- Patient's visual and ocular history, including:
  - Previous or current use of glasses or any other visual devices.
- Family ocular history (e.g. blindness, glaucoma).
- Presence of any common causes of visual impairment (see *Section 7.1*).
- Presence of warning signs specifically related to the vision (see *Table 7.2*).

Warning Signs of Visual Impairment[3]		
Appearance	**Behaviour**	**Reported Symptoms**
• Wandering eye. • Nystagmus. • Absence of response to bright light. • Eye turns in or out. • White pupil. • Ptosis.	• Tilting head to one side. • Excessive blinking. • Excessive rubbing of the eye. • Closing or covering one eye. • Photophobia. • Does not respond to parent's face. • Does not follow moving objects. • Does not show interest in toys or colour. • Bumping into things. • Confusion with the alphabet.	• Headache. • Dizziness, nausea. • Blurred or double vision. • Unusual sensitivity to light. • Burning or itchy eyes. • Watching TV and reading at short distances.

Table 7.2: Warning signs of potential visual impairment[3]**.**

7.3 Examination

A full ophthalmological examination may require more than one visit or one visit with many short breaks as children may tire easily[5].

The basic examination should include[2] [**L1, RGA**].:

- Clinical examination of the craniofacial region, including eyes and skull.
- Confirmation of visual developmental milestones.
- Qualitative and quantitative vision testing[5,17].

For children younger than 3 years, examination may include[18]:

- The fixation and follow test or pictures chart (for visual acuity).
- The red reflex test (for media opacity).
- The corneal light reflex test (for strabismus).

For children older than 3 years and adolescents, examination may include[18]:

- The red reflex test (for media opacity).
- The cover-uncover test (for strabismus).
- The corneal light reflex test (for strabismus).
- Visual acuity tests (e.g. Snellen, Lea Symbols, and HOTV charts).
- Autorefraction.
- Stereoacuity tests.

Use *Table 7.5* below to determine the severity of a visual impairment.

<table>
<tr><th rowspan="2">Categories</th><th colspan="2">Binocular</th><th rowspan="2">Monocular</th></tr>
<tr><th>Worse than:</th><th>Equal to or better than:</th></tr>
<tr><td>Mild Impairment or Normal Vision</td><td>-</td><td>6/18</td><td>-</td></tr>
<tr><td>Moderate</td><td>6/18</td><td>6/60</td><td>One eye: Moderate impairment
Contralateral eye: Normal vision or mild impairment</td></tr>
<tr><td>Severe</td><td>6/60</td><td>3/60</td><td>One eye: Severe impairment
Contralateral eye: Normal vision or mild/moderate impairment</td></tr>
<tr><td rowspan="2">Blindness</td><td>3/60</td><td>-</td><td rowspan="2">One eye: Blindness
Contralateral eye: Normal vision or any category of vision impairment</td></tr>
<tr><td colspan="2">No light perception</td></tr>
</table>

Table 7.5: Severity of Visual Impairments[69]**.**

NB: If acuity cannot be assessed, visual impairment may be diagnosed if the child fails to achieve normal visual developmental milestones[3].

7.4 Investigation

Consider the following investigations, accordingly to the findings of initial assessment and examination:

- MRI or computed tomography (CT) scans:
  - If periventricular leukomalacia, encephalomalacia, gliosis in the parieto-occipital cortex, or other neurological condition, is suspected[5] [**L1, RGA**].
- Visual evoked potentials (VEP) and retinal dystrophy electroretinogram (ERG)[17] [**L2**].
- Genetic testing[16] [**L2**].

7.5 Differential Diagnosis

If visual impairment is suspected, consider the following common diagnoses[1,5,15,17,18]:

- Refractive errors:
  - Myopia.
  - Hyperopia.
  - Astigmatism.
- Anisometropia.
- Congenital cataracts.
- Infantile glaucoma.
- Amblyopia.
- Strabismus.
- Optic nerve lesions and cerebral visual impairment.
- Retinal dystrophy.
- Delayed visual maturation.
- Retinoblastoma.
- Ophthalmia neonatorum.
- Retinopathy of prematurity.

Note:

- Some systemic conditions may also lead to ocular abnormalities[1,17]. These should be diagnosed and treated[17] [**L2, RGA**].
- Visual and hearing impairments are often associated with one another[1]. Refer to *Section 8* for details and diagnosis of hearing impairments.

7.6 Criteria for Specialist Referral

Refer the child to an ophthalmologist, if at least one of the following is present[3,9,19] [**L1, RGA**]:

- Structural abnormalities of the eye.
- Abnormal pupillary reflex (white or asymmetric).
- Abnormal red reflex.
- Asymmetric corneal light reflex.
- No response to bright light.
- Nystagmus.
- Monocular visual acuity is ≤6/9 at age 3-6 years.
- Substantial difference in acuity between the eyes.
- Key visual developmental milestones are not achieved.
- Regression in visual milestones is observed.
- History of prematurity.
- Family history of retinoblastoma, inherited eye disease, or developmental delay.

View Pathway

8 Hearing Impairment

8.1 Common Causes

Common causes of early hearing impairments include[7,20–22]:

- Genetic factors, including:
  - Syndromic (~30%) such as:
    - Alport syndrome (with progressive renal failure).
    - Pendred syndrome (with goiter due to faulty iodine metabolism).
    - Cogan syndrome (with interstitial keratitis).
    - Waardenburg syndrome (with partial albinism and lateral displacement of the lacrimal puncta).
    - Usher syndrome (with retinitis pigmentosa).
    - Osteogenesis imperfecta (collagen disorder, bony fractures).
    - Goldenhar syndrome (malformation of the pinna, dysmorphic facies).
    - Pierre-Robin syndrome (microgenia, cleft palate).
    - Franceschetti syndrome (craniofacial dysmorphism).
    - Other >300 congenital hearing loss syndromes.
  - Non-syndromic (70%, half of them due to connexin 26 mutation):
    - Autosomal recessive (80%).
    - Autosomal dominant (17%).
    - X-chromosomal (3%).
    - Mitochondrial inheritance (<1%).
- Acquired factors:
  - Perinatal causes:
    - Prematurity.
    - Low Apgar scores.
    - Hyperbilirubinemia with kernicterus.
    - Ototoxic drugs like aminoglycosides.
    - Hypoxia and noise exposure in NICU.
    - Prolonged mechanical ventilation.
    - Extracorporeal membrane oxygenation.
  - Infections, including:
    - Acute otitis media particularly if recurrent.
    - Otitis media with effusion.
    - Otitis externa.
    - Ossicular erosion.
    - Bacterial meningitis.
    - Measles.
    - Mumps.
    - Varicella.
    - Rubella.
    - Lyme disease.
    - Cytomegalovirus (CMV) infection.
  - Foreign body (including cerumen).
  - Cholesteatoma.
  - Nutritional deficiencies (e.g. vitamin B12).
  - Ototoxic causes:
    - Medications.
    - Industrial substances.
    - Abused substances.
    - Viral and bacterial toxins.
    - Metabolic causes.

- Trauma (e.g. ossicular disruption, tympanic membrane perforation).
- Accidental injury.
- Radiation therapy for head and neck tumours.
- Neurodegenerative or demyelinating disorders (e.g. Alport or Cogan syndromes).
- Chemotherapy.

Common causes of late-onset hearing impairment in children, include[7]:

- CMV infection.
- Genetic syndromes associated with progressive hearing loss.
- Neurodegenerative disorders.
- Trauma.
- Bacterial meningitis in the neonatal period and thereafter.

8.2 Detailed History

In addition to general history, ask specifically about the following[20,22,25,84]:

- Caregiver concern regarding hearing, speech, language, or developmental delay.
- History of in utero infections.
- Patient's hearing history, including:
  - Admission to the NICU for more than 48 hours.
  - Culture-positive postnatal infections associated with sensorineural hearing loss.
  - History of paracusis and diplacusis.
  - Noise exposure.
  - Head trauma, especially basal skull/temporal bone fracture.
  - Use of hearing devices.
  - Chemotherapy.
- Family history of hearing loss, including:
  - Childhood-onset hearing impairments.
  - Permanent childhood hearing loss.
  - Syndromes associated with early- or late-onset hearing impairments.
  - Developmental delays.
- Syndromes associated with hearing loss or progressive or late-onset hearing loss.
- Neurodegenerative disorders (such as Hunter syndrome or sensory motor neuropathies).
- Presence of speech or language issues or developmental delays.
- Balance problems.
- School achievements and failures.
- Presence of warning signs specifically related to the hearing.
- Presence of any common causes of hearing impairment (see *Section 8.1*).

8.3 Examination

It is not recommended to diagnose hearing loss in an infant through observation alone[21] [**L2,RGC**]. An examination using appropriate equipment calibrated every 6 months, should be used[23] [**L1**]. The hearing examination should be conducted in a quiet environment[12] [**L1, RGA**]. Noise can lead to less accurate screening results.

The basic hearing examination should include[12,22,84]:

- Clinical examination of craniofacial region, including ears, nose, oral cavity, and skull for craniofacial anomalies (including those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies).
- Visual examination and physical findings such as a white forelock.
- Bilateral otoscopy.
- Appropriate hearing tests.
- Vestibular examination.
- Communication assessment (e.g. cries, babbles, laughs).

For infants younger than 1 month of age, the following tests may be considered[12,24]:

- Automated auditory brainstem response (AABR).
- Transient evoked otoacoustic emissions (OAEs).
- Distortion product OAEs.

Children with increased risk of congenital hearing loss should be examined with both AABR and OAEs[7,24] [**L1, RGA**]. Children in a low-risk category should be screened with OAE and AABR at 2 months of age with the first vaccination at the health center [**R-GDG**].

For children older than 1 month of age and adolescents, the following tests may be considered[9,21,22]:

- Behavioural observation audiometry (for children <6 months of age).
- Visual reinforcement audiometry (for children 6 months-2.5 years old).
- Play audiometry (for children 2.5-5 years old).
- Conventional audiometry (for children >5 years old).
- OAEs (for children of any age).
- Tympanometry (for children of any age except newborns) along with the measurement of middle ear reflexes.
- Auditory brainstem response (for children of any age):
    - Diagnostic Auditory Brainstem Response Evoked Potentials for identification of hearing threshold, should be performed using click and frequency-specific stimuli[96].
    - Ear-specific and frequency-specific behavioural response hearing testing using a VRA protocol (conditioned response) should accompany ABR testing, which is the basis for the initial hearing aid fitting, and may be performed at approximately 4-5 months of age, depending on the infant's developmental status[97].

Screening approaches using unconditioned behavioral responses (e.g. eye shift after sound presentation, responding to hand clapping) are not recommended due to their low sensitivity[12] [**L1, RGC**].

Notes:

- The cultural, linguistic, and family factors of the child should be taken into consideration[12].
- Preterm infants may show signs of hypersensitivity to stimuli and may not respond in the same way as full-term babies[12].
- 20-60% of children with permanent childhood hearing impairment also have visual impairments[84]. They should not remain undetected[24,84].
- Every identified child should have a regular evaluation by an ophthalmologist to document visual acuity and rule out concomitant or delayed-onset vision disorders, such as cataracts or Usher syndrome[98].

Use *Table 8.3* based on WHO and ASHA guidelines to determine severity of a hearing impairment.

Note:

- The hearing threshold level using audiometry, is to be taken as the better ear average for four frequencies 0.5, 1, 2, and 4 kHz[72].

Severity of impairment	Mean Hearing Loss in Pure-Tone Audiogram
Slight	21-25 dB
Mild	26-40 dB
Moderate	41-55 dB
Moderately severe	56-70 dB
Severe	71-90 dB
Profound	>90 dB

Table 8.3: Classification of Severity of Auditory Impairments[72,73].

8.3.1 Assessing Infants with Suspected Auditory Neuropathy Spectrum Disorder (ANSD)

Auditory neuropathy may occur in association with specific conditions (i.e., extreme prematurity, hyperbilirubinemia, hydrocephalus), or it may present in infants with no obvious causative factor.

Diagnosis is made by[99]:

- The presence of OAEs and/or cochlear microphonics accompanied by poor morphology of the ABR and absent or elevated middle ear muscle reflexes.
    - When the ABR shows no response, a specialised protocol (high intensity click stimulus at positive and negative polarities) should be completed to assess possible auditory neuropathy.

The hallmark of the auditory neuropathy ABR is[100]:

- A prominent cochlear microphonic, that follows the stimulus polarity when it is reversed.
- Waveforms after the polarity-reversing cochlear microphonic are typically absent or significantly aberrant (e.g. poorly defined, delayed and/or low-amplitude subsequent waveforms).

When the infant is developmentally able to participate in behavioural testing[23,101]:

- The audiogram is typically characterised by bilateral or unilateral fluctuating or stable thresholds which may range from mild to profound.
- Some of these children may have severe neurological involvement.

Children with ANSD require frequent audiological monitoring to[23,101]:

- Assess progression, improvement, or fluctuation in electrophysiological threshold estimates, until a reliable behavioural threshold can be determined.
- Establish appropriate hearing aid settings for hearing aid fitting.

8.4 Investigation

Appropriate tests and investigations should be selected based on history and examination findings. Consider the following investigations[24,25,84]:

- MRI and CT:

  - Any child with sensorineural hearing loss, whether unilateral or bilateral.
  - Meningitis (bacterial or viral)[84] [**L1, RGA**].
  - Auditory neuropathy.
  - For children with permanent conductive hearing loss, CT is preferred.
- Serology:
  - If infection is suspected e.g. congenital syphilis, congenital rubella, congenital HIV, etc[24].
- Haematology and biochemistry:
  - Recommended for all children with progressive hearing loss and suspected CMV[24,84].
  - Should be considered in children with epilepsy, neurodegeneration and developmental delay[24].
- Saliva swabs [**R-GDG**]:
  - If congenital cytomegalovirus (cCMV) is suspected.
- Urine examination:
  - Recommended if microscopic haematuria or proteinuria is found[24].
  - If cCMV is suspected [**R-GDG**].
- Investigation for autoimmune diseases[24].
- ECG:
  - Recommended in children with bilateral severe to profound hearing loss and a family history of childhood sudden death or a personal history of syncope or known cardiac arrhythmia[24].
- Genetic testing:
  - Recommended for all cases of bilateral progressive hearing loss[24,84].
  - Positive family history and consanguinity [**R-GDG**].
  - Should be considered if unilateral syndromic hearing loss is suspected[21,24].
  - Should be offered to all children with ANSD.

8.5 Differential Diagnosis

The differential diagnosis for hearing loss is very broad. Detailed history and thorough examination are important for the correct diagnosis and management [22].

If hearing impairment is suspected, consider the following common diagnoses[20–22,24,102]:

- Otitis media with effusion.
- Dysfunction of the Eustachian tube.
- Cholesteatoma.
- CMV infection.
- Bacterial meningitis.
- Syndromic hearing loss.
- Ototoxic causes.
- Otosclerosis.

8.6 Criteria for Specialist Referral

Patients should be referred to a specialist and receive a full audiological assessment if at least one of the following is present[9,12,21,25]:

- Confirmed hearing loss of any degree.
- Failed auditory screening/testing.

- Family history of congenital hearing loss.
- Parental or caregiver concern about potential hearing loss.
- Child identified as being high risk for hearing impairment.
- History of recurrent or persistent otitis media with effusion with flat tympanogram for >3 months.
- Confirmed middle ear dysfunction.
- Regression or failure to achieve key speech-language developmental milestones.
- Malignancy is suspected.
- Surgical intervention is considered.

Note:

- Preterm infants may exhibit unusual or incorrect responses[12].
- Further observation is required.
- If hearing impairment is suspected, the child should be referred to a specialist.

All children >6 months with hearing loss should receive a complete assessment of their communicative competence, including language and nonverbal communication skills[12] [**L1, RGA**].

8.7 Specialist Management

Specialist management of hearing impairment comprises of [**R-GDG**] but not limited to:

- Medication.
- Surgical intervention.
- Paediatric amplification (hearing amplification devices and cochlear implant) (see *Section 8.7.1*).
- Auditory-verbal therapy.

8.7.1 Paediatric Hearing Amplification

The purpose of amplification is to provide access to as much of the auditory environment and speech as possible to maximize the opportunities for the child to develop age-appropriate oral communication, language, literacy skills, and psychosocial skills [103].

Successful amplification should be based on complete and accurate diagnosis of hearing sensitivity using best practices, employing developmentally appropriate tests, and result in reliable and valid findings [103] [**L1**].

- All children <3 years who are diagnosed with hearing loss should be evaluated with at least one ABR test [103] [**L1**].
- Bilateral amplification is routinely recommended unless contraindicated [103] [**L1, RGA**].

Hearing aid fitting process involves the following steps [103,104]:

- Assessment (see *Section 8.7.1.1*).
- Candidacy (see *Section 8.7.1.2*) and hearing aid selection (see *Section 8.7.1.3*).
- Fitting and verification (see *Section 8.7.1.4*).
- Validation (see *Section 8.7.1.5*).
- Orientation (see *Section 8.7.1.6*).
- Follow up (see *Section 8.7.1.7*).

8.7.1.1 Assessment

Assessment and testing of the hearing ability should be determined based on the child's age and developmental status. Consider the following options [**R-GDG**]:

- Otoacoustic emissions.
- Auditory brainstem response.
- Behavioural testing (including visual reinforcement audiometry or conditioned play audiometry).
- Speech detection or recognition testing.

Click threshold data alone from ABR is not sufficient to fit amplification. Alternating polarity clicks and tone bursts (500 to 4000 Hz) are essential [**R-GDG**].

At a minimum, thresholds by air- and bone-conduction for a low and high frequency stimulus must be obtained in each ear separately. ABR thresholds measured in dB nHL (normal hearing level) should be converted to estimated behavioural hearing level (dB eHL) using the correction values [104,105].

8.7.1.2 Audiologic Candidacy Criteria

The following patients should receive hearing aids [103] [**L2**]:

- All infants and children with moderate to greater degrees of bilateral sensorineural hearing loss.
- Children with ANSD:
    - Patients should have a trial with hearing aids prior to candidacy evaluation for cochlear implantation.
    - The amplification should be provided based on behavioural observations by the clinician and by parents and not based on the presence or absence of otoacoustic emissions or ABR results.
- Children with permanent conductive hearing loss:
    - Consider air conduction hearing aids when anatomically possible.
    - Consider bone conduction hearing aids (e.g., bone anchored hearing aid, BAHA) if anatomy is insufficient for coupling.
- All potential candidates for a cochlear implant:
    - Patients should have a trial with hearing aid amplification prior to implantation.
    - Negative ABR results should not exclude a child from hearing aid candidacy.
    - Refer to *Section 8.7.2* for details on cochlear implantation.

Children with mild bilateral or aidable unilateral hearing loss may also be considered as candidates for the amplification systems [103] [**L2**].

8.7.1.3 Hearing Aid Selection

Amplification systems should be considered for patients with any type or degree of hearing loss that could possibly interfere with normal development [103] [**L1**].

Review the following factors, when selecting an appropriate digital signal processing hearing aid [103,104]:

- Gain and output requirements.
- Suitable response range to match the generated prescription target.
- Size and shape of the patient’s ear as well as expected changes in concha and ear canal size.
- Comfort and skin sensitivity.
- Paediatric features, e.g. tamper proof battery drawer (essential for safety with young infants), paediatric earhook, ease of operation of on/off switch and other controls, compatibility with FM.
- Cosmetic concerns and patient preferences.

Behind-the-ear (BTE) hearing aid style is usually the preferred choice for the paediatric patients [103,106] [**L1**]:

- There is a possibility to replace only the relatively inexpensive ear mold as the child's ears grow.
- Tubing size, occlusion, and receiver placement can be individualized based on:
  - Ear canal dimensions.
  - Hearing loss severity and configuration.
  - Patient preferences.
- Standard BTEs provide the opportunity for appropriate coupling with listening devices that may assist in educational and social settings.

BAHA may be worn as a completely external device that transmits sound energy through vibration of the skull, bypassing the eardrum and the middle ear hearing bones.

- Implantable BAHA are not recommended for children aged <5 years [103,106] because of low cortical bone thickness and vulnerability to the implant or when the skull bone <2.5 mm thick [**R-GDG**].
- Non-implanted bone conducted amplification via a soft headband is recommended in children younger than 5 [103].
- Objective audiologic criteria for BAHA in conductive or mixed hearing loss, include [**R-GDG**]:
  - An adequate sensorineural reserve measured by a pure tone average (PTA) bone-curve of at least 45 dB HL.
  - An unaided word recognition score ≥60%.
- Otological indications for BAHA include [**R-GDG**]:
  - Congenital malformations of the external and middle ear.
  - Chronically discharging ear.
  - Conductive hearing losses attributable to ossicular disease.
  - Single sided deafness.

Contralateral routing of the signal (CROS) and Bilateral routing of the signal (BICROS) fittings should be considered in patients with unilateral hearing loss or with bilateral hearing loss when one ear is unaidable [103].

- An FM system with the wireless remote microphone receiver portion coupled to the open, good ear may be preferred over the CROS arrangement in classroom situations in children with unilateral deafness as it provides the benefit of increased signal to noise ratio [103].

Recommendations for adequacy of earmold [103]

- Earmold replacement should be arranged as the child grows especially every three months in the first year of life.
- Automatic feedback suppression should be considered in order to resolve feedback issues temporarily while awaiting new earmolds.
- Using offsite/remote microphone may be beneficial to fully eliminate feedback in infants.
- Approach venting cautiously in paediatric earmolds because of space limitations.
- A long, but comfortable earmold canal length should be provided.
- Paediatric ear hooks may be used to promote retention of BTEs.

8.7.1.4 Fitting and Verification

Targets for hearing aid fitting should be generated by entering the predicted audiogram into the real ear measurement software using a prescription formula for paediatric patients, i.e. desired sensation level (DSL) or National Acoustic Laboratories' nonlinear fitting procedure, version 2 (NAL-NL2) [104].
Verification of a hearing aid fitting is an objective measure that ensures the hearing aid is operating appropriately [107]. There are two options for hearing aid verification available in children:

- **Real-ear to coupler difference (RECD)** [103,104]:
    - Should be measured using the baby's own ear mould or a foam insert earphone tip.
    - The output of the hearing aid is measured in a 2cc coupler. The following should be taken into account in young infants:
        - The differences between the acoustics of the ear canal and the 2cc coupler
        - The individual variation between patients.
    - For binaural fittings, the RECD should be measured separately for each ear.
        - If measurements for each ear are not possible, the same measured RECD may be used.
    - This option is recommended for:
        - Unvented fittings.
        - Fittings that cannot be verified on the ear without feedback.
        - For infants and young children who cannot sit for real-ear measurements.

- **Real-ear aided response (REAR)** probe microphone measurements [103,107]:
    - The output of the hearing aid is measured in the child's ear using a probe microphone.
    - The response should be measured for a variety of input levels to ensure that the signals are audible across the frequency spectrum.
    - This option is recommended for:
        - Highly vented fittings.
        - For children with earmold tubing that is longer than 35 mm than simulated real-ear aided response measurements.

8.7.1.5 Validation

Validation is a subjective measure that captures the hearing aid user's perceived benefit, satisfaction, and handicap reduction by use of hearing amplification [107].

To validate how the hearing aids are working, consider the age-appropriate outcomes assessment [103]:

- Parental reports such as:
    - Infant-Toddler Meaningful Auditory Integration Scale (IT-MAIS).
    - Children's Abbreviated Profile of Hearing Aid Benefit (CA-PHAB).
    - Client Oriented Scale of Improvement for Children (COSI-C).
    - LittlEARS.
- Clinic/laboratory assessments such as:
    - Aided audiogram.
    - Ling 6 Sounds Test.

8.7.1.6 Orientation

Counselling and orientation should be provided to the child and their parents (or caregivers) [104] [**L1**]. The following topics should be covered [104]:

- When and how the aids are to be worn.
- Handling method(s).
- Operational techniques.
- Maintenance strategies including daily checks and trouble shootings.
- Realistic performance expectations.
- Contact names and/or telephone numbers for support.

Written information on hearing aid use should be handed to parents (or caregivers) [104] [**L1**].

8.7.1.7 Follow up

Routine hearing aid reviews following the hearing aid fitting should be arranged in a family friendly manner [104] [**L1**]. They should be scheduled at least every 3 months in the first 1-2 years of life and every 6 months until age 5 [103]. The following arrangements are required [103,104]:

- Behavioural testing (at each appointment).
- Real ear measures (at each appointment).
- Evaluation and adjustment of amplification (when necessary).
- Adjustment of aid programming (at each appointment).
- RECD measurements (every 3 months in the first year of life; after every ear mold change and or repair).
- Patient/family education and adjustment counselling (social and emotional support).

Note:

- Children experience fluctuation or progression of hearing loss over time more frequently than adults [103]. Thus, more frequent visits and device adjustments may be required.

8.7.2 Cochlear Implantation

8.7.2.1 Selection Criteria

The implantation may be considered in patients with bilateral severe-to-profound sensorineural hearing loss who do not receive adequate benefit from acoustic hearing aids. The following criteria should be fulfilled [**R-GDG**]:

- <50% aided speech recognition in the ear to be implanted.
- <60% aided speech recognition in the un-implanted ear.
- Psychological and motivational suitability.

Consider cochlear implantation in patients with *pre-lingual deafness* (i.e. hearing loss occurred before a child develops speech and language skills) who fulfil the following criteria[**R-GDG**]:

- Age:
    - 12-23 months (weight >10 kg):
        - Bilateral profound SNHL with PTA for both ears >90 dB.
        - Hearing evaluation includes ABR, OAE, cochlear microphonics and impedance audiometry.
        - Objective tests are mandatory in this age group.
    - ≥24 months:
        - PTA >70 dB & open set sentence recognition with best fitting hearing aid <30% (if possible) or failure to develop auditory skills after amplification for over 3 months.
        - Hearing evaluation includes: ABR, OAE, cochlear microphonics, play audiometry, impedance audiometry.
        - Objective tests are mandatory in this age group.
- Not benefiting from powerful hearing aids.
- Family is willing and able to take part in extensive pre- and post-implant assessment and therapy.
- Motivation and appropriate expectations of candidate and the family.
- The school age child must have access to school and therapy programme with a strong auditory emphasis (preferably an oral programme).
- No medical contra-indications.

Auditory verbal therapy training for at least 3 months is required before the implantation [**R-GDG**].

View Pathway

8.7.2.2 Emergency Referral For Cochlear Implantation

Cochlear implantation is recommended in patients with [**R-GDG**]:

- Meningitis complicated by bilateral severe to profound SNHL:
    - The implant is required as early as possible as this condition causes cochlear ossification.
- Imaging indicative of ossification irrespective of the degree of hearing loss.

In patients with meningitis complicated by unilateral hearing loss, the need for cochlear implant should be discussed on case to case merit [**R-GDG**].

9 Physical Impairment

9.1 Common Causes

Common causes of physical impairments include[19,26–34]:

- Perinatal events.
- Birth injuries and teratogens.
- Metabolic disorders.
- Chromosomal and genetic conditions.
- Maternal chronic conditions and malnutrition.
- Acquired health conditions.
- Infections (e.g. meningitis, encephalitis).
- Accidental and non-accidental injury.

9.2 Detailed History

In addition to general history, ask specifically about the following[26,108–110]:

- Child's moving preferences, specific features (standing, walking, running, climbing stairs).
- Presence of aches and pains. If present, specify the type.
- Presence and frequency of seizures (if any).
- Presence of any other impairment.
- Child's relation and attitude to physical activities and sports.
- Family history of physical impairments, genetic syndromes of metabolic conditions that may be associated with physical impairment.
- Presence of warning signs specifically related to the physical status [**R-GDG**]:
    - Does not reach for toys.
    - Has trouble releasing objects voluntarily.
    - Does not reach across the body during play.
    - Hand preference in the first year of life.
    - Does not put hands out if falling.
    - Has poorly developed hand or finger coordination and cannot pick up or hold objects.
    - Has poor balance or stumbles and trips frequently.
- Presence of common causes of physical impairments (see *Section 9.1*).
- Ability to complete activities of daily living.
- Equipment used and needed, if any [**R-GDG**].

9.3 Examination

General physical examination should include the following components:

- Growth parameters, including head circumference trajectories[110,111].
- Weight monitoring and assessment[9,109,112]:
    - For a child with significant contractures, consider using tibial length to estimate linear growth and to calculate BMI[112].
    - For details refer for the NCG on *The Management of Obesity in Children* by MOPH[113].
- Screen for the presence of delay in motor milestones.
- Screen for the presence of any dysmorphic features (e.g. microcephaly/plagiocephaly, polydactyly, albinism, piebaldism)[5,110].
- Screen for the presence of any asymmetries.

- Aspects of general behaviour (e.g. presence of drooling).
- Systemic examination including skin for neurocutaneous stigmata[110]:
- Neurological and musculoskeletal examination [**R-GDG**]:
    - Abnormal posture.
    - Persistent primitive reflexes.
    - Presence of protective reflexes (parachute, positive supporting, etc.).
    - Abnormal head control.
    - Abnormal movements (e.g. hyperkinesia, rigidity, choreoathetoid movements, ataxia).
    - Abnormal gait.
    - Presence of contracture, deformities, or loss of muscle mass (including leg length discrepancies).
    - Assess range of movement (active and passive).
    - Assess muscle tone.
    - Assess power.
    - Assess deep tendon reflexes (assess primitive reflexes in infants).
    - Cranial nerve examination.
- Signs of non-accidental injury or neglect[47].

9.4 Investigation

When diagnosis is not possible following the examination and clinical evaluation, consider investigations and laboratory testing.

Brain and spinal cord imaging or electroencephalogram (EEG) are frequently required to support a diagnosis of cerebral palsy[30], spina bifida[27], congenital and acquired hydrocephalus[28,31], and other conditions impacting brain morphology and functioning.

Consider the following options:

- MRI (preferred over CT scans[31]).
- CT scan (if MRI is not available or contraindicated).
- Cranial ultrasound scan (in a young infant).
- EEG[30].

Note:

- MRI and CT scans can be used in combination when required, e.g. to diagnose congenital and acquired hydrocephalus[31].

If the diagnosis is unclear, consider further investigations:

- Genetic and metabolic screening (blood and urine tests)[30,33,114].
- Electromyogram (EMG)[30,33].
- 12-lead electrocardiogram (ECG)[33].
- Chest radiograph[33].
- Ultrasound scans:
    - Urinary tract if spina bifida is suspected[27].
- Muscle biopsy[114,115]:
    - Consider if muscular dystrophy is suspected and genetic testing is negative.
- Nerve conduction studies [**R-GDG**].

Radiography of affected limbs should be performed in patients with congenital limb, hip, and spinal deformities[116].

9.5 Differential Diagnosis

If a physical impairment is suspected, consider the following diagnoses:

- Osteogenesis imperfecta[29].
- Limb deficiency disorder[116].
- Developmental dysplasia of the hip[117].
- Club foot deformity [**R-GDG**].
- Severe genu valgus or varus [**R-GDG**].
- Cerebral palsy [19,26,30,52,118].
- Tourette syndrome [49,119].
- Spina bifida[26,27].
- Muscular dystrophy[114,115].
- Hydrocephalus[27,28,31].
- Congenital heart disease, including[32]:
    - Atrial septal defect.
    - Atrioventricular septal defect.
    - Coarctation of the aorta.
    - Double-outlet right ventricle.
    - d-Transposition of the great arteries.
    - Ebstein anomaly.
    - Hypoplastic left heart syndrome.
    - Interrupted aortic arch.
    - Pulmonary atresia.
    - Single ventricle.
    - Tetralogy of Fallot.
    - Total anomalous pulmonary venous return.
    - Tricuspid atresia.
    - Truncus arteriosus.
    - Ventricular septal defect.
    - Other.
- Congenital pulmonary disease, including[37,120]:
    - Diaphragm (e.g. hernia of the diaphragm, cong diaphragmatic hernia).
    - Lungs:
        - Chronic obstructive pulmonary disease.
        - Lung sequestration.
        - Bronchopulmonary dysplasia.
        - Pulmonary fibrosis.
        - Cystic adenomatoid malformation.
        - Bronchogenic or foregut cyst.
        - Asthma.
    - Blood supply (e.g. aberrant vascularisation, double arch of the aorta).
    - Airways (e.g. tracheal rings, tracheomalacia, tracheal atresia).
    - Larynx and oral cavity.
- Other conditions.

View Pathway

9.6 Criteria for Specialist Referral

9.6.1 Referral to General Paediatrics

Patients should be referred to a general paediatrician, if at least one of the following is present[9,19,36,37]:

- Age < 14 years.
- Delay or regression in motor milestones.
- Failure to thrive.
- Presence of non-physical impairments (e.g. hearing, visual or intellectual).
- Clinical suspicion of physical impairment.
- Parent, carer, or health care provider suspects a physical impairment.

9.6.2 Referral to Paediatric Rehabilitation

Patients should be referred to paediatric rehabilitation if they have a motor impairment that interferes with function[38]. For example:

- Cerebral palsy.
- Spina bifida.
- Any other brain or spinal injury.
- Limb deficiency.
- Myopathy.
- Neurodegenerative disorders.
- Neuromuscular weakness.
- Peripheral neuropathy.
- Genetic or metabolic disorders resulting in significant functional limitations.
- Acquired brain injury (traumatic, infectious, epileptogenic, etc.) [**R-GDG**].
- Severe disabling burn injury [**R-GDG**].

10 Intellectual and Developmental Disabilities

10.1 Common Causes

Common causes of intellectual impairments include[39,40]:

- Genetic conditions:
  - Neurodevelopmental disorders.
  - Neurodegeneration.
  - Metabolic disorders.
  - NB: Consanguinity is a risk factor for genetic disorders.
- Maternal conditions in pregnancy:
  - Infections (i.e. rubella, HIV, CMV, syphilis, and toxoplasmosis).
  - Medication (e.g. teratogenic medications, opioids).
  - Foetal alcohol syndrome.
- Birth defects, including:
  - Asphyxia.
  - Head trauma.
- Associated health conditions, including:
  - Spina bifida and hydrocephalus.
  - Encephalopathy.
  - Intracranial tumour.
  - Seizures.
- Infections (e.g. encephalitis and meningitis).
- Malnutrition (e.g. iron deficiency).
- Exposure to toxic substances (including chemotherapy, lead poisoning).
- Accidental injury.
- Non-accidental injury.

10.2 Detailed History

In addition to general history taking (*Section 5*), ask specifically about the following[6,39,40]:

- Language and communication skills.
- Socioemotional skills and social interactions.
- Challenging behaviours (if any).
- Child's mood.
- If school aged to ask about:
  - Academic performance at school.
  - Leisure-time activities, manner of playing (e.g. immature play).
  - Any behavioural disturbance reported at school.
- Parent language, education, and employment.

Also check for the child's awareness to dangers, their mannerisms, and emotional behaviours like empathy, or seeking parental attention [**R-GDG**].

10.3 Examination

The basic examination for intellectual impairments should include:

- General physical examination (see *Section 9.3*) and the following in particular:

    - Screen for the presence of any dysmorphic features (e.g. facial dysmorphisms, microcephaly or macrocephaly)[40].
    - Measure head circumference[40] (when required) and evaluation of head shape[4].
- Developmental evaluation in order to identify delays in the developmental milestones and diagnose developmental delays or conditions [**R-GDG**]:
    - Consider the following developmental assessments:
        - Schedule of growing skills (SOGS).
        - The *Griffith Mental Development Scales*.
        - The *Bayley Scales of Infant and Toddler Development*.
        - The *Ages and Stages Questionnaire* for young children[40,121].
- Evaluation of communication skills[40]:
    - Verbal communication skills:
        - Form, function, and use of language.
        - Fluency.
        - Tone.
        - Comprehension.
        - Frequency and complexity of verbal communication.
        - Vocabulary.
        - Echolalia.
    - Non-verbal communication skills:
        - Gestures (including articulation).
        - Body language.
        - Facial expression.
- Observation of general behaviour (e.g. oddities in behaviour, attention span, presence of drooling)[5,6].
- Mental status examination:
    - Evaluation of challenging behaviours and psychiatric problems (if any)[4].
- Evaluation of intellectual and adaptive functioning through neuropsychological testing:
    - IQ tests may be used to assess the intellectual function of the patient[39]. Consider other assessment strategies if IQ tests are not applicable (e.g. children <3 years old)[6].
    - Consider using *Vineland Adaptive Behavioural Scale* [122] to assess adaptive behaviour[6].

Use *Table 7.4.3* to determine severity of an intellectual impairment. An appropriate standardised test of intellectual aptitude should be selected for children. Consider [41,42]:

- The *Wechsler Preschool and Primary Scale of Intelligence, Third Edition* (age range 2 years 6 month – 6 years old).
- The *Wechsler Intelligence Scale for Children, Fourth Edition* (school children).
- The *Wechsler Adult Intelligence Scale, Third Edition* (for adolescents ≥16 years old.)
- *Stanford Binet Intelligence Scales, Fifth Edition* (age range 2 to 85+ years).

Categories	IQ Score	Daily Activities
Mild	50-69	Can live independently with minimum levels of support.
Moderate	36-49	Independent living may be achieved with moderate levels of support, such as those available in group homes.
Severe	20-35	Requires daily assistance with self-care activities and safety supervision.
Profound	<20	Requires 24-hour care.

Table 7.4.3: Severity of Intellectual Impairments[123].

10.4 Investigation

When a specific diagnosis is not clear following the examination and clinical evaluation, consider investigations and laboratory testing.

Neuroimaging is frequently required to assess morphology and functioning of the brain. It is particularly useful to identify micro- and macrocephaly, cerebral developmental abnormalities or in the evaluation of seizures[39,40].

Consider the following options if any of the above diagnoses are suspected or when neurological examination is abnormal[35,39,40]:

- MRI:
  - Preferred over CT scans[4].
  - Sedation may be needed [**R-GDG**].
- CT scans:
  - Radiation exposure should be considered [**R-GDG**].

If diagnosis is not clear, consider other tests according to the clinical presentation:

- Blood tests, including[4,39,40]:
  - Complete blood count.
  - Copper, ceruloplasmin levels.
  - Ferritin and vitamin B12 if dietary restriction or pica are present.
  - Lead levels.
  - Thyroid function tests[4,40]:
    - If thyroid stimulating hormone is abnormal.
    - If acquired hypothyroidism is suspected.
  - Creatine phosphokinase.
  - Plasma amino acids.
- Urine biochemistry, including[4,39]:
  - Organic acids.
  - Creatine metabolites.
  - Purines, pyrimidines.
  - Glycosaminoglycans.
- EEG[4,39]:
  - If epilepsy is suspected.
- Testing for congenital infections[4].
- Vision and hearing testing[4,35]:
  - Refer to *Sections 7* and *8*.
- Testing for specific metabolic disorders[40].
- Testing for genetic syndromes (e.g., fragile X syndrome) and chromosomal microarray analysis[39,40].

10.5 Differential Diagnosis

Children <5 years old with developmental delays should not receive a diagnosis of intellectual impairment[4]. Global Developmental Delay (GDD) may be considered instead.

The diagnosis of intellectual disability in children requires deficits in intellectual function, and deficits in adaptive function, and onset before the age of 18[39,77].

Children with suspected intellectual impairment should be investigated and managed in the same way as children with GDD [**R-GDG**].

Certain intellectual impairments can be determined in pre-school children >5 years old, when cognitive abilities become more stable[40]. Children with mild levels of intellectual disability may not be identified and adequately diagnosed until school age[39,40].

Severity of the impairment may be estimated by IQ test results (see *Table 7.4*).

If an intellectual impairment is suspected, consider the following most common underlying causes:

- Phenylketonuria[39,124].
- Down syndrome[39,125].
- Congenital hypothyroidism[126].
- Fragile X syndrome[39,127].
- Foetal alcohol spectrum disorders[39,87].
- Prader-Willi syndrome[128].
- Cri du chat syndrome[129].
- Other genetic syndromes and inherited metabolic disorders, include[39]:
    - Lesch-Nyhan syndrome.
    - Niemann-Pick disease.
    - Hunter disease.
    - Hurler disease.
    - Maple syrup urine disease.
    - Hartnup disease.
    - Classical homocystinuria.
    - Galactosaemia.
    - Neurofibromatosis 1.

If an intellectual impairment is suspected but a specific diagnosis cannot be reached, consider the following[39,40,77]:

- Debilitating medical disease.
- Sensory disability:
    - Other impairments (e.g. deafness or blindness) may lead to a false-positive diagnosis of intellectual disability.
- Childhood anxiety disorder [**R-GDG**]:
    - Selective mutism may interfere with educational achievement.
- Speech/language disorder:
    - Aphasia may be mistaken for intellectual disability.
- Child abuse:
    - It can cause developmental delays in language and socialisation leading to defects in adaptive functioning.

10.6 Criteria for Specialist Referral

Patients should be referred to a developmental paediatrician if at least one of the following is present[4,39,40]:

- A genetic or metabolic disorder is suspected.
- Diagnosis of GDD.
- Delay in achieving developmental milestones.
- Regression in milestones.
- Identification of learning difficulties in school-age children.

- Parental, carer, or health care provider suspects any kind of intellectual impairment.
- Other impairments (hearing, visual or physical) are present.

11 Mental Health Disorders

Appropriate screening for mental and behavioural problems should be performed in all patients with disabilities to evaluate and assess mental health disorders, challenging behaviours, suicidal thoughts and self-harm attempts, which are frequent in such patients[4,6,19,26,40,43].

Note that parents and carers play a central role in recognising and assessing emotional difficulties and mental health problems (see details in *Section 13.8*)[19].

11.1 Differential Diagnosis

If a child is suspected for a mental health disorder, consider the following most common diagnoses[19,40]:

- Depression.
- Generalised anxiety disorder (GAD).
- OCD.
- ADHD.
- Disruptive behaviour disorders:
    - Conduct disorder.
    - Oppositional defiant disorder.
- Panic disorder.
- Psychotic disorders.
- Eating disorders (e.g. anorexia/bulimia)

11.2 Challenging Behaviours

Challenging behaviours include any abnormal patterns of behaviour which are above the expected norm for age and level of development[44]. Challenging behaviours in children with impairments are strongly associated with parental stress[130] and are usually triggered by pain, discomfort, physical and emotional distress, sleep disturbances, and socio-emotional deficits[19,40].

Challenging behaviours can take both internalising and externalising forms, manifested as[40,44,49]:

- Aggression, including physical aggression towards self or others.
- Poor self-esteem.
- Withdrawal.
- Antisocial behaviour.
- Non-compliance.
- Tantrums, including meltdowns.
- Anti-social behaviours (e.g. property destruction).

In addition to impairments, such children frequently have psychological problems manifested as[39,40,90,130]:

- Challenging behaviours, talking many forms from aggression to withdrawal[19,40].
- Mental health disorders (see *Section 11*).

11.3 Criteria for Specialist Referral

Patients should be referred to a specialist if at least one of the following is present[43–45]:

- Repeated negative contents of play.

- Signs of disinhibition.
- Persistent exposure to harmful influences (e.g. neglect, traumatising environment).
- Persistent negative mood for ≥2 weeks.
- Persistent hyperkinetic behaviour.
- Aggression.
- Severe affective symptoms.
- Suicidal thoughts or attempts.

12 Specialist Management

12.1 Multidisciplinary Management

Care to children with impairments, especially those with complex needs, should be provided by an MDT of professionals, using an interdisciplinary approach[1,2,19], which has been individualised to the needs of the patient. The management may require consultation with or referral for additional treatment, therapy, or rehabilitation[1,2,6,19].

The composition of the MDT and the roles of specialists may vary depending on their expertise and resources available in the clinical setting. The MDT may include the following specialists[2,19,22,74,112]:

- Patient's primary care physician.
- Paediatrician.
- Physical therapist.
- Nurse.
- Occupational therapist.
- Rehabilitation physician (physiatrist).
- Speech and language therapist.
- Psychologist or psychiatrist.
- Ophthalmologist.
- Orthoptist.
- Educational psychologist.
- Otolaryngologist.
- Social worker.
- Neurologist (for those with neurological symptoms).
- Dietician (for those with overweight, obesity, or poor weight gain).
- Paediatric rheumatologist or immunologist (if an autoimmune disease is suspected).
- Surgeon (e.g. orthopaedic or neurosurgeon).
- Developmental paediatrician.
- Nephrologist (for those with spina bifida and genitourinary anomalies).
- Urologist (for those with spina bifida and genitourinary anomalies).

The MDT tasks should include[1,19]:

- Assessment and treatment of the patient's primary condition.
- Assessment and treatment of comorbid conditions.
- Assessment of child's environment both at school and home [**R-GDG**].
- Recognition and assessment of psychological problems.
- Practical developmental advice.
- Careful and systematic education of the family and patient about the natural history of the condition, most effective interventions, and expected outcomes [**R-GDG**].
- Support for the child and parents.
- Provision of an enhanced clinical and developmental follow-up programme for children who are at increased risk of developing disability.
- Early intervention rehabilitation programme [**R-GDG**].
- Assign a patient care coordinator who will arrange appointments with specialists for early assessment [**R-GDG**].

Documents should be reviewed as and when required and dictated by clinical pathways and quality reviews towards efficiency and efficacy of interventions or treatment plans [**R-GDG**].

12.2 Assessment and Planning for Early Intervention

Accurate assessment is required to obtain useful and accurate information about a child's skills and functioning and about the surrounding environment. It is required to assist parents, health-care providers, and other individuals involved in providing care to the child to better understand, plan for and support the development and inclusion of the child with a disability [47].

Early childhood intervention (ECI) is a system designed to support family patterns of interaction that best promote child development [131].

ECI programmes and services provide individualised attention and support to [132] [**L1**]:

- Children who are at high risk of developmental delay; and
- Children with developmental delays
- Children with disabilities.

These programmes and services include [47,131,132]:

- Medical.
- Rehabilitation (e.g. therapy and assistive devices).
- Early childhood development programmes.
- Family-focused support (see *Sections 13.3* and *13.8*).
- Social and psychological.
- Special education needs.
- Service planning and coordination.
- Assistance and support to access mainstream services such as preschool and child-care (e.g. referral).

12.3 Shared Care with Primary Care

Children with impairments and/or disability frequently require interdisciplinary assessment and care (see *Section 13.1*) [1,2,19]. Collaboration within and among Primary and Secondary Care settings as well as among professionals within the same specialty is crucial especially when treating children with complex care needs [48].

The aim of the collaboration is to[48]:

- Improve the efficiency and the continuity of care.
- Improve quality outcomes.
- Coordinate care across all levels and between specialists.
- Assist parents and caregivers in providing optimal care to the child

The communication process between professionals is facilitated by[48,133,134]:

- Demonstration of a team culture and interdisciplinary atmosphere of trust.
- Sharing medical records between specialists.
- Sharing professional roles and expertise, planning, and decision-making.
- Utilisation of communication strategies that promote intra-team communication:
    - Introduction of a common terminology.
    - Adoption of a standard language (e.g. Unified Modelling Language, UML [135]).
- Providing a sufficient team staffing to meet the needs of patients and enhance smooth functioning.
- Delivering quality patient-focused care within complex contexts with documented outcomes.

12.4 Psychological Support

Children with impairments are more likely to be bullied and experience abuse[40,49–51] and, therefore, require recognition of psychological problems and psychological support[19] [**L1, RGA**]:

- Signs of abuse and neglects should always be recorded and assessed[47].
- Symptoms of depression should not be overlooked in individuals with intellectual and language impairments when other behavioural problems are prominent[39].
- Challenging behaviours should be managed[47] according to *Section 13.6* and the respective guidelines.

Psychological interventions should be personalised. They should be developed, planned and implemented in collaboration with patients and their parents or carers[50] [**L1, RGA**]. The interventions may focus on[50]:

- Enhancing strengths wellbeing.
- Reducing stress.
- Ameliorating skill deficits.
- Recognizing and addressing health promotion issues.
- Providing parent support.

12.5 Managing Pain and Distress

It should be explained to the patient, parents and/or carers that pain is common in children and young people with impairments and disabilities, especially in those with severe symptoms[19,88].

Assessing the presence and degree of pain, discomfort, distress, and sleep disturbances should be carried out at every visit[19] [**L1, RGA**]:

- It can be challenging, especially in children with:
    - Communication difficulties.
    - Learning or intellectual disabilities.
    - Difficulties with registering or processing sensory information.
- Consider using tools to identify pain or assess severity of pain:
    - For children and young people with communication difficulties:
        - Paediatric Pain Profile.
        - Non-communicating Children's Pain Checklist – postoperative version.
        - FLACC for non-verbal or pre-verbal children [**R-GDG**].
    - For children and young people without communication difficulties:
        - Numeric pain rating scale.

Common causes of pain, discomfort, and distress include[17,19]:

- Headaches.
- Musculoskeletal problems (e.g. scoliosis, hip disease, non-specific back pain).
- Increased muscle tone (including dystonia and spasticity).
- Muscle fatigue and immobility.
- Osteopenia [**R-GDG**].
- Constipation.
- Gastro-oesophageal reflux disease.
- Dysmenorrhea.
- Non-specific abdominal pain.
- Tooth decay / dental pain
- Infections and inflammations (e.g. UTIs).
- Non-physical causes:

- Psychological and emotional distress.
- Increased sensitivity to environmental triggers (e.g. light or sounds).
- Thirst or hunger.

Note that some patients may have additional hidden (non-visible) disabilities (e.g. epilepsy or respiratory disorders) in addition to the primary impairment[26]. They may cause or worsen stress and pain.

Initial management of pain and distress should focus on identifying and relieving the source of pain. If the source of pain cannot be relieved easily (severe tooth decay, osteopenia) then analgesics should be suggested for patient comfort until the issues can be addressed [**R-GDG**].

Behavioural and psychological interventions may be needed for long term, chronic pain that leads to significant behavioural or psychiatric symptoms [**R-GDG**].

12.6 Managing Challenging Behaviours

If challenging behaviours are present, the following treatment options may be considered[39,40,53] [**L1, RGA**]:

- First-line: non-pharmacological management with behavioural therapy (see *Section 13.6.1*).
- Second-line: pharmacological management with psychotropic medications (see *Section 13.6.2*).

12.6.1 Non-Pharmacological Management

If management of challenging behaviour is required, consider the following therapies delivered to the child[39,40,53] [**L1, RGA**]:

- Cognitive behavioural therapy.
- Applied behavioural analysis.
- Functional behavioural analysis.
- Behavioural planning.
- Other approaches.

Behavioural therapies should aim at[39,40]:

- Encouraging positive behaviours while discouraging undesirable behaviours.
- Providing positive reinforcement and benign punishments.
- Avoiding triggers of negative demeanour.
- Shunning misconduct.
- Prevention or reduction of any troublesome behaviours.
- Adjusting negative thoughts and emotional stress.
- Coping with pain.

Consider involving parents or carers in the management of challenging behaviours and providing them with special parent-training programmes (see *Section 13.8*)[40,44,53,54] [**L1, RGA**]. Note that sustained continuous therapy is more effective than episodic programming[53].

If behavioural therapies alone do not provide sufficient management of behavioural symptoms, consider adjuvant therapy with medications (see *Section 13.6.2*).

12.6.2 Pharmacological Management

Pharmacological therapy with psychotropic medications should only be started if[53] [**L1, RGC**]:

- Other interventions alone are insufficient.
- If the risk to the person or others is very severe (e.g. due to violence, aggression, or self-injury).

It should only be prescribed and monitored by a developmental paediatrician or psychiatrist working as part of an MDT [**R-GDG**] and in accordance with the respective guidelines:

- The preference should be given to the combined (behavioural management along with pharmacological therapy) over pharmacological therapy only[39,40].
- Psychiatrists should guide the appropriate balance of behaviour and medication[40].

If pharmacotherapy is required:

- Benefits and harms of the pharmacotherapy should be discussed with the patient (when applicable), family members, and carers[53] [**L1**].
- Consider medications listed in *Table 8.6.2* below.
- Low starting doses, slow titration are recommended[40] [**L2, RGA**].
- Systematic evaluation of symptoms is mandatory as patients with disabilities are at high risk for polypharmacy[39,40] [**L2, RGA**]. They may be at a higher risk of side effects and may need lower dosages[39].
- Medications should be withdrawn if the patient is not benefiting from taking them [**R-GDG**].

Type of Medications	Target Behaviours
Typical antipsychotics: • Haloperidol. • Chlorpromazine.	• Agitation. • Aggression. • Hyperactivity. • Self- injurious behaviour.
Atypical antipsychotics: • Risperidone. • Aripiprazole. • Olanzapine.	• Aggression. • Disruptive behaviours. • Hyperactivity. • Irritability. • Self- injurious behaviour. • Repetitive behaviours.
Selective serotonin reuptake inhibitors (SSRIs): • Fluoxetine. • Paroxetine. • Sertraline. • Fluvoxamine.	• Anxiety. • Depressed mood. • OCD. • Self- injurious behaviour. • Repetitive behaviours. • Stereotyped motor movements.
Selective serotonin and norepinephrine reuptake inhibitor (SNRIs): • Atomoxetine.	• ADHD. • Hyperactivity.
Mood stabilisers: • Lithium. • Valproic acid. • Carbamazepine.	• Aggression. • Impulsivity. • Mood lability. • Self- injurious behaviour.

Type of Medications	Target Behaviours
Stimulants: • Methylphenidate. • Melatonin.	• ADHD. • Depressed mood. • Insomnia. • Loss of appetite.
Alpha-agonists: • Clonidine. • Guanfacine.	• ADHD. • Hyperactivity. • Impulsivity. • Inattention. • Tics.

Table 8.6.2: Psychopharmacology in Children and Adolescents with Challenging Behaviours[39,40,53,136].

12.7 Managing Adolescents

Sexual development and the onset of puberty may be displaced in patients with disabilities:

- Girls with neurodevelopmental disabilities may have earlier sexual development[137].
- Girls with ASD may have a delay in the onset of menarche[138].
- Adolescents chronic inflammation or nutritional imbalance may have a delay in the onset of puberty[55].

Patients and their parents or carers should be provided with information about the following topics tailored to their individual needs[19,47,55–58]:

- Menstruation, including:
  - Consequences of suppressing menarche.
  - Mood alterations.
  - Premenstrual behavioural changes.
  - Changes in symptoms (e.g. changes in the seizure pattern).
  - Heavy menses and pain management.
  - Assistance in managing menses.
- Fertility and contraception.
- Sex and sexuality.
- Parenting.
- Risks of sexual abuse and violence.
- Protection measures and how to report abuse.

Note that certain medications can lead to hormonal imbalance (e.g. elevated prolactin concentrations) and sexual problems (e.g. infertility, anovulation, amenorrhea)[55,139].

Challenging behaviours are especially common in young people with disabilities[51]. Refer to *Section 13.6* and the corresponding guidelines for the management.

12.8 Involving Parents and Family

Parents and carers are key partners in the early intervention, assessment, and planning process as well as in the clinical and developmental follow-up programme[19,47,131] [**L1**]. They play central role in recognising and assessing emotional difficulties and mental health problems in children with impairments and/or disability[19] [**L1**]. They are also central in the child's adjustment to, and acceptance of their condition.

Siblings and other key relatives can also be involved in the care plan[6,48] [**L2**]. Shared decision making is a critical element in providing optimal care [**R-GDG**].

Parents or carers should be provided with clear and up-to-date information in simple language on an ongoing basis[6,19,39] [**L1, RGA**]. They may also require counselling and support on how to address the child's needs[47,52].

- Information about the impairment/disability:
    - Risk factors.
    - Diagnosis.
    - Prognosis.
    - Comorbidities.
    - Treatment options.
- Contact details for:
    - Local and national support organisations.
    - Organisations that can provide advice on welfare benefits.
    - Organisations that can provide information on educational support and social care.
- Information to help prepare for the future (e.g. transition to adult services).
- Disability certificate for the child.
- Information and education about the role of physical, occupational, and/or speech therapists.
- Information about the importance of home-based programmes to achieve optimal outcomes for children with physical disabilities.

A family assessment should be conducted to determine the resources, concerns, and priorities of the family [12]. They may need[6,27,39,44,90]:

- Resources for health care and therapy.
- Special equipment and mobility aids (e.g. wheelchairs, leg braces).
- Supporting devices (e.g. word boards, electronic voice output communication aids, magnification lenses, etc.).
- Educational support or special education arrangements.
- Vocational training.
- Individual or group counselling, caregiver training, support programmes, self-help groups.

When required, parents or carers should be provided with an individualised parental skills training:

- Consider the following parent-training programmes[40,44,53,54] [**L1, RGA**]:
    - *Stepping Stones Triple P* - Positive Parenting Programme.
    - Parent child interaction therapy.
    - *NAS EarlyBird* - Autism Parenting Programme.
    - Parent-mediated or parent-delivered interventions.
    - More Than Words - The Hanen programme.
- The programme should focus on[44]:
    - Improving parenting skills to manage child behaviour (including challenging behaviours).
    - Learning how to identify, define and observe problem behaviours in new ways.
    - Learning strategies to prevent and respond to oppositional behaviour.

Provide parents with the following advice:

- Ensure safety of the home environment[3]:
    - Cover sharp corners.
    - Keep floor and pathways clear of objects.
    - Ensure floor is not slippery (e.g. polished floors, mats or rugs, water on floor).
    - Cover electrical sockets and cords.
    - Ensure safety on stairs.
- Children with learning disabilities may require a predictable structure to their daily routine (e.g. they may find it hard to understand why and when they need to sleep)[90].

- Some children may need an extended toilet training programme, or they may never learn to use the toilet on their own. Some health conditions require a permanent colostomy or ileostomy[90].
- Stress the importance of physical activity in children with disabilities[109]. Encourage participation in daily recreation [**R-GDG**]. Refer to sports programmes that are adapted for children with special needs [**R-GDG**].
- Ensure safety of the child in society:
    - Social isolation, powerlessness, and stigma faced by children with disabilities make them vulnerable to sexual and psychological abuse, neglect, violence, and exploitation[47,88].

Parents of children with impairments and/or disabilities and other family members often bear a significant amount of stress, which can lead to social isolation, life dissatisfaction and/or mental health problems[39,51]. Healthcare specialists must[1,6,39]:

- Provide emotional support.
- Routinely screen parents and primary caregivers for stress-related disorders.
- Suggest referral to support services as needed.

13 Prevention of Disabilities in Early Childhood

Anticipatory guidance specific to the age of the patient should be provided at every well-child visit [**R-GDG**] and include[140–142]:

- Parent and child education and counselling regarding feeding and nutrition, sleeping, nurturing, injury prevention, growth, learning, behaviour, discipline, communication, language development, and toileting (see some key points below).
- Information about the cognitive and social-emotional development of the child.
- Information about creating stimulating, challenging, and supportive environments (including positive parent-child interaction) to promote optimal developmental outcomes.
- Information about the benefits of healthy lifestyles and practices that promote injury and disease prevention (e.g., using bicycle helmets, sunscreen, etc.).

Some health conditions associated with disability may be detected during prenatal screening as well as during or after birth[47]. Early identification and proper management of these health conditions helps to prevent disability or reverse the damage caused by the impairment to some extent[6,18]:

The best available strategy to prevent disability in children is to identify and eliminate or control environmental risk factors that may potentially cause trauma and/or lead to disability (i.e. family issues and environmental control).

- Safety regulations and using safety restraints when in the car from infancy onward:
    - Motor vehicle crashes are the most common cause of traumatic brain injury related death and acquired disability in children[143].
    - Wearing a seatbelt in the front seat reduces the risk of fatal injury by 45% and moderate to critical injury by 50%[144].
    - The use of car seats increases a baby's chance of surviving by 70% and avoids serious harm in older children by 50-80%[143].
- Avoidance of environmental toxins in air, water, and soil[145].
- Dietary recommendations:
    - Proper nutrition and supplementation before and during pregnancy (e.g. folic acid supplements to prevent spina bifida)[27].
    - Avoidance of alcohol and toxic substances before and during pregnancy (e.g. to prevent foetal alcohol spectrum disorders)[39,87].
    - Practicing healthy eating[113] and adherence to a diet when necessary (e.g. low-protein diet to prevent the neurologic sequela of phenylketonuria)[124].
- General prophylaxis:
    - Credé's prophylaxis and antenatal testing before and during pregnancy (e.g. to prevent ophthalmia neonatorum or hearing loss)[15,59].
    - Preventing infections through good hygiene[59].
    - Follow-up and screening of infants and children who fall within a high risk group[7,24].
- Immunisation:
    - Immunisation of children against childhood diseases[59].
    - Immunisation of adolescent girls and women of reproductive age against rubella before pregnancy[59].
- Infections:
    - Treatment of parental infections including sexually transmitted diseases before and during pregnancy[15,59].
    - Treatment of and immunisation against childhood infections (e.g. mumps, measles, rubella, meningitis to prevent visual and hearing impairments)[14,59].
    - Avoiding the use of particular medications and substances which may be harmful (e.g. aminoglycoside antibiotics to prevent hearing loss) unless prescribed and monitored by a qualified specialist[20,59].

Non-modifiable risk factors include genetics, ethnicity, gender and other parameters that are out of control:

- Genetic counselling may be considered for families that have children with impairments/disabilities[1] [**L2, RGA**] as they may have an increased chance of having another child with similar health conditions (e.g. ASD)[53,146,147].

Education of population in general on impairments and disability, their causes, prevention, and identification is highly desirable[59] [**L1**].

14 Key Considerations for Patient Preferences

Patient preferences refer to patient/caregiver perspectives, beliefs, expectations, and goals for health and life, and to the steps employed by individuals in assessing the potential benefits, harms, costs, and limitations of the management options in relation to one another. Patients and caregivers may have preferences when it comes to defining their problems, identifying the range of management options and selecting or ranking the outcomes used to compare these options.

It is important for healthcare professionals to develop an understanding of the patient as an individual and the unique way in which each person experiences a condition and its impact on their life.

The following recommendations are therefore made for physicians and other healthcare professionals regarding general principles of patient care in Qatar:

- **Respect Patients:** Treat patients with respect, kindness, dignity, courtesy and honesty. Ensure that the care environment is conducive to discussion and that the patient's privacy is respected, particularly when discussing sensitive, personal issues. Ask the patient how they wish to be addressed and ensure that their choice is respected and used.

- **Maintain Confidentiality:** Respect the patient's right to confidentiality and avoid disclosing or sharing patients' information without their informed consent. In this context, students and anyone not directly involved in the delivery of care should first be introduced to the patient before starting consultations or meetings, and let the patient decide if they want them to stay.

- **Clarify Third-Party Involvement:** Clarify with the patient at the first point of contact whether and how they like their partner, family members or carers to be involved in key decisions about their care or management and review this regularly. If the patient agrees, share information with their partner, family members or carers.

- **Obtain Informed Consent:** Obtain and document informed consent from patients, in accordance with MOPH policy and guidance.

- **Encourage Shared Decision Making:** Ensure that patients are involved in decision making about their own care, or their dependent's care, and that factors that could impact the patient's participation in their own consultation and care including physical or learning disabilities, sight, speech or hearing impairments and problems with understanding, reading or speaking English are addressed.

- **Disclose Medical Errors:** Disclose errors when they occur and show empathy to patients.

- **Ensure Effective Communication:** Explore ways to improve communication including using pictures, symbols or involving an interpreter or family members (only if an interpreter is unavailable). Avoid using medical jargon. Use words the patient will understand and confirm understanding by asking questions.

- **Ensure Continuity of Care:** Provide clear and timely sharing of patient information between healthcare professionals especially at the point of any transitions in care.

15 Performance Measures

A list of potential performance measures is given below in *Table 16.1*.

Number	Numerator	Denominator
ED01	The number in the denominator who have a named lead practitioner.	The number of patients aged <18 years with a recorded disability.
ED02	The number in the denominator who have received a referral for a full assessment in the specialist care settings.	The number of patients aged <18 years with a recorded disability.
ED03	The number in the denominator who have received a specific diagnosis.	The number of patients aged <18 years with a recorded disability.
ED04	The number in the denominator who had a health check within the past 12 months.	The number of patients aged <18 years with a recorded disability.

Table 16.1: Performance Indicators.

16 References

1. Keil, S., Fielder, A. & Sargent, J. Management of children and young people with vision impairment: diagnosis, developmental challenges and outcomes. *Arch Dis Child* **102**, 566–571 (2017).
2. Freeman, K. F. *Care of the Patient with Visual Impairment (Low Vision Rehabilitation)*. (American Optometric Association, 2007).
3. Family Health Development Division. CARE OF CHILDREN WITH SPECIAL NEEDS. Manual on the Management of Children with Visual Impairment. (2003).
4. Bélanger, S. A., Caron, J. & Canadian Paediatric Society. POSITION STATEMENT. Evaluation of the child with global developmental delay and intellectual disability. *Paediatr Child Health* **23**, 403–410 (2018).
5. Swaminathan, M., Jayaraman, D. & Jacob, N. Visual function assessment, ocular examination, and intervention in children with developmental delay: A systematic approach. Part 1. *Indian J Ophthalmol* **67**, 196–203 (2019).
6. Kishore, M. T., Udipi, G. A. & Seshadri, S. P. Clinical Practice Guidelines for Assessment and Management of intellectual disability. *Indian J Psychiatry* **61**, 194–210 (2019).
7. Wroblewska-Seniuk, K. E., Dabrowski, P., Szyfter, W. & Mazela, J. Universal newborn hearing screening: methods and results, obstacles, and benefits. *Pediatric Research* **81**, 415–422 (2017).
8. Shribman, S. & Billingham, K. Healthy Child Programme – Pregnancy and the first first five years. (2009).
9. *Well Baby Service Protocol. Last reviewed: March 2020*. (2014).
10. Qatar's NPEDHL committee. Guidelines for National Program of Early Detection of Hearing Loss (NPEDHL) in State of Qatar. (2021).
11. DH/DCSF. Healthy Child Programme: From 5–19 years old. (2009).
12. New York State Department of Health. *Clinical Practice Guideline: Quick Reference Guide, Hearing Loss, Assessment and Intervention for Young Children (Age 0-3 Years)*. (New York State Department of Health, 2007).
13. Ministry of Public Health (MOPH) Qatar. The Diagnosis and Management of Autism Spectrum Disorder. (2020).
14. World Health Organization (WHO). Blindness and vision impairment prevention. *WHO* http://www.who.int/blindness/causes/priority/en/.
15. Gogate, P., Gilbert, C. & Zin, A. Severe Visual Impairment and Blindness in Infants: Causes and Opportunities for Control. *Middle East Afr J Ophthalmol* **18**, 109–114 (2011).
16. Singh, M. & Tyagi, S. C. Genes and genetics in eye diseases: a genomic medicine approach for investigating hereditary and inflammatory ocular disorders. *Int J Ophthalmol* **11**, 117–134 (2018).
17. *Practical Management of Pediatric Ocular Disorders and Strabismus: A Case-based Approach*. (Springer New York, 2016). doi:10.1007/978-1-4939-2745-6.
18. US Preventive Services Task Force *et al.* Vision Screening in Children Aged 6 Months to 5 Years: US Preventive Services Task Force Recommendation Statement. *JAMA* **318**, 836 (2017).
19. National Institute for Health and Care Excellence (NICE). *Cerebral palsy in under 25s: assessment and management. NICE guideline [NG62]*. (NICE, 2017).
20. Zahnert, T. The Differential Diagnosis of Hearing Loss. *Dtsch Arztebl Int* **108**, 433–444 (2011).
21. Gifford, K. A., Holmes, M. G. & Bernstein, H. H. Hearing Loss in Children. *Pediatrics in Review* **30**, 207–216 (2009).
22. Anastasiadou, S. & Al Khalili, Y. Hearing Loss. in *StatPearls* (StatPearls Publishing, 2020).
23. Joint Committee on Infant Hearing. Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Journal of Early Hearing Detection and Intervention* **4**, 1–44 (2019).
24. Liming, B. J. *et al.* International Pediatric Otolaryngology Group (IPOG) consensus recommendations: Hearing loss in the pediatric patient. *International Journal of Pediatric Otorhinolaryngology* **90**, 251–258 (2016).
25. Joint Committee on Infant Hearing. Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Pediatrics* **120**, 898–921 (2007).

26. Scully, C. Impairment and disability. in *Scully's Medical Problems in Dentistry* 676–686 (Elsevier, 2014). doi:10.1016/B978-0-7020-5401-3.00028-X.
27. The National Health Service (NHS). Spina bifida. *nhs.uk* https://www.nhs.uk/conditions/spina-bifida/treatment/ (2017).
28. The National Health Service (NHS). Hydrocephalus. *nhs.uk* https://www.nhs.uk/conditions/hydrocephalus/ (2020).
29. Lister Hill National Center for Biomedical Communications, U.S. National Library of Medicine, National Institutes of Health & Department of Health & Human Services. Osteogenesis imperfecta. (2020).
30. The National Health Service (NHS). Cerebral palsy. *nhs.uk* https://www.nhs.uk/conditions/cerebral-palsy/ (2020).
31. Wright, Z., Larrew, T. W. & Eskandari, R. Pediatric Hydrocephalus: Current State of Diagnosis and Treatment. *Pediatrics in Review* **37**, 478–490 (2016).
32. Centers for Disease Control and Prevention (CDC). What are Congenital Heart Defects? *Centers for Disease Control and Prevention* https://www.cdc.gov/ncbddd/heartdefects/facts.html (2019).
33. The National Health Service (NHS). Muscular dystrophy. *nhs.uk* https://www.nhs.uk/conditions/muscular-dystrophy/ (2018).
34. Bourke, J. *et al.* Predicting Long-Term Survival Without Major Disability for Infants Born Preterm. *The Journal of Pediatrics* **215**, 90-97.e1 (2019).
35. Balagué, F., Mannion, A. F., Pellisé, F. & Cedraschi, C. Non-specific low back pain. *The Lancet* **379**, 482–491 (2012).
36. Institute of Medicine (US) Committee on Social Security Cardiovascular Disability Criteria. *Congenital Heart Disease*. (National Academies Press (US), 2010).
37. European Respiratory Society (ERS). European Lung White Book: Paediatric respiratory diseases. *erswhitebook* https://www.erswhitebook.org/chapters/paediatric-respiratory-diseases/.
38. Hamad Medical Corporation (HMC). HMC Qatar Rehabilitation Institute Guideline. (2020).
39. Lee, K., Cascella, M. & Marwaha, R. Intellectual Disability. in *StatPearls* (StatPearls Publishing, 2020).
40. Marrus, N. & Hall, L. Intellectual Disability and Language Disorder. *Child Adolesc Psychiatr Clin N Am* **26**, 539–554 (2017).
41. Sansone, S. M. *et al.* Improving IQ measurement in intellectual disabilities using true deviation from population norms. *J Neurodev Disord* **6**, 16 (2014).
42. Braaten, E. B. & Norman, D. Intelligence (IQ) Testing. *Pediatrics in Review* **27**, 403–408 (2006).
43. American Academy of Neurology (AAN). The Treatment of Tics in People with Tourette Syndrome and Chronic Tic Disorders. (2019).
44. Ogundele, M. O. Behavioural and emotional disorders in childhood: A brief overview for paediatricians. *World J Clin Pediatr* **7**, 9–26 (2018).
45. von Klitzing, K., Döhnert, M., Kroll, M. & Grube, M. Mental Disorders in Early Childhood. *Dtsch Arztebl Int* **112**, 375–386 (2015).
46. Gerdts, J. *et al.* Interdisciplinary Team Evaluation: An Effective Method for the Diagnostic Assessment of Autism Spectrum Disorder. *Behavioral Pediatrics* **0**, 11 (2018).
47. World Health Organization & UNICEF. *Early childhood development and disability: a discussion paper.* (WHO, 2012).
48. Luzi, D. *et al.* Modelling collaboration of primary and secondary care for children with complex care needs: long-term ventilation as an example. *Eur J Pediatr* **178**, 891–901 (2019).
49. The National Health Service (NHS). Tourette's syndrome. *nhs.uk* https://www.nhs.uk/conditions/tourettes-syndrome/ (2018).
50. American Psychological Association (APA). Guidelines for Assessment of and Intervention with Persons with Disabilities. *https://www.apa.org* https://www.apa.org/pi/disability/resources/assessment-disabilities.
51. Maxey, M. & Beckert, T. E. Adolescents with Disabilities. *Adolescent Res Rev* **2**, 59–75 (2017).
52. Novak, I., Cusick, A. & Lannin, N. Occupational therapy home programs for cerebral palsy: double-blind, randomized, controlled trial. *Pediatrics* **124**, e606-614 (2009).

53. British Medical Journal (BMJ) Publishing Group. Autism spectrum disorder. (2018) doi:https://bestpractice.bmj.com/topics/en-us/379/pdf/379.pdf.
54. Shields, J. The NAS EarlyBird Programme: partnership with parents in early intervention. The National Autistic Society. *Autism* **5**, 49–56 (2001).
55. Quint, E. H., O'Brien, R. F., Adolescence, C. O. & Gynecology, T. N. A. S. for P. and A. Menstrual Management for Adolescents With Disabilities. *Pediatrics* **138**, (2016).
56. Jones, N., Presler-Marshall, E. & Stavropoulou, M. Adolescents with disabilities. Enhancing resilience and delivering inclusive development. *Gender and Adolescence: Global Evidence (GAGE)* 226 (2018).
57. Kirkham, Y. A. *et al.* Trends in menstrual concerns and suppression in adolescents with developmental disabilities. *J Adolesc Health* **53**, 407–412 (2013).
58. Cheng, M. M. & Udry, J. R. Sexual behaviors of physically disabled adolescents in the United States. *J Adolesc Health* **31**, 48–58 (2002).
59. World Health Organization (WHO). Deafness and hearing loss. https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss.
60. World Health Organization (WHO). *International Classification of functioning, Disability and Health (ICF)*. (WHO, 2001).
61. World Health Organization (WHO). *International classification of functioning, disability and health: children & youth version (ICF-CY)*. (World Health Organization, 2007).
62. Holm, V. A. Developmental Disabilities: Delivery of Medical Care for Children and Adults. *JAMA* **262**, 2935–2936 (1989).
63. Convention on the Rights of Persons with Disabilities. *United Nations* https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html (2008).
64. Irwin, L., Siddiqi, A. & Hertzman, C. *Early Child Development: A Powerful Equalizer Final Report*. https://www.who.int/social_determinants/resources/ecd_kn_report_07_2007.pdf (2007).
65. Vasudevan, P. & Suri, M. A clinical approach to developmental delay and intellectual disability. *Clin Med (Lond)* **17**, 558–561 (2017).
66. Committee on Children With Disabilities. Developmental Surveillance and Screening of Infants and Young Children. *Pediatrics* **108**, 192–195 (2001).
67. Dworkin, P. H. Detection of behavioral, developmental, and psychosocial problems in pediatric primary care practice. *Curr. Opin. Pediatr.* **5**, 531–536 (1993).
68. First 5 Early Identification Guide for Medical Professionals. (2017).
69. World Health Organization. *International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10). Visual disturbances and blindness (H53-H54)*. (WHO: Geneva., 2016).
70. World Health Organization (WHO). Vision impairment and blindness. https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment.
71. *Guidelines for Identification and Management of Infants and Young Children with Auditory Neuropathy Spectrum Disorder*. (The Children's Hospital, 2008).
72. World Health Organization (WHO). Grades of hearing impairment. *WHO* http://www.who.int/deafness/hearing_impairment_grades/en/.
73. The American Speech-Language-Hearing Association (ASHA). Hearing Loss - Beyond Early Childhood. *American Speech-Language-Hearing Association (ASHA)* https://www.asha.org/Practice-Portal/Clinical-Topics/Hearing-Loss/.
74. The Area Special Education Cooperative's Total Special Education System (TSES). Disability Criteria: Physically Impaired. http://www.asec.net/tses/Disability%20Criteria/physimpair.htm.
75. Handicaps Welfare Association. General Information on Physical Disabilities. https://hwa.org.sg/general-information-on-physical-disabilities/.
76. American Association on Intellectual and Developmental Disabilities (AAIDD). Frequently Asked Questions on Intellectual Disability. https://www.aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability.
77. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders: DSM-V*. (American Psychiatric Association, 2013). doi:10.1176/appi.books.9780890425596.

78. Tomas, E. & Vissers, C. Behind the Scenes of Developmental Language Disorder: Time to Call Neuropsychology Back on Stage. *Front Hum Neurosci* **12**, (2019).
79. Berkman, N. D. *et al. Screening for Speech and Language Delays and Disorders in Children Age 5 Years or Younger: A Systematic Review for the U.S. Preventive Services Task Force*. (Agency for Healthcare Research and Quality (US), 2015).
80. Rosenbaum, S. *et al. Childhood Speech and Language Disorders in the General U.S. Population*. (National Academies Press (US), 2016).
81. *Annual Statistical Abstract for health services and disabilities. Chapter IX Disabilities.* (2018).
82. Avilés, M. B. *et al.* The impact of the International Convention on the Rights of Persons with Disabilities on the Internal Legislation of Qatar: Analysis and Proposals. in *Qatar Foundation Annual Research Conference Proceedings Volume 2016 Issue 1* (Hamad bin Khalifa University Press (HBKU Press), 2016). doi:10.5339/qfarc.2016.SSHAOP1104.
83. El-Ouarradi, R. M. Educating Children with Disabilities in Qatar. https://sites.northwestern.edu/qtaaleam/educating-children-with-disabilities-in-qatar/#.XrAsYagzY2w (2018).
84. British Association of Audiovestibular Physicians. Guidelines for aetiological investigation into progressive permanent childhood hearing impairment. (2018).
85. Li, M. *et al.* The Association of Maternal Obesity and Diabetes With Autism and Other Developmental Disabilities. *PEDIATRICS* **137**, e20152206–e20152206 (2016).
86. Xiang, A. H. *et al.* Maternal Gestational Diabetes Mellitus, Type 1 Diabetes, and Type 2 Diabetes During Pregnancy and Risk of ADHD in Offspring. *Diabetes Care* **41**, 2502–2508 (2018).
87. Centers for Disease Control and Prevention (CDC). Basics about Fetal Alcohol Spectrum Disorders (FASDs). *Centers for Disease Control and Prevention* https://www.cdc.gov/ncbddd/fasd/facts.html (2019).
88. Centers for Disease Control and Prevention (CDC). Disability and Health Related Conditions. *Centers for Disease Control and Prevention* https://www.cdc.gov/ncbddd/disabilityandhealth/relatedconditions.html (2019).
89. Centers for Disease Control and Prevention (CDC). Facts About Developmental Disabilities. *Centers for Disease Control and Prevention* https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html (2019).
90. The National Health Service. How to care for a disabled child. *nhs.uk* https://www.nhs.uk/conditions/social-care-and-support-guide/caring-for-children-and-young-people/how-to-care-for-a-disabled-child/ (2018).
91. Berg, A. L. Newborn Hearing Screening in the NICU: Profile of Failed Auditory Brainstem Response/Passed Otoacoustic Emission. *PEDIATRICS* **116**, 933–938 (2005).
92. National Center for Hearing Assessment and Management (NCHAM) & American Academy of Pediatrics (AAP). Early Hearing Detection and Intervention Guidelines for Primary Care and Medical Home Providers. Last updated: 2017. *American Academy of Pediatrics (AAP)* 10 (2009).
93. Burger, M. & Louw, Q. A. The predictive validity of general movements--a systematic review. *Eur J Paediatr Neurol* **13**, 408–420 (2009).
94. Porro, M. *et al.* Early detection of general movements trajectories in very low birth weight infants. *Scientific Reports* **10**, 13290 (2020).
95. Lee, S. Y. & Mesfin, F. B. Blindness. in *StatPearls* (StatPearls Publishing, 2020).
96. McCreery, R. W. *et al.* The impact of degree of hearing loss on auditory brainstem response predictions of behavioral thresholds. *Ear Hear* **36**, 309–319 (2015).
97. Widen, J. E. *et al.* A multisite study to examine the efficacy of the otoacoustic emission/automated auditory brainstem response newborn hearing screening protocol: results of visual reinforcement audiometry. *Am J Audiol* **14**, S200-216 (2005).
98. Dammeyer, J. Development and characteristics of children with Usher syndrome and CHARGE syndrome. *International Journal of Pediatric Otorhinolaryngology* **76**, 1292–1296 (2012).
99. Hood, L. J. Auditory Neuropathy/Dys-Synchrony Disorder. *Otolaryngologic Clinics of North America* **48**, 1027–1040 (2015).
100. Starr, A., Picton, T. W., Sininger, Y., Hood, L. J. & Berlin, C. I. Auditory neuropathy. *Brain* **119**, 741–753 (1996).

101. Attias, J. & Raveh, E. Transient Deafness in Young Candidates for Cochlear Implants. *Audiol Neurotol* **12**, 325–333 (2007).
102. Centers for Disease Control and Prevention (CDC). Congenital CMV Infection. https://www.cdc.gov/cmv/clinical/congenital-cmv.html (2019).
103. American Academy of Audiology. *American Academy of Audiology Clinical Practice Guidelines: Pediatric Amplification*. (2013).
104. Guidelines for Fitting Hearing Aids to Young Infants. Version 2.0. (2014).
105. National Health Service (NHS). Guidelines for the early audiological assessment and management of babies referred from the Newborn Hearing Screening Programme. Version 3.1. (2013).
106. Lu, L., Zhang, X. & Gao, X. Non-implantable Artificial Hearing Technology. in *Hearing Loss: Mechanisms, Prevention and Cure* (eds. Li, H. & Chai, R.) vol. 1130 145–163 (Springer Singapore, 2019).
107. Jorgensen, L. E. Verification and validation of hearing aids: Opportunity not an obstacle. *J Otol* **11**, 57–62 (2016).
108. Huff, J. S. & Murr, N. Seizure. in *StatPearls* (StatPearls Publishing, 2020).
109. Murphy, N. A. & Carbone, P. S. Promoting the Participation of Children With Disabilities in Sports, Recreation, and Physical Activities. *Pediatrics* **121**, 1057–1061 (2008).
110. History and Physical Examination of the Pediatric Rehabilitation Patient. *Musculoskeletal Key* https://musculoskeletalkey.com/history-and-physical-examination-of-the-pediatric-rehabilitation-patient/ (2019).
111. Ashwal, S., Michelson, D., Plawner, L. & Dobyns, W. B. Practice Parameter: Evaluation of the child with microcephaly (an evidence-based review). *Neurology* **73**, 887–897 (2009).
112. Rempel, G. The importance of good nutrition in children with cerebral palsy. *Phys Med Rehabil Clin N Am* **26**, 39–56 (2015).
113. Ministry of Public Health (MOPH) Qatar. National Clinical Guideline: The Management of Obesity in Children. (2019).
114. Birnkrant, D. J. *et al.* Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management. *Lancet Neurol* **17**, 251–267 (2018).
115. Bushby, K. *et al.* Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and pharmacological and psychosocial management. *Lancet Neurol* **9**, 77–93 (2010).
116. Wilcox, W. R., Coulter, C. P. & Schmitz, M. L. Congenital limb deficiency disorders. *Clin Perinatol* **42**, 281–300, viii (2015).
117. Yang, S., Zusman, N., Lieberman, E. & Goldstein, R. Y. Developmental Dysplasia of the Hip. *Pediatrics* **143**, (2019).
118. Novak, I. *et al.* Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment. *JAMA Pediatr* **171**, 897–907 (2017).
119. Cath, D. C. *et al.* European clinical guidelines for Tourette Syndrome and other tic disorders. Part I: assessment. *Eur Child Adolesc Psychiatry* **20**, 155–171 (2011).
120. Social Security Administration US. Disability Evaluation Under Social Security: Respiratory-Childhood. https://www.ssa.gov/disability/professionals/bluebook/103.00-Respiratory-Childhood.htm.
121. Singh, A., Yeh, C. J. & Boone Blanchard, S. Ages and Stages Questionnaire: a global screening scale. *Boletín Médico del Hospital Infantil de México* **74**, 5–12 (2017).
122. Sparrow, S. S., Cicchetti, D. V. & Saulnier, C. A. *Vineland Adaptive Behavior Scales (Vineland-3).* (Pearson, 2017).
123. *ICD-10: International statistical classification of diseases and related health problems.* (World Health Organization, 2011).
124. The National Health Service (NHS). Phenylketonuria. *nhs.uk* https://www.nhs.uk/conditions/phenylketonuria/ (2019).
125. Akhtar, F. & Bokhari, S. R. A. Down Syndrome (Trisomy 21). in *StatPearls* (StatPearls Publishing, 2020).
126. Grosse, S. D. & Van Vliet, G. Prevention of intellectual disability through screening for congenital hypothyroidism: how much and at what level? *Arch Dis Child* **96**, 374–379 (2011).

127. Reches, A. Fragile X Syndrome: Introduction. in *Fragile-X Syndrome* (eds. Ben-Yosef, D. & Mayshar, Y.) vol. 1942 3–10 (Springer New York, 2019).
128. Lister Hill National Center for Biomedical Communications, U.S. National Library of Medicine, National Institutes of Health & Department of Health & Human Services. Prader-Willi syndrome. *Genetics Home Reference* https://ghr.nlm.nih.gov/condition/prader-willi-syndrome (2020).
129. National Institutes of Health (NIH) & Genetic and Rare Diseases Information Center (GARD). Cri du chat syndrome. https://rarediseases.info.nih.gov/diseases/6213/cri-du-chat-syndrome.
130. Baker, B. L. *et al.* Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *J Intellect Disabil Res* **47**, 217–230 (2003).
131. European Agency for Development in Special Needs Education. *Early childhood intervention: analysis of situation in Europe : key aspects and recommendations. Summary Report*. (European Agency for Development in Special Needs Education, 2005).
132. The United Nations Children's Fund (UNICEF). *Early childhood intervention, special education and inclusion: a focus on Belarus*. https://www.unicef.by/uploads/models/2017/02/belarus.eci.english.pdf (2009).
133. Nancarrow, S. A. *et al.* Ten principles of good interdisciplinary team work. *Hum Resour Health* **11**, 19 (2013).
134. Cascio, C. J., Woynaroski, T., Baranek, G. T. & Wallace, M. T. Toward an Interdisciplinary Approach to Understanding Sensory Function in Autism Spectrum Disorder. *Autism Res* **9**, 920–925 (2016).
135. Vasilakis, C., Lecnzarowicz, D. & Lee, C. Application of Unified Modelling Language (UML) to the Modelling of Health Care Systems: An Introduction and Literature Survey. *International Journal of Healthcare Information Systems and Informatics* **3**, 39–52 (2010).
136. Handen, B. L. & Gilchrist, R. Practitioner review: Psychopharmacology in children and adolescents with mental retardation. *J Child Psychol Psychiatry* **47**, 871–882 (2006).
137. Siddiqi, S. U., Van Dyke, D. C., Donohoue, P. & McBrien, D. M. Premature sexual development in individuals with neurodevelopmental disabilities. *Dev Med Child Neurol* **41**, 392–395 (1999).
138. Knickmeyer, R. C., Wheelwright, S., Hoekstra, R. & Baron-Cohen, S. Age of menarche in females with autism spectrum conditions. *Dev Med Child Neurol* **48**, 1007–1008 (2006).
139. Kinon, B. J., Gilmore, J. A., Liu, H. & Halbreich, U. M. Hyperprolactinemia in response to antipsychotic drugs: characterization across comparative clinical trials. *Psychoneuroendocrinology* **28 Suppl 2**, 69–82 (2003).
140. Dosman, C. & Andrews, D. Anticipatory guidance for cognitive and social-emotional development: Birth to five years. *Paediatr Child Health* **17**, 75–80 (2012).
141. Combs-Orme, T., Holden Nixon, B. & Herrod, H. G. Anticipatory Guidance and Early Child Development: Pediatrician Advice, Parent Behaviors, and Unmet Needs as Reported by Parents From Different Backgrounds. *Clin Pediatr (Phila)* **50**, 729–737 (2011).
142. National Academies of Sciences, E. *et al. Parenting Knowledge, Attitudes, and Practices*. (National Academies Press (US), 2016).
143. Car seats could have kept child crash victims safe, says Qatar doctor. https://www.qf.org.qa/stories/car-seats-could-have-kept-child-crash-victims-safe-says-qatar-doctor (2019).
144. National Highway Traffic Safety Administration (NHTSA). Seat Belts. *NHTSA* https://www.nhtsa.gov/risky-driving/seat-belts (2016).
145. Rauch, S. A. & Lanphear, B. P. Prevention of Disability in Children: Elevating the Role of Environment. *The Future of Children* **22**, 193–217 (2012).
146. Murphy, C. *et al.* Autism spectrum disorder in adults: diagnosis, management, and health services development. *Neuropsychiatric Disease and Treatment* **Volume 12**, 1669–1686 (2016).
147. The National Institute for Health and Care Excellence (NICE). Autism spectrum disorder in under 19s: recognition, referral and diagnosis. NICE Guideline [NG128]. https://www.nice.org.uk/guidance/cg128 (2017).

Appendix: Detailed Description of the Literature Search

A systematic search for existing literature on the early disabilities was performed in the period March 25th – September 28th, 2020.

The search for clinical practice guidelines on dementia diagnosis and/or management was performed in the *PubMed* database and websites of relevant organisations and societies including the *Down Syndrome International, World Health Organisation (WHO), Centers for Disease Control and Prevention (CDC), The National Health Service (NHS), The Amputee Coalition, The Royal College of Speech & Language Therapists (RCSLT), The Association for Child and Adolescent Mental Health (ACAMH),* and other. The present guideline is primarily based on UK NICE and BMJ guidelines and is supplemented with other relevant studies.

Peer-reviewed scientific publications were found in PubMed and via *Google Scholar* Internet search engine. Non-peer reviewed studies were identified in *bioRxiv*. Books were checked on PubMed. Information published on medical websites and drug prescribing information sheets were found via Google search engine.

The included publications were identified using the term "impairment or disability and child" and specified with the following terms in combinations:

Child, adolescent, infant, definition, disability, disorder, prevalence, impairment, milestone, developmental delay, loss, vision, visual, hearing, audiological, physical, intellectual, congenital, pulmonary, heart, warning sign, red flag, classification, severity, aetiology, associated, health, history, screening, examination, investigation, test, cause, syndrome, metabolism, muscular dystrophy, osteogenesis imperfecta, cerebral palsy, spina bifida, amputation, limb deficiency, hydrocephalus, epilepsy, Down/Tourette, Autism, phenylketonuria, fragile X syndrome, foetal alcohol spectrum, cri du chat, language, speech, challenging behaviour, behavioural intervention/therapy, parent training/course/skill, nutrition, referral, primary/secondary care, multidisciplinary, pain, psychological, prevention, Qatar.

Figure A.1 below demonstrates graphically the results of the search and application of exclusion criteria.

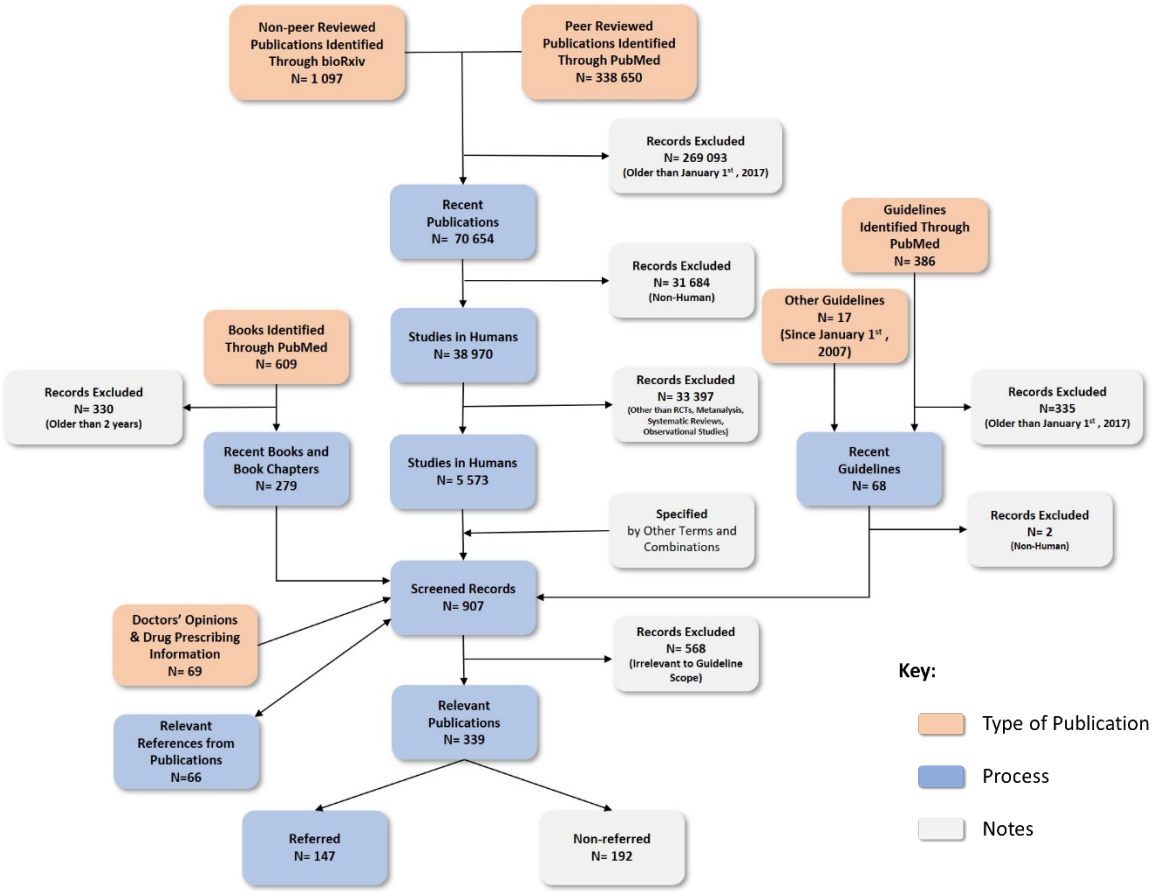


Fig A.1: Literature search results and application of exclusion criteria.

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