USAID
FROM THE AMERICAN PEOPLE

humanity
&inclusion

| Rehabilitation Guidelines | Cerebral Palsy | Speech & Language Therapy |

Rehabilitation Guideline for the Management of Children with Cerebral Palsy

| Speech & Language Therapy Guideline |

Humanity & Inclusion
2019

Advancing Medical Care and Rehabilitation Education Project

A project funded by the USAID and Implemented by Humanity & Inclusion in collaboration with the Ministry of Health in Vietnam*

** Since January 2018, Humanity & Inclusion is **Handicap International**'s new operating name*

Rehabilitation Guideline for the Management of Children with Cerebral Palsy

| Speech & Language Therapy Guideline |

This guideline is made possible by the generous support of the American people through the United States Agency for International Development (USAID)

Foreword

In the framework of the "Advancing Medical Care and Rehabilitation Education" project in Vietnam, and with the guidance and support of the Ministry of Health, Humanity & Inclusion (previously known as Handicap International) and its partners contribute to the strengthening of medical and rehabilitation care for persons with disabilities due to brain lesion (i.e. stroke, traumatic brain injury, cerebral palsy and spina bifida and hydrocephalus).

In order to provide rehabilitation specialists (rehabilitation doctors, nurses, therapists…) with the tools they need to properly support persons with disabilities, the project, with the financial support of the United States Agency for International Development (USAID), has developed up-to-date and comprehensive "Rehabilitation Guidelines".

With the assistance of international experts and Vietnamese specialists, these guidelines have been developed based on the latest available scientific evidences or, where evidences are still lacking, internationally-recognized best-practices. The constant involvement and support received from Vietnamese medical and rehabilitation professionals in the development process ensured contextualization and ownership of these guidelines as they brought in not only their technical expertise but also their knowledge and experiences on the Vietnamese context and the local needs and resources.

Two types of documents have been developed. Besides the General Rehabilitation Guidelines, which provide wide-ranging recommendations on care provision and quality principles, more “Technical” Guidelines have also been produced for each of the targeted conditions. These technical guidelines are specific to one "type" of care (physiotherapy, occupational therapy, speech and language therapy; and for some conditions medical and nursing care as well). They provide rehabilitation professionals with more specific, detailed technical guidance, allowing them to better understand their specific role in the general rehabilitation approach and the provision of multi-disciplinary, person-centred and evidence-based care.

The result of this process is a comprehensive set of guidelines that we hope will be widely spread and support all rehabilitation actors in providing better and higher quality care to the people in need.

The present English version of the Rehabilitation Guidelines has been developed with valued support from the Vietnamese Ministry of Health. It is our hope that the Vietnamese version of the respective guidelines will be officially endorsed by the Ministry as national guidelines for rehabilitation care of persons with brain lesions.

On Behalf of Humanity & Inclusion,
Didier Demey
Country Director

Acknowledgments

Humanity & Inclusion would like to thank the **Ministry of Health**, and in particular the department of Administration of Medical Services (AMS) for their support and encouragement during the development of the Rehabilitation Guidelines for persons with brain lesions.

We also would like to extend our gratitude to the **United States Agency for International Development** (USAID) for their guidance and financial support, without which the present document could not have been produced.

Furthermore, Humanity & Inclusion would like to thank **Janella Christie** and **Leila Ball** for their support in developing these guidelines. Their commitment towards strengthening medical and rehabilitation care in Vietnam is greatly appreciated. We thank **Trinh Foundation Australia** for the technical support they provided for the development of the guidelines and to Ms. Christie and Ms. Ball in particular.

Finally, we would like to acknowledge and thank all the **national experts and medical and rehabilitation professionals** who, through their participation to the guidelines development and review workshops have greatly contributed to the development of these guidelines. In particular, we would like to recognize the members of the Guidelines Development Committee:

Prof. Trần Trọng Hải, Chairman of VINAREHA
Prof. Cao Minh Châu, VINAREHA
Assoc. Prof. Nguyễn Thị Ngọc Dung, Pham Ngoc Thach University of Medicine
Dr. Hà Chân Nhân, Hue University of Medicine and Pharmacy
Dr. Trịnh Quang Dũng, Vietnam National Children's Hospital
Dr. Nguyễn Hữu Chút, Vietnam National Children's Hospital
Dr. Cao Bích Thủy, Danang University of Medical Technology and Pharmacy
Dr. Đinh Thị Hoa, Hai Duong Medical technical University
Dr. Lê Khánh Điền, An Binh University
Đỗ Thị Bích Thuận BSc, City Children's Hospital
and other colleagues for their great contributions during the development of Rehabilitation Guidelines.

FOREWORD 4
ACKNOWLEDGMENTS 5
LIST OF ABBREVIATIONS 7
1. INTRODUCTION 8
1.1. THE NEED FOR GUIDELINES 8
1.2. WHO ARE THE GUIDELINES FOR 8
1.3. AIM OF THE GUIDELINE 9
1.4. STATEMENT OF INTENT 9
1.5. MONITORING AND EVALUATING SERVICE DELIVERY 9
1.6. WHAT IS CP 10
1.7. DESCRIBING CP 11
1.8. ASSOCIATED CONDITIONS 13
1.9. CLASSIFICATION TOOLS 13
1.10. WHAT IS SPEECH & LANGUAGE THERAPY 18
2. PATHWAYS AND PRINCIPLES OF REHABILITATION 20
2.1. INTRODUCTION 20
2.2. REHABILITATION CYCLE 21
2.3. ICF 22
2.4. CHILD CENTRED AND FAMILY CENTRED CARE 25
2.5. GENDER EQUALITY IN HEALTH 27
2.6. ORGANIZATION OF REHABILITATION SERVICES 28
2.7. MULTIDISCIPLINARY TEAMS AND INTERPROFESSIONAL TEAM APPROACH 32
3. THE REHABILITATION CYCLE 33
3.1. EVIDENCE-BASED PRACTICES IN CP 33
3.2. NEUROPROTECTIVE AND PREVENTIVE STRATEGIES 34
3.3. DIAGNOSIS, ASSESSMENT, PROGNOSIS AND GOAL SETTING 34
3.4. MANAGING THE MOTOR DISORDER 39
3.5. PRESCRIBING ADAPTIVE AND ASSISTIVE TECHNOLOGY (AAT) 39
3.6. MANAGING COMMUNICATION IMPAIRMENTS 40
3.7. MANAGING OTHER CONDITIONS WHICH AFFECT COMMUNICATION 45
3.8. MANAGING DYSPHAGIA - EATING, DRINKING, SWALLOWING AND DROOLING DIFFICULTIES 47
3.9 MANAGING OTHER CONDITIONS ASSOCIATED WITH CP 55
3.10. REHABILITATION NEEDS ACROSS THE LIFESPAN 61
3.11. PARENT, FAMILY AND CAREGIVER SUPPORT 62
4. SUPPORTING AND MONITORING THE IMPLEMENTATION OF THE GUIDELINES IN HOSPITALS 63
GLOSSARY 64
REFERENCES 66

List of Abbreviations

AAC	Augmentative and Alternative Communication
ADL	Activities of Daily Living
AAT	Adaptive & Assistive Technology
CBR	Community-based rehabilitation
CFCS	Communication Function Classification System
COPM	Canadian Occupational Performance Measure
CP	Cerebral Palsy
EBP	Evidence-based practice
EDACS	Eating and Drinking Ability Classification System
ENT	Ear, Nose & Throat
FCCS	Functional Communication Classification System
FEES	Flexible Endoscopic Evaluation of Swallowing
FMS	Functional Mobility Scale
GAS	Goal Attainment Scaling
GMFCS	Gross Motor Function Classification System
GMFM	Gross Motor Function Measure
GORD	Gastro-Oesophageal Reflux Disease
ICF	International Classification of Function
KPI	Key Performance Indicator
MACS	Manual Abilities Classification Scale
MOET	Ministry of Education & Training
MOH	Ministry of Health
NCH	National Children's Hospital
OPD	Oropharyngeal Dysphagia
OT	Occupational Therapy/Therapist
PT	Physiotherapy/Physiotherapist
SLT	Speech and Language Therapy/Therapist
SOMA	Schedule for Oral-Motor Assessment
ST	Speech Therapist
SMART	Specific, Measurable, Attainable/Achievable, Realistic, Time-bound
VFSS	Videofluoroscopic Swallow Study
WHO	World Health Organization

1. Introduction

1.1. The Need for Guidelines

Cerebral palsy (CP) is a complex disorder. It is the most common cause of childhood physical disability and arises from multiple and varied aetiologies, resulting in multiple and varied presentations. Variable characteristics of cerebral palsy include the distribution of motor impairments, the type of movements seen, the severity of the motor disorder (and therefore functional abilities) and the presence of secondary/associated conditions.

Children with CP have impairments and support needs that are addressed through the health care, rehabilitation care and social care systems in Vietnam. Guidelines for the management of children with cerebral palsy are required to:

- Facilitate clear expectations around roles and responsibilities of health professionals across all levels of health and rehabilitation care in Vietnam
- Enable timely access to appropriate interventions to maximise functional abilities and quality of life for children with cerebral palsy and their families.

These guidelines consist of several components - a general rehabilitation guideline, a technical guideline for physiotherapy, a technical guideline for occupational therapy and a technical guideline for speech and language therapy (this document). Collectively these documents make up a set of guidelines (known as ‘the guidelines’) for the holistic management of children with cerebral palsy.

The present **Speech and Language Therapy (SLT) Guideline for Cerebral Palsy** provide recommendations and guidance on type of rehabilitation care to be provided as well as "cross-cutting" recommendations in regard of requirements for a system organization, multidisciplinary and comprehensive care, person-centred care, family support and involvement, care pathway and referrals, discharge and follow-up, community reintegration and social participation.

1.2. Who Are the Guidelines For

The present guideline is primarily a practical resource tool for Speech and Language Therapists who are involved in rehabilitation with children with CP.

The guideline will also be useful to any professional with an interest in rehabilitation for children with CP including doctors, neurologists, rehabilitation doctors, nurses, physiotherapists, occupational therapists, dieticians, orthotists, pharmacists, psychologists, specialists in public health, social workers, community workers and persons with cerebral palsy and their family and carers.

1.3. Aim of the Guideline

The guidelines are meant to be a resource guide for the rehabilitation management of those people in Vietnam who are affected by cerebral palsy. The guidelines are not prescriptive. They contain various ideas for management but, depending on the local situation, not all of the activities will have to be implemented. In some cases activities should be adjusted to local circumstances.

They are also intended to not only be a practical resource but an educational tool to assist all health staff and the public as to what is necessary for facilitating effective outcomes of rehabilitation care. They may also act as an awareness tool for all staff as to roles and functions of those people who are concerned with rehabilitation care for children with CP. They can be simplified in order to adapt to a more junior level trained staff and for children with CP and family themselves.

They can also highlight the gaps and needs in the workforce for specific staff e.g. fully qualified speech and language therapists (SLT) and occupational therapists (OT) and as well as give target recommendations for the coming 5-10 years in how to improve the quality of rehabilitation care for children with CP in Vietnam.

1.4. Statement of Intent

The guidelines are not intended to serve as a standard of medical care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to the guidelines will not ensure a successful outcome in every case, the ultimate judgment regarding a particular clinical procedure or treatment plan must be made in light of the clinical data presented by the patient and diagnostic and treatment options available. However, it is advised that significant departures from these guidelines should be fully documented in the patient’s case notes at the time the relevant decision is taken.

1.5. Monitoring and Evaluating Service Delivery

Capacity to evaluate the quality of health care delivery is essential for informing clinical practice and improving patient outcomes. It is important and crucial to assess, monitor and evaluate key performance indicators and outcome measures in order to demonstrate effectiveness and efficiencies of rehabilitation services.

Data collection should be:

- linked to recommendations in the guidelines and measure adherence to evidence-based care
- routine and ongoing
- linked to benchmarking and become part of an evidence-based quality improvement cycle

Data elements should reflect the essential aspects of rehabilitation care for children with CP and include measures of:

- Processes of care
- Functional change
- Participation in life activities and the community
- Quality of life
- Patient and family satisfaction

1.6. What is CP

CP is an umbrella term that describes 'a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy and by secondary musculoskeletal problems.' (Rosenbaum et al., 2007).

The prevalence of CP in high-resource countries is 1.4-2.1 per 1000 live births (ACPR, 2016; Sellier et al, 2015). Vietnam does not yet have a national cerebral palsy register. The establishment of a national register would enable incidence and prevalence to be determined.

Little is known about the epidemiology CP in Vietnam. An ongoing hospital based surveillance of CP at the National Children's Hospital (NCH) in Hanoi is aims to define the aetiology, motor function and its severity, associated impairments, and nutritional and rehabilitation status of children with CP (aged <18 years) in Hanoi, Vietnam (Khandaker et al. BMJ Open 2017). Preliminary findings (personal communication 2.2.2018, Prof Elliott, Principal Investigator) from this study show that among children with CP who attended the rehabilitation department at NCH, Hanoi:

- Mean age of diagnosis of CP was 20.7 months (ranging 1 month - 13 years)
- CP type at diagnosis:
    - 66% spastic quadriplegia
    - 21% hemiplegia/monoplegia
    - 6.4% diplegia
- 1.5% had predominantly athetosis
- 54% had intellectual impairment and 12.7% had probable intellectual impairment
- Based on the Gross Motor Function Classification System (GMFCS):
    - 16% Level V function

- 27% Level IV function (indicating requirement for a manual or powered wheelchair) yet none had access to a wheelchair
- 13% Level III function
- 16% Level II function
- 23% Level I function

1.7. Describing CP

This section provides definitions of the motor types of CP. The next session deals with associated conditions.

1.7.1. Motor Type

Motor type refers to the motor disorder seen. This is closely related to the area of the brain that is damaged.

(I) Spasticity

Spasticity is a velocity-dependent resistance to stretch by the muscles. It is characterised by an excessive stiffness in the muscles when the child attempts to move or maintain a posture against gravity. Spasticity can vary according to the child's state of alertness, emotions, activity, posture or presence of pain (Sanger, Delgado et al. 2003).

(II) Dyskinesia/Hyperkinesia

Dyskinesia/hyperkinesia refers to an increase in muscular activity that can result in excessive abnormal movements, excessive normal movements, or a combination of both. Dyskinetic/hyperkinetic CP is characterised by abnormalities of tone and various movement disorders including dystonia, athetosis and chorea (Sanger, Chen et al. 2010).

- **Dystonia** is characterised by sustained or intermittent muscle contractions causing repetitive or twisting movements.
- **Athetosis** is characterised by uncontrolled, slow and writhing movements that prevent maintenance of a stable posture. It involves continuous smooth movements that appear random and are not composed of recognisable sub-movements or movement fragments. Athetosis is made worse by attempts to move however it may also be present at rest. Athetosis is distinguished from dystonia by the lack of sustained postures, and from chorea by the lack of identifiable movement fragments (Sanger et al, 2010, page 1543).
- **Chorea** is an ongoing random-appearing sequence of one or more discrete involuntary movements or movement fragments. Chorea is distinguished from dystonia due to the apparently random, unpredictable, and continuously ongoing nature of the movements, compared with the more predictable and stereotyped movements or postures of dystonia. The movements of chorea often appear more rapid than those associated with dystonia. Although chorea may be worsened by movement, attempts at movement, or stress, particular movements are not triggered by voluntary attempts with the same

degree of temporal specificity as in dystonia (Sanger et al, 2010, page 1542). Children with chorea present as fidgety or in constant motion.

Athetosis and chorea usually co-present in CP and together are known as choreoathetosis.

(III) Ataxia

Ataxia is characterised by shaky movements and affects a person's coordination and balance. It is the least common form of CP.

(IV) Mixed motor types

CP where more than one motor type is present, for example spasticity and dystonia. Usually one motor type will be dominant.

For further details on motor types and classification of motor types: see the General Guideline and the Physiotherapy and Occupational Therapy Guidelines on the Management of CP.

1.7.2. Topography

Topography refers to the distribution of the motor impairments or the body parts affected. Motor impairments can be unilateral (affecting one side of the body only) or bilateral (affecting both sides of the body).

(I) Unilateral CP

- **Monoplegia** - one limb is affected. This can be the arm or leg on the left or right side of the body.
- **Hemiplegia** - one half of the body is affected. This can be the left side or the right side. The arm and leg do not need to be equally affected.

(II) Bilateral CP

- **Diplegia** - both legs are primarily affected. Children with diplegia frequently have some impairment in upper limb function.
- **Triplegia** - three limbs are affected with sparing of the fourth limb.
- **Quadriplegia** - all four limbs are affected with the head, neck and trunk also affected.

1.7.3. Severity

CP can be described or classified according to the severity of the motor impairments. Four classification systems of motor function, communication and eating and drinking ability are internationally recognised. They relate to how an individual with CP mobilises (GMFCS), how they use their hands in everyday activities (MACS), how they communicate with familiar and unfamiliar people (CFCS) and their ability to eat and drink safely (EDACS). These severity classification tools are detailed below. The severity classification tools relevant to Speech and Language Therapists are detailed in this guideline in Section 1.9.4 and 1.9.5.

1.8. Associated Conditions

The motor impairments of CP are almost always accompanied by one or more secondary impairments (Rosenbaum, et al., 2007). For many children, these secondary conditions are more disabling than their physical impairment:

- 3 in 4 will experience chronic pain
- 1 in 2 will have an intellectual impairment
- 1 in 3 will be unable to walk
- 1 in 3 will experience hip displacement
- 1 in 4 will be unable to talk
- 1 in 4 will have epilepsy
- 1 in 4 will have a behaviour disorder
- 1 in 4 will have bladder incontinence
- 1 in 5 will have a sleep disorder
- 1 in 10 will have a vision impairment
- 1 in 25 will have a hearing impairment
- 1 in 15 will be unable to eat orally.

(Novak et al., 2012)

1.9. Classification Tools

1.9.1. Functional Motor Ability

(I) Gross Motor Function Classification System (GMFCS)

(Palisano, Rosenbaum, Walters, Russell, Wood & Galuppi, 1997; Palisano, Rosenbaum, Bartlett & Livingston, 2008).

The Gross Motor Function Classification System (GMFCS) is a 5 level classification that describes the gross motor function of children with CP on the basis of their self-initiated movement with particular emphasis on sitting, walking, and wheeled mobility. Distinctions between levels are based on functional abilities, the need for assistive technology, including hand-held mobility devices (walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, their quality of movement.

(II) Functional Mobility Scale (FMS)

(Graham, Harvey, Rodda, Nattras & Piripis, 2004)

The Functional Mobility Scale (FMS) (version 2) has been constructed to classify functional mobility in children 4 to 18 years, taking into account a range of assistive devices a child might use over three distances: 5 metres (in and around the home), 50 metres (in and around school/preschool) and 500 metres (in the community). The FMS is sensitive to detect change after operative intervention.

1.9.2. Gait Classifications

Classifications of common gait patterns seen in hemiplegic and diplegic CP have been developed. Classifying gait patterns is important when considering medical and surgical interventions to improve gait and functional mobility.

Administration
Assessor: Medical practitioners familiar with observational gait assessment, physiotherapists
How: Gait patterns are classified following a thorough observational gait assessment and physical assessment
Time: 15-45 minutes depending on the complexity of the gait pattern and physical assessment and experience of the assessor

(I) Classification of Gait Patterns: Hemiplegic Gait
(Winters, Gage & Hicks, 1987)

The Winters, Gage and Hicks (1987) classification of hemiplegic gait describes four types of gait patterns based on the sagittal plane kinematics of the pelvis, hip, knee and ankle:

Type 1 - Foot Drop Foot drop in swing phase of gait, normal dorsiflexion range in stance phase
Type 2A - True Equinus Excessive plantar flexion of ankle in both stance and swing phase of gait
Type 2B - True Equinus/ Recurvatum Deviations plus limited flexion/extension range of motion at knee during stance and swing phases of gait
Type 3 - True Equinus/Knee jump Deviations plus limited flexion/extension range of motion at hip during stance and swing phases of gait.
Type 4 - Equinus/Knee jump Equinus with flexed, stiff knee, flexed, internally rotated and adducted hip with anterior pelvis tilt.

(II) Classification of Gait Patterns: Diplegia Gait
(Rodda & Graham, 2001)

The classification of common gait patterns seen in children with spastic diplegia has been developed by Rodda & Graham (2001) and Rodda et al (2004). Diplegic gait patterns include:

Group I - True Equinus Ankle plantar flexion throughout stance with hips and knees extended
Group II - Jump gait Ankle in equinus, the hip and knee in flexion, anterior pelvis tilt and an increased lumbar lordosis. Often a stiff knee due to rectus femoris activity in the swing phase of gait.
Group III - Apparent Equinus Walking on toes, however equinus is apparent rather than real with sagittal plane kinematics showing ankle has normal range of dorsiflexion but the hip and knee are in excessive flexion throughout stance phase of gait.

Group IV - Crouch Gait	Excessive ankle dorsiflexion in combination with excessive flexion at the hip and knee.
Group V - Asymmetric Gait	A combination of any of the above two patterns.

1.9.3. Manual Ability

(I) Manual Ability Classification System (MACS) & Mini-MACS

(Eliasson, Krumlinde Sundholm, Rösblad, Beckung, Arner, Öhrvall & Rosenbaum, 2005)

The Manual Ability Classification System (MACS) provides a systematic method of classifying how children with CP, aged 4 to 18 years use their hands when handling objects during daily activities.

Mini-MACS is an adaptation of MACS for children aged one to four years. Mini-MACS classifies children's ability to handle objects that are relevant for their age and development as well as their need for support and assistance in such situations.

For more details on the paragraphs 1.9.1 to 1.9.3 see the General Guideline and the Physiotherapy and Occupational Therapy Guidelines on the Management of CP

1.9.4. Communication Ability

(I) Communication Function Classification System (CFCS)

(Hidecker, Paneth, Rosenbaum, Kent, Lillie, Eulenberg, Chester, Johnson, Michalsen, Evatt & Taylor, 2011)

The Communication Function Classification System (CFCS) classifies everyday communication performance into one of 5 descriptive levels. Communication classification is based on the individual's performance as a sender and receiver of a message, the pace of the communication and the familiarity of communication partner to the individual. All methods of communication are considered including speech, gestures, behaviours, eye gaze, facial expression and augmentative and alternative communication systems (AAC). Communication effectiveness is based on the individual's current skill in everyday communication situations, rather than capacity for learning new skill.

Level 1	Effective sender and receiver with familiar and unfamiliar partners
Level 2	Effective but slow sender with familiar and unfamiliar partners
Level 3	Effective sender and receiver with familiar partners
Level 4	Inconsistent sender and/or receiver with familiar partners
Level 5	Seldom effective sender and receiver even with familiar partners

Administration

Assessor: Parent, caregiver or professional who is familiar with the child's communication.

How: Completed either via parent/caregiver report and/or observation during regular appointment

Time: N/A
Availability: Can be accessed via: www.cfcs.us

(II) Functional Communication Classification System (FCCS)
(Barty, Caynes and Johnston, 2016)

The Functional Communication Classification System (FCCS) is a classification of children's communication in everyday activities. It provides information about how the child usually communicates and who they communicate with.

Level 1	**An effective communicator in most situations** Can independently communicate a wide variety of messages/topics to familiar and unfamiliar people in most environments
Level 2	**An effective communicator in most situations, but does need some help** Can communicate a variety of messages/ topics to familiar people but may experience some difficulties with unfamiliar people/topics and environments and may need prompts, such as, prompt questions, repetitions (to make themselves understood) and loudness. An AAC user who requires assistance with set up, and/or programming; and whose listener may need some assistance with orientation/ interpretation of AAC strategies.
Level 3	**An effective communicator in some situations. Can communicate a small range of messages/ topics to most familiar people** Effective communicator with familiar people and activities and in familiar settings about their needs and wants, and things that are happening but require assistance with unfamiliar people/topics and environments. Relies on a familiar communication partner to interpret AAC or speech attempts, and to prepare, set up and support communication.
Level 4	**Assistance is required in most situations, especially with unfamiliar people and environments. Communicates daily/routine needs and wants with familiar people** Can initiate and attract attention but needs a familiar person who is familiar with their routine, recent/significant experiences and likes and dislikes, and to interpret their communication. Responds to familiar voices, sounds and routines using body movement, facial expression and vocalisation.
Level 5	**Communicates unintentionally with others, using movement and behaviour** Daily/routine needs and wants are interpreted by familiar people from observation of the individual's emotional state, body movement and behaviour. Needs full assistance from a familiar person to observe, interpret movements and behaviours, anticipate, and problem solve based on their experience, training and observation.

Administration

Assessor: Parent, caregiver or professional who is familiar with the child.
Time Allocated: N/A – completed via report or observation.
Availability: Can be accessed via: https://onlinelibrary.wiley.com/doi/abs/10.1111/dmcn.13124
Note: the FCCS is under supporting information, the file is "dmcn13124-sup-0001-AppendixS1.pdf".
Contact: The Centre for Cerebral Palsy and Cerebral Palsy League of Queensland, info@cplqld.org.au.

(III) Viking Speech Scale

(Pennington et al., 2013)

The Viking Speech Scale classifies the clarity of the child's speech production as understood by an unfamiliar listener. It is designed for children aged over 4 years. It is not intended to classify communication clarity of children who use alternative and augmentative communication. The scale does not evaluate overall communicative competency, focussing rather on speech intelligibility.

Level 1	Speech is not affected by motor disorder
Level 2	Speech is imprecise but usually understandable to unfamiliar listeners
Level 3	Speech is unclear and not usually understandable to unfamiliar listeners out of context
Level 4	No understandable speech

Administration

Assessor: SLT or professional who is familiar with the child.
Time Allocated: N/A – completed via informal assessment, information gathering and observation.
Availability: Can be assessed via: http://www.scpenetwork.eu/assets/SCPE-Tools/VSS/Viking-Speech-Scale-2011-Copyright..pdf
Contact: Lindsay Pennington, lindsay.pennington@ncl.ac.uk

1.9.5. Eating and Drinking Ability

(I) Eating and Drinking Ability Classification System (EDACS)

(Sellers, Mandy, Pennington, Hankins & Morris, 2014)

The Eating and Drinking Ability Classification System (EDACS) is a system for classifying eating and drinking ability in children with CP from age 3 years. The EDACS focuses on the aspects of eating and drinking such as chewing, swallowing, sucking, biting and keeping food and liquid in the mouth. The distinctions between the five levels consider functional ability, requirement for adaptation to texture, techniques used and assistance required. EDACS describes five distinct levels of ability using the key features of safety and efficiency:

Level I	Eats and drinks safely and efficiently
Level II	Eats and drinks safely but with some limitations to efficiency
Level III	Eats and drinks with some limitations to safety; there may be limitations to efficiency
Level IV	Eats and drinks with significant limitations to safety
Level V	Unable to eat or drink safely, tube feeding may be considered to provide nutrition

An additional classification of degree of help required during mealtimes can be used to further supplement EDACS. This includes: Independent (Ind), requires assistance (RA) or totally dependent (TD). It classifies usual rather than best performance. EDACS is complementary to the GMFCS, MACS and CFCS and its purpose is to be utilised both clinically and in research.

Administration
Assessor: Parent, caregiver or health professional who is familiar with the child's eating and drinking ability.
How: Completed either via parent/caregiver report and/or observation.
Time: N/A
Availability*:* Can be accessed via: www.EDACS.org

Recommendation -
> The classification systems for CP be adopted for use across Vietnam.

1.10. What is Speech & Language Therapy

1.10.1. Definition

Speech and language therapy is a field of expertise practiced by a clinician known as a speech and language therapist (SLT) or a speech therapist, also sometimes referred to as a speech and language pathologist. Speech and Language Therapy is a client-centred health profession with the primary goal being to prevent, assess, diagnose, and treat speech, language, social communication, cognitive-communication, and swallowing disorders in children and adults.

SLTs are autonomous professionals; that is their services are not prescribed or supervised by another professional but they frequently collaborate with other professionals. SLTs provide services across all of the following domains: advocacy, clinical services, consultation, education, prevention, population health and research for communication and swallowing disorders across the lifespan. Speech therapists are responsible for ensuring they work within the limits of their competence and update their professional knowledge and skills as needed (Speech Pathology Australia, 2010a).

1.10.2. Domain and Scope of Practice of Speech Therapy

The speech and language therapist is the professional who engages in clinical services, prevention, advocacy, education, administration, and research in the areas of communication and swallowing across the life span from infancy through geriatrics. The overall objective of speech and language therapy services is to optimize individuals' ability to communicate and swallow, thereby improving quality of life.

The International Classification of Functioning, Disability and Health is a multipurpose health classification system developed by World Health Organization (ICF; WHO, 2001). This classification system provides a standard language and framework for the description of functioning and health. The ICF framework is useful in describing the breadth of the role of the speech and language therapist in the prevention, assessment, and habilitation/ rehabilitation, enhancement, and scientific investigation of communication and swallowing.

Speech and language therapists work to improve quality of life by reducing impairments of body functions and structures, activity limitations, participation restrictions, and barriers created by contextual factors in relation to communication and swallowing.

Speech and language therapists may influence contextual factors through education and advocacy efforts at local and national levels. Examples in speech and language therapy include a user of an augmentative communication device needing classroom support services for academic success.

Refer to section 2.3 for further information on the role of the SLT in relation to the ICF model.

2. Pathways and Principles of Rehabilitation

2.1. Introduction

2.1.1. Rehabilitation

WHO describes rehabilitation as “an essential part of the continuum of care, along with prevention, promotion, treatment and palliation, and should therefore be considered an essential component of integrated health services. Rehabilitation is a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment. Health condition refers to disease (acute or chronic), disorder, injury or trauma. A health condition may also include other circumstances such as pregnancy, ageing, stress, congenital anomaly, or genetic predisposition.” (WHO, 2017) “Rehabilitation measures target body functions and structures, activities and participation, environmental factors, and personal factors.” (WHO, 2011)

Rehabilitation can include a variety of activities in various sectors. In the health sector, rehabilitation addresses chronic, or long-term, conditions and impairments with the goal of reversing or limiting their impact. Services may include speech therapy, physiotherapy, occupational therapy, the provision of assistive devices, and special surgeries to correct deformities and other types of impairment.

Key aspects of rehabilitation care include:

- Multidisciplinary screening and assessment
- Identification of functional difficulties and their measurement
- Treatment planning through goal setting
- Delivery of interventions which may either effect change or support the person in managing persisting change
- Evaluation of effectiveness of the intervention
- Reporting

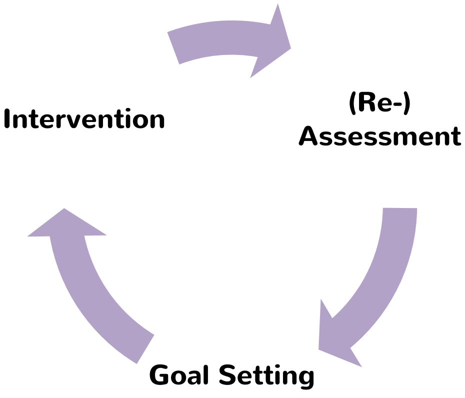
2.1.2. Habilitation

Habilitation involves interventions that help individuals keep, learn, or improve skills and functioning for daily living. The focus is on learning of new skills when an individual is born with a disability that impacts typical development (and therefore typical skill attainment). These are skills that may only be mastered through skilled and targeted therapy services.

Examples include teaching a nonverbal child to use an Augmentative and Alternative Communication (AAC) system. It could also include environmental modification to ensure safe eating through texture modification and/or changes in posture.

2.2. Rehabilitation Cycle

The conventional approach to rehabilitation is a cyclical process:



2.2.1. Assessment

- The patient is assessed and needs are identified and quantified;

2.2.2. Goal setting

- On the basis of the assessment the goals for rehabilitation of the patient are defined. These can be short term, medium term and long term goals;
- A plan to reach these goals is formulated

2.2.3. Intervention

- Giving relevant treatment in order to achieve the goals;

2.2.4. Re-Assessment

- Progress is assessed as to whether the intervention has been effective in order to achieve the agreed goals. If not then goals and consequent intervention can be revisited.

2.2.5. Discharge

- Cerebral Palsy will impact typical development and therefore typical skill attainment. Discharge could be considered if goals have been attained and/or if there is no progress with goals due to the effect of associated conditions e.g. epilepsy, motivation etc.

- Post discharge reviews may be required to enable those with disabilities to maintain maximum independence as the individual transitions to adulthood.

2.2.6. Summary of Rehabilitation Cycle

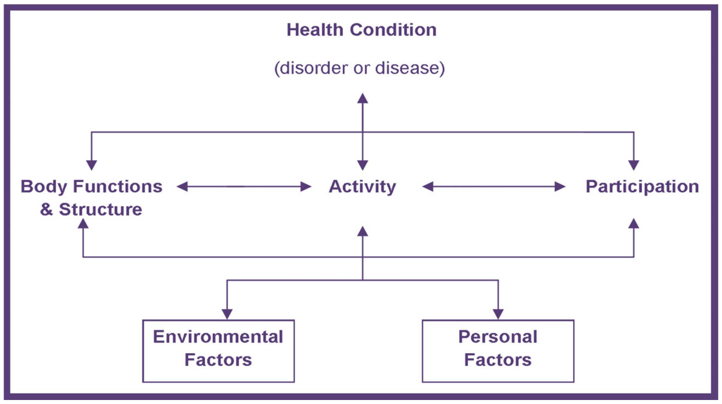
In many cases, children with CP will not reach age appropriate development in terms of communicative and swallowing function. This is due to permanent neurological damage and sensory and motor impairments.

The role of the SLT may be to work within episodes/ cycles of care targeting maximising activity and participation through clearly defined functional goals. Intervention should also focus on increasing the skills of the family and improving environmental factors.

Therefore rehabilitation throughout childhood may include periods of direct intervention and periods of discharge or review, whereby caregivers can opt to re-enter the cycle when circumstances change in terms of impairment, activity, participation and environmental factors. For example this may be during transition into a new educational setting or during a period of illness or reduced ability level.

2.3. ICF

2.3.1. What is the ICF



WHO (2001). ICF Model

Rehabilitation can be summarised in the ICF (International Classification of Functioning, Disability and Health) model developed by WHO (2001). The ICF conceptualises a person's level of functioning as a dynamic interaction between her or his health condition, environmental factors, and personal factors. It is a biopsychosocial model, based on an integration of the social and medical models of disability. All components of disability are important and any one may interact with another. Environmental factors must be taken into consideration as they affect everything and may need to be changed.

- **Body Functions** are the physiological or psychological functions of body systems.
- **Body Structures** are anatomic parts of the body such as organs, limbs and their components.
- **Impairments** are problems in body function or structure such as a significant deviation or loss.
- **Activity** is the performance of a task or action by an individual.
- **Activity Limitations** are difficulties an individual may have in the performance of activities.
- **Participation** is an individual's involvement in life situations in relation to Health Conditions, Body Functions and Structure, Activities, and Contextual factors.
- **Participation Restrictions** are problems an individual may have in the manner or extent of involvement in life situations.
- **Environmental factors.** These factors range from physical factors (such as climate, terrain or building design) to social factors (such as attitudes, institutions, and laws).
- **Personal factors** include race, gender, age, educational level, coping styles, etc.

The ICF framework is useful in describing the breadth of the role of the speech and language therapist in the prevention, assessment, and habilitation/ rehabilitation, enhancement, and scientific investigation of communication and swallowing. Speech and language therapists work to improve quality of life by reducing impairments of body functions and structures, activity limitations, participation restrictions, and barriers created by contextual factors.

The health condition component of the ICF can be expressed on a continuum of functioning from intact functioning to completely compromised functioning. The contextual factors interact with each other and with the health conditions and may serve as facilitators or barriers to functioning.

The interrelated components of the ICF include:

- Health Conditions
    - Body Functions and Structures: involve the anatomy and physiology of the human body.
        - examples include craniofacial anomalies, vocal fold paralysis, cerebral palsy, stuttering, and language impairment.
    - Activity and Participation: Activity refers to the execution of a task or action. Participation is the involvement in a life situation.
        - examples include difficulties with swallowing safely for independent feeding, participating actively in class and accessing the general education curriculum.
- Contextual Factors
    - Environmental Factors: make up the physical, social, and attitudinal environments in which people live and conduct their lives.
        - examples include the role of the communication partner in augmentative and alternative communication, the impact of accessing a cafe or classroom to maintain nutrition and hydration.
    - Personal Factors: are the internal influences on an individual's functioning and disability and are not part of the health condition. These factors may include, age, gender, ethnicity, educational level, social background, and profession.
        - examples may include a person's background or culture that influences his or her reaction to a communication or swallowing disorder.

Dysphagia example:

- **Health Disorder**: Cerebral Palsy
- **Body Function/Structure Impairment**: Unable to control opening of mouth due to oral hypertonicity. Unable to move tongue laterally
- **Activity Limitation**: Unable to chew or swallow
- **Participation Limitation**: Difficulty eating meals with family and out in the community
- **Environment considerations**: Physical access to community buildings, school, cafe, street food vendor

- **Personal factors**: Age and gender of child; motivation of child

Communication example:

- **Health Disorder**: Cerebral Palsy
- **Body Function/Structure Impairment**: Motor speech impairment. Unable to coordinate muscle movement in speech subsystems: respiratory, phonatory, resonatory and articulatory.
- **Activity Limitation**: Unable to produce intelligible speech/ speech is unclear
- **Participation Limitation**: Difficulty communicating with others; expressing ideas in class; difficulty expressing wants and needs; difficulty making friends
- **Environment considerations**: Access to AAC; access to speech therapy service; supportive educational environment; skill and patience level of communication partners
- **Personal factors**: Age and gender of child; motivation of child

Speech and language therapists may influence contextual factors through education and advocacy efforts at local and national levels. Relevant examples in speech and language therapy include a user of an augmentative communication device needing classroom support services for academic success.

Recommendation -

> That the ICF be adopted as the framework that guides rehabilitation services across Vietnam

2.3.2. The ICF, Rehabilitation and CP

This guideline has been developed using the International Classification of Functioning, Disability and Health (ICF) to guide clinical thinking and the delivery of services to children with CP and their families.

The use of the ICF as a framework for clinical practice provides health care workers with a guide to the selection of measurement tools, to inform goal setting and decision making processes and determine outcomes meaningful to children with CP and their families (Rosenbaum and Stewart 2004). Use of the ICF in the management of CP enables us to expand our thinking beyond "fixing" primary impairments to a view that places equal value on promoting functional activity and facilitating the child's full participation in all aspects of life (Rosenbaum & Stewart 2004).

In other words, children with CP should be assessed and have interventions provided, wherever possible, within their different life domains including (but not limited to) home, schools, recreational or other settings, to have a full understanding of the child's functional abilities in different environments and facilitate full integration to their community living. This may require developing/strengthening relationships with or partnering with local charitable organisations, non-government organisations and CBR projects to facilitate continuity of care once a child with CP is discharged from hospital.

2.4. Child Centred and Family Centred Care

Best practice service delivery when working with children with CP and their families is to adopt person-centred and family-centred approaches. Child and family-centred care is the delivery of health care based on partnerships between patients, families and all those involved in the care of the child and family. Child and family-centred care recognizes that the child or patient is at the centre of care and that the family is central in the child's life and therefore central to the professional team's care processes.

A child centred approach recognises that the child's rights and needs are the primary focus for care in the context of the family, culture, community and nation (https://www.unicef.org).

Child and family-centred care is achieved through: respect, whereby patients and families receive personalized and compassionate care; communication, which promotes mutual understanding; and partnership, whereby children and families are engaged in their care in an authentic and collaborative way. Children and young people should be involved in the decision making of their care as much as possible. This approach results in optimal health, patient safety, health equity, and a positive patient and family experience.

2.4.1. Person-Centred Approach

Person-centred care is a way of thinking and doing things that sees the people using health and social services as equal partners in planning, developing and monitoring care to make sure it meets their needs. This means putting people and their families at the centre of decisions and seeing them as experts, working alongside professionals to get the best outcome (https://healthinnovationnetwork.com).

Treatment and care should take into account individual needs and preferences. Patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If the patient agrees, families and carers should have the opportunity to be involved in decisions about treatment and care. Families and carers should also be given the information and support they need (NICE, 2014).

A person-centred approach should underpin the goal setting process. Treatment goals are more likely to be achieved if patients are involved in setting them. Moreover, there is also evidence that this goal setting process has positive therapeutic value in encouraging the patients to reach their goals (Hurn, Kneebone, Cropley, 2006).

Person-centred practice places the individual in the centre and emphasises building partnerships with persons with CP and their families in which they are valued members of the rehabilitation team. It emphasises four aspects:

- Each individual is unique
- Each individual is an expert in their own lives

- Partnerships are key
- There is a focus on an individual's strengths

Person centred practice situates power and control with the person and their family. It tailors supports to achieve the person's goals and future and aims for social inclusion, valued roles, and community participation.

Ensuring that people are involved in and central to their care is now recognised as a key component of developing high quality healthcare (Simces, 2003).

2.4.2. Family-Centred Approach

Family-centred practice adopts a similar philosophy to person-centred practice and goes further to recognise that families and carers are pivotal decision makers when working with children with CP. Family-centred practice is made up of a set of values, attitudes, and approaches to services for children with CP and their families. The family works with service providers to make informed decisions about the services and supports the child and family receive. In a family-centred approach, the strengths and needs of all family members and carers are considered. The family defines the priorities of the intervention and services.

It is based on the premises that families know the child best, that optimal recovery outcomes occur within a supportive family and community environment, and that each family is unique. Service providers support and respect each family's capacity and resources. Family capacity includes the knowledge and skills the family requires to support the child's needs and well-being. Capacity is the amount of physical, intellectual, emotional and spiritual energy necessary to support the child with CP, and it directly influences the sense of competency a family member experiences when caring for a child with CP.

2.4.3. Parent Empowerment

The WHO defines empowerment as a process through which people gain greater control over decisions and actions affecting their health.

Family-centred practice supports parent empowerment. Example behaviours that service providers should adopt to promote family-centred practice and parent empowerment include:

- Encourage parent decision-making in partnership with other team members (to utilise family empowerment strategies.)
- Assist families to identify their strengths and build their own resources.
- Inform, answer, and advise parents (to encourage informed choices).
- Work in partnership with parents and children and help them identify and prioritise their needs from their own perspective.
- Collaborate with parents at all levels (care of the individual child; program development, implementation and evaluation; policy formation).

- Provide accessible services that will not overwhelm families with processes and documentation.
- Share complete information about the child's care on an ongoing basis.
- Respect the values, wishes and priorities of families.
- Accept and support decisions made by families.
- Listen.
- Provide flexible and individualised services (and to respond to the changing needs of the family).
- Be knowledgeable about and accept diversity among families (racial, ethnic, cultural and socio-economic).
- Believe and trust parents.
- Communicate in a language understandable by parents.
- Consider and be sensitive to the psychosocial needs of all family members.
- Provide an environment that encourages the participation of all family members.
- Respect the family's own style of coping without judging what is right and what is wrong.
- Encourage family-to-family support and the use of natural community supports and resources.

(Law et al, 2003)

Recommendation -

> Rehabilitation services should adopt the philosophies of child- and family- centred and parent empowerment practice.

2.5. Gender Equality in Health

Gender equality in health means that women and men, across the life-course and in all their diversity, have the same conditions and opportunities to realize their full rights and potential to be healthy, contribute to health development and benefit from the results (WHO, 2015).

It is recommended to disaggregate data and conduct gender analyses to identify sex and gender-based differences in health risks and opportunities and to design appropriate health interventions.

Addressing gender inequality improves access to and benefits from health services. It is recommended to develop gender-responsive health programs which are appropriately implemented and are beneficial for men and women. It will assist CP prevention and care initiatives meet its strategic objectives and targets to reduce inequalities in health and in making a difference to the lives of girls, boys, women and men by improving the quality of services provided in relation to the prevention, diagnosis and treatment of CP and improve patient outcomes.

2.6. Organization of Rehabilitation Services

2.6.1. Current Situation of SLT in Vietnam

(I) Availability of SLT services

At present there is no Ministry of Education & Training (MOET) or Ministry of Health (MOH) approved university bachelor or masters course in SLT in Vietnam. Some PTs, nurses and doctors have attended training courses in SLT and work across their professional discipline and include SLT practice. There are paediatric PT/SLTs and Dr/SLTs working in the Rehabilitation, National, University and Children's Hospitals in Hue, HCMC, Hanoi, Danang, Hai Duong and Dong Nai.

There is an inadequate number of SLTs to provide an efficient and effective service and waiting lists may be long. Participants commented that many regional areas do not have an SLT service and that there is generally an imbalance of service development and skill in rural areas.

(II) Referral Process

Parents are able to refer directly to ST services. However they may not, due to:

- lack of awareness of service
- wanting to hide their child's disability due to societal stigma
- lack of knowledge to notice early development abnormalities resulting in late diagnosis
- better awareness of their child's movement difficulties than communication and swallowing so will generally seek PT services first.

Healthcare professionals:

- In some hospitals, any hospital department can refer the patient directly to SLT
- In some hospitals, the Rehabilitation doctor decides if a referral to SLT is required

(III) Awareness of SLT service

Families & Community:

- Parent awareness of service may be limited
- Parents may become aware of SLT via parents of children receiving SLT service (word of mouth)
- Internet coverage is good across Vietnam (even in rural areas) allowing information about SLT to be widely advertised
- SLTs are providing seminars to introduce SLT to the community and are providing training on basic SLT services

Professionals:

- awareness of SLT varies between hospitals depending on the public relations departments and the hospital website
- some hospitals have a monthly professional development meeting with all staff so SLTs use this forum to raise awareness within their hospital
- many doctors don't know to refer to SLTs

Recommendations -

> There is a need to review the current approach to the provision of rehabilitation services to children with CP to enable greater ability/flexibility to respond to the needs of children and their families in their own community according to the ICF framework.

> There is a need to understand the impact of continuous hospital-based intervention for children with CP on family functioning and engagement in life activities especially learning opportunities (preschool and school for the child and work and community activities for parents and carers).

>There is a need to support the development of a government approved SLT training course.

>There is a need to further develop awareness of SLT services at national, provincial, district and commune levels to ensure children with CP and their families have knowledge about SLT services across urban and rural areas.

2.6.2. Recommendations for Rehabilitation Departments

The WHO report, *Rehabilitation in Health Systems* (2017), provides recommendations to support the growing international demand for rehabilitation services. Recent studies on values and preferences, acceptability and feasibility for quality services support the integration of rehabilitation in and between primary as well as secondary and tertiary levels of the health system. The recommendations from the WHO report called for better coordination among levels of health care and sectors to maximise the efficiency of services and to optimise health outcomes:

- **Integration of rehabilitation services** at all levels can facilitate the provision of person-centred care.
- **Ensure the availability of rehabilitation services at each leve**l, with established coordination mechanisms, so that rehabilitation can follow the continuum of care as required to support families and the overall care of the patient.
- **Families and patients will require different types and intensities of rehabilitation** at different levels of the health system, as they may move between primary, secondary and tertiary levels during their care.
- **The level of care and types of rehabilitation services are dependent on the families and patient's needs** and the interventions available to address the primary goals of rehabilitation.

Recommendations -

> Rehabilitation services should be available at all levels of healthcare with equitable access for all patients and their families.

> Rehabilitation departments should establish and maintain strong links/relationships with other hospital departments especially neonatology, maternal health, obstetrics/gynaecology, ultrasound, diagnostic imaging, gastroenterology, paediatric department, neurology and traditional medicine, to enable/facilitate referral pathways and care for infants deemed at high risk of CP and for ongoing care of children with CP.

> Rehabilitation services should include speech therapy services for children with CP.

> Rehabilitation departments should establish and maintain strong links/relationships with each other regarding professional development, research, and teaching.

2.6.3. Rehabilitation Service Management and Service Improvement

(I) Workforce and resources

There should be a full range of team members with an appropriate skill base and training to provide comprehensive, evidenced-based programs of care. Multidisciplinary team members should utilise an inter-disciplinary approach (see 2.7 below for further detail).

It is more important that the right therapy is provided rather than dictating which team member should provide care. This is particularly important in rural and remote areas which do not have access to all the recommended staff. However, clinicians should be aware of their scope and limitations of practice to ensure patient safety and quality of care.

Specialist high tech resources e.g. videofluoroscopy dysphagia assessment could be available centrally. Providers of this service could accept referrals from rural areas or from services where there is no SLT.

The use of telerehabilitation as a possible service model linking specialist/trained staff to other centres/remote families can assist to overcome shortfalls in less resourced centres, and areas without services; however the resource commitment at the major centre should also be factored into workforce numbers.

(II) Philosophies of practice

Rehabilitation should be client-centred. Health professionals should move towards and enable an equal partnership in care with clients, their families and significant others. Goals, activities and prioritise should be determined through collaborative goal setting (see 2.6 below for further detail).

Service provision should be evidence-based. Processes to promote the implementation of evidence and best practice should be in place to support safe and effective care. Evidence-based practice should be supported through professional development, teaching, quality research and quality assurance activities.

(III) Essential aspects of rehabilitation care for children with CP

- Early diagnosis
- Early intervention
- Assessment and management of the motor disorder
- Assessment of functional skills and maximising abilities (cognitive, motor, communication, eating and drinking)

- Assessment and management of associated conditions
- Prescription and provision of appropriate assistive and adaptive technology

In addition, the establishment of a national CP register would enable determination of the prevalence CP in Vietnam. It would also enable outcomes to be monitored and evaluated on a population level.

Recommendations -

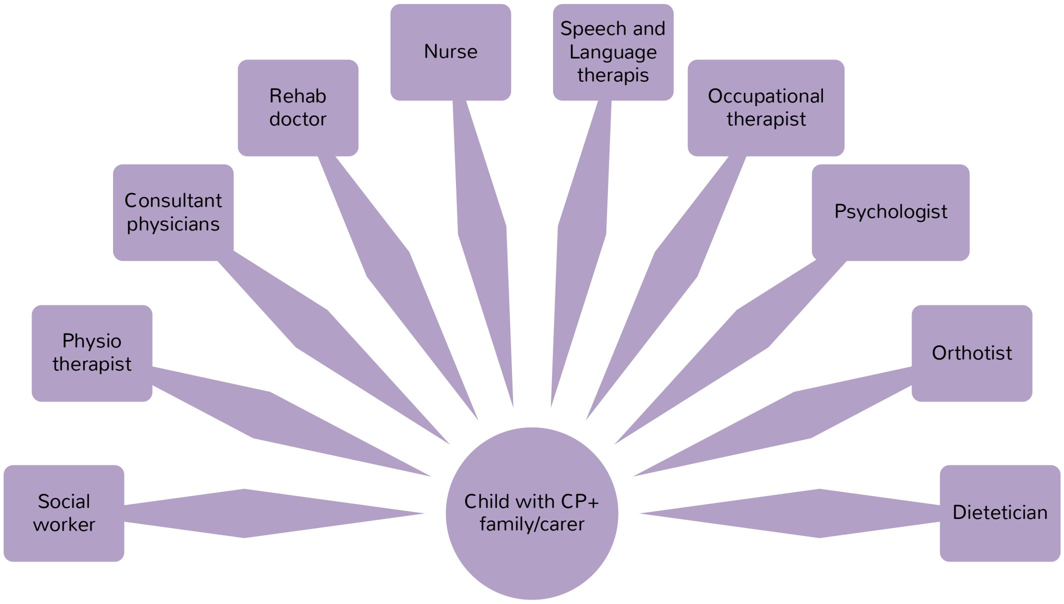
> Telerehabilitation offers a way to improve reach of rehabilitation services to children and families in rural and remote areas of Vietnam. It should be considered as a means of supporting children and families following discharge. Appropriate workforce resourcing is required.

> Rehabilitation departments should establish mechanisms to review services on a regular basis and facilitate team members in keeping current with best practice approaches to rehabilitation for children with CP and for service improvements.

> Rehabilitation departments should establish key performance indicators (KPIs) for monitoring the effectiveness of the service. Key performance areas include monitoring referral pathways/early diagnosis, admissions, assessment and planning (including person/family-centred practice), service provision (including EBP), patient/client outcomes, parent/carer/family education and transfer/discharge pathways. Where possible, these key performance areas should be standard across Vietnam.

>Hospitals need access to university portals for review of journal articles to ensure healthcare professionals are responsible for their own evidence based professional development and are providing evidence based care for their patients.

2.7. Multidisciplinary Teams and Interprofessional Team Approach



Recommendations -

> Rehabilitation services should be comprised of a multidisciplinary team which utilises an interprofessional team approach to service planning and provision.

> Within multidisciplinary teams, processes are established to promote and facilitate teamwork and collaboration including (but not limited to) case conferencing, keeping common patient files and progress notes.

> Multidisciplinary teams should participate in collaborative interdisciplinary research and present at national and international conferences.

3. The Rehabilitation Cycle

3.1. Evidence-Based Practices in CP

Evidence-based decision making involves the integration of best available clinical evidence from systematic research, the proficiency and judgment clinicians acquire through clinical experience and client values and preferences in making clinical decisions about their care (Sackett, Rosenberg, Gray, Haynes, Richardson,1996). Decision making is also made with consideration to the organisational context (for example local policies, procedures and beliefs around approaches) (Figure 3).

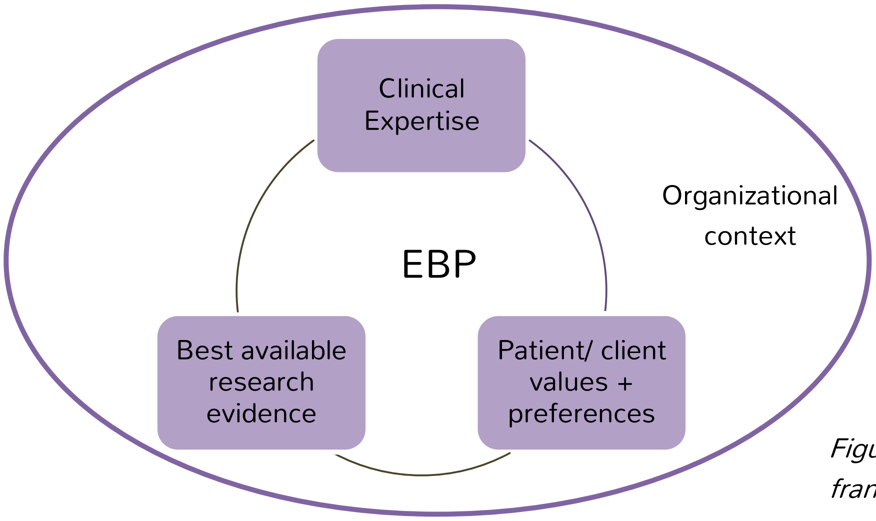


Figure 3. EBP framework

Evidence-based practice should guide the management of children with CP across Vietnam.

The ICF guides evidence-based practice in the management of children with CP. Research findings demonstrate that interventions for CP are only effective for the domain of the ICF that they target. That is, interventions targeting the body functions and structure impairments will have outcomes at the body functions and structure domain only. If outcomes are desired at the activities and participation domains of the ICF, interventions that are proven to impact these domains are directed at the activity and participation limitations.

The intervention strategies outlined in these guidelines represent the current and highest level of evidence-based practice for the management of children with CP.

3.2. Neuroprotective and Preventive Strategies

Strategies to reduce CP in infants should be considered and implemented if shown to be effective in order to reduce the impact of disability on individuals, families, health care and society (RCOG, 2011).

3.2.1. Antenatal Magnesium Sulfate (MgSO4)

For more details on this preventive strategy see: General Guideline and the Physiotherapy and Occupational Therapy Guidelines on the Management of CP

3.2.2. Therapeutic Hypothermia (Cooling)

For more details on this preventive strategy see: General Guideline and the Physiotherapy and Occupational Therapy Guidelines on the Management of CP

3.3. Diagnosis, Assessment, Prognosis and Goal Setting

Cerebral palsy is diagnosed by clinical presentation based upon the presence of a motor disorder caused by damage to, or maldevelopment of the infant brain. A diagnosis of CP is made by a medical professional (e.g. general practitioner, paediatrician, paediatric neurologist).

Refer to the general rehabilitation guideline for more detailed information regarding diagnosing cerebral palsy.

Physiotherapists may however be the first health professional to see a child because of concerns that the child is not developing typically physically. Therefore it is important for physiotherapists to be able to identify signs of cerebral palsy and know when to refer children to a medical professional for further assessment and diagnosis.

For the majority of children, the cause of their brain injury or maldevelopment is unknown. It is widely accepted that cerebral palsy does not result from a single cause but rather from a series of ‘causal pathways’ that can result in or accelerate injury to the developing brain.

3.3.1. Early Diagnosis of CP

Early diagnosis allows prompt referral to early intervention to

- optimise motor & cognitive development
- prevent secondary complication (45% have health issues)
- enhance caregiver well being

For more details on early diagnosis refer to: General Guideline on the Management of CP

The following have been identified as independent risk factors which may indicate an increased risk of cerebral palsy :

- antenatal factors:
    - preterm birth (with risk increasing with decreasing gestational age)
    - chorioamnionitis
    - maternal respiratory tract or genito-urinary infection treated in hospital
- perinatal factors:
    - low birth weight
    - chorioamnionitis
    - neonatal encephalopathy
    - neonatal sepsis (particularly with a birth weight below 1.5 kg)
    - maternal respiratory tract or genito-urinary infection treated in hospital
- postnatal factors:
    - meningitis (NICE 2017)

As premature birth is associated with an increased risk of cerebral palsy (35% of CP infants are born prematurely and 10% of preterm infants have CP), difficulties with feeding and swallowing in the neonate may be the first signs of potential neurodisability and require SLT assessment to determine safety of oral intake.

Children who have any of the risk factors listed above (so who are at increased risk of developing cerebral palsy) or who have feeding difficulties of unknown etiology, require an enhanced clinical and developmental follow up programme by a multidisciplinary team for children up to 2 years (corrected for gestational age).

The MDT Clinical & Developmental Follow-up Program should include:

- History taking questions related to
    - the mother's health, pregnancy and birth
    - the infant's medical status at birth, postnatally and current.
    - the infant's developmental history with a specific focus on feeding development.

- Consideration of joint session with PT using the General Movement Assessment (GMA) during routine neonatal follow up assessments for children between 0-3mths who are at increased risk of cerebral palsy.

- Recognising the following as possible early motor features in the presentation of cerebral palsy:
    - unusual fidgety movements or other abnormalities of movement, including **asymmetry or paucity of movement**
    - **abnormalities of tone,** including hypotonia (floppiness), spasticity (stiffness) or dystonia (fluctuating tone)
    - abnormal motor development, including **late head control**, rolling and crawling
    - **feeding difficulties**.

- Referral to SLT if feeding difficulties are identified, for an urgent comprehensive feeding assessment.

Recommendation -

> As premature birth is associated with an increased risk of cerebral palsy, it is recommended that the capabilities of SLTs to manage feeding difficulties in neonates be developed over time.

3.3.2. Prognosis

There are a number of key prognostic messages that can be shared with parents to support them with accurate information.

(I) Life-long disability

- CP is a life-long disability
- CP does not get worse over time, though the exact symptoms can change over a person's lifetime.
- Ageing occurs earlier
- Rehabilitation planning must consider adulthood

(II) Normal life expectancy

- Almost all children with CP will have a normal life expectancy
- 5-10% of children with CP will die in childhood
- The risk of premature death increases with co-occurring epilepsy, intellectual disability, and severe physical impairment.
- There is an association between reduced life expectancy and the need for enteral tube feeding, but this reflects the severity of swallowing difficulties and is not because of the intervention. (NICE, 2017)

(III) Prognosis for walking

For more details on this paragraph refer: General Guideline and the Physiotherapy and Occupational Therapy Guidelines on the Management of CP.

(IV) Prognosis for talking

- 1 in 4 children with CP will be non-verbal so it is important to assess and augment speech early
- Around 1 in 2 children with CP have some difficulty with elements of communication
- Around 1 in 3 children have specific difficulties with speech and language
- Communicative frustration can lead to behavioural disorders
- The more severe the child's physical, functional or cognitive impairment, the greater the likelihood of difficulties with speech and language
- Uncontrolled epilepsy may be associated with difficulties with all forms of communication, including speech
- A child with bilateral spastic, dyskinetic or ataxic CP is more likely to have difficulties with speech and language than a child with unilateral spastic CP

(V)Prognosis for eating / drinking/ swallowing

- 1 in 15 children will need non-oral feeding (Novak, 2014). The need for enteral tube feeding reflects the severity of swallowing difficulties and there is an association with reduced life expectancy.
- The prevalence of oropharyngeal dysphagia (OPD) in children with cerebral palsy is unclear, but estimated to range from 19% to 99%, depending on definitions and tools used (Goh, Choi, Kim, Park, & Park, 2018). Feeding problems have been reported to occur in 85% of 18-36 month old Australian children with CP (Benfer et al, 2015).
- Failure to treat and properly manage dysphagia can lead to a number of additional health problems, including:
  - Dehydration
  - Aspiration and respiratory problems
  - Pneumonia
  - Malnutrition
- 2 in 5 children with CP have a problem with drooling (Novak, 2012)

(VI) Presence of associated conditions affect outcomes

- CP is almost always accompanied by associated conditions
- Screening for the presence of associated conditions should be routine and associated conditions managed if present.
- The presence of epilepsy if not well controlled and if seizures occur during a mealtime, the risk of aspiration may be increased.

(VII) Severity predictions

- Children with generalised severe motor impairment e.g. spastic quadriplegia are likely to experience greater swallowing difficulties than those with diplegia, but oropharyngeal dysphagia is prevalent even in children with mild CP (Arvedson, 2013).

(VIII) Using MRI to predict prognosis

For more details on these paragraphs see: General Guideline and the Physiotherapy and Occupational Therapy Guidelines on the Management of CP.

3.3.3. Assessment and Goal Setting

Building authentic partnerships with families has positive implications for the rehabilitation process in general, and in particular, on determining which goals will be addressed during the rehabilitation process. A goal can be defined as a specific and measurable objective. The main purpose of therapy is goal attainment and goals are set to reduce limitations in activity and participation (Harty, Griesel, & van der Merwe, 2011). All team members actively participate to reach consensus on the overall rehabilitation goals. This increases the likelihood of positive and sustainable outcomes, as everyone agrees as to which goals are particularly important for the family and child (Harty, Griesel, & van der Merwe, 2011).

Rehabilitation teams should use the ICF's activities and participation domains as a common language to help identify important goals for the family and child. The ICF allows both individual, as well as contextual factors to be taken into consideration, which is essential in successful rehabilitation approaches.

The two most commonly used goal setting measures are the Canadian Occupational Performance Measure (COPM) and Goal Attainment Scaling (GAS). In many cases they can be used together.

(I) Goal Attainment Scaling (GAS)

Goal Attainment Scaling (GAS) involves individualised, patient-generated goals scored on a 5 point scale. GAS is used to evaluate services or an individualised program based on the attainment of individualised goals.

Health professionals can use GAS to help people with cerebral palsy work out goals to work on during therapy or intervention. Setting personal goals can help focus the attention and energy of the individual and their health care provider. Importantly, a second GAS is completed after therapy or intervention to measure whether the goals have been achieved.

It requires extensive therapist training and experience to set goals adequately. Therapist's correct judgement of the impact of the intervention and therapist's ability to set realistic, accurate goals may be difficult to establish.

Administration

Assessor: This tool can be conducted by any rehabilitation team member/s to set therapy goals and evaluate intervention.

How: A five point goal scale is developed, usually via interview with the client/family and graded levels of possible goal attainment with descriptions of anticipated outcome are described for each goal. Goals are scaled from least favourable to most favourable outcome, with an expected outcome level in the middle. Goals need to follow SMART principles:

- Specific
- Measurable
- Achievable
- Realistic
- Time frame defined

Time: approximately 20 to 30 minutes to establish goals, 10 minutes to reassess attainment.

Note: Freely available from

- McDougall, J. and King, G. (2007) Goal Attainment Scaling: Description, Utility, and Applications in Pediatric Therapy Services. (2nd ed.). London, ON: Thames Valley Children's Centre.
- Turner-Stokes, L. (2009) "Goal Attainment Scaling (GAS) in rehabilitation: a practical guide." Clinical Rehabilitation,23, 4, 362-370.

Recommendations -
> GAS is an internationally recognised tool for setting and evaluating goals. It is recommended that the capabilities of clinicians to utilise GAS be developed over time.
> Rehabilitation services should engage in collaborative goal setting involving the child, their family and the multidisciplinary rehabilitation team.

3.4. Managing the Motor Disorder

For more details on managing the motor disorders, see: the General Guideline and the Physiotherapy and Occupational Therapy Guidelines on the Management of CP.

3.5. Prescribing Adaptive and Assistive Technology (AAT)

Adaptive and assistive technology is a widely used intervention for people with CP and other disabilities (Novak et al, 2012).

Adaptive and assistive technology should be a component of an overall management plan and not an isolated intervention.

Examples of AAT linked to SLT include (but are not limited to):
- Positioning equipment including posture chairs, bed positioning
- Adaptive cutlery, bowls, plates, cups, bottles, teats etc
- Low tech and high tech communication aids
- Accessible toys

Access to suitable AAT may be limited for many individuals with CP. This may be due to limited suppliers, limited options or limited funding. Abandonment rates of AAT increase when AAT is recommended without trial, when clients and families are not involved in goal setting and AAT identification, when AAT implementation is not supported in the home/community setting and when there is limited follow up.

Best practice prescription of adaptive and assistive technology involves:
- A comprehensive assessment that considers all levels of the ICF
- Trial of identified options (wherever possible)
- Intervention strategies to support implementation of device(s) including skill development and parent/carer education
- Follow up and review of adaptive and assistive technology to evaluate impact of the device(s) on goal achievement and to identify challenges with use of the device(s)
- Collaboration between OT and SLT in the selection, design and implementation of AAC.

Further detail will be outlined in the technical guidelines for Occupational Therapy and Physiotherapy.

Recommendations -

> Strategies should be identified for increasing access to AAT and post-prescription follow up of AAT. The use of telerehabilitation may offer one strategy for increasing follow up.

> Ongoing collaboration between OTs and SLTs in decision making and follow up for AAT as professions develop in Vietnam.

3.6. Managing Communication Impairments

CP can affect multiple aspects of communication including speech, language, cognition and gestural development. Communication difficulties associated with CP can be multifactorial, arising from motor, intellectual and sensory impairments. Children with CP can experience mild to severe difficulties in expressing themselves. They are often referred to speech and language therapy (SLT) services to maximise their communication skills.

3.6.1. Interventions for Communication Impairments

Strategies should address the early communication problems of children at high risk for CP to maximise long-term emotional health and social participation of the child (Parkes, Hill, Platt, & Donnelly, 2010; Pennington, Goldbart, & Marshall, 2004).

- **Family education** should focus on appropriate social interactions to promote a positive environment for infant speech and language development. Families should be educated on appropriate developmental milestones for language and communication skills.
- **Individual speech-language therapy** can improve communication behaviours, word formation, vocabulary development, requests for objects or actions, responses to others' communication use of expressive, language structures and understanding of spoken words.
- Speech-language therapy can also include introducing **augmentative and alternative communication (AAC)** systems, such as symbol or picture charts or computer-based communication aids with synthetic speech. Access to suitable AAC is essential for supporting inclusion across a child's life and all activities that they undertake. Evaluation for appropriate AAC should be considered within the context of the environment in which the device will be used for example home and school.
- Speech-language therapy can also target **control of respiration, phonation, resonance, articulation and prosody** for improved production of sounds and words.

(I) Managing Prelinguistic Communication

Children with CP are at risk of delay in their prelinguistic communication development. Prelinguistic forms of communication include: eye gaze, fine motor acts such as pointing, gross motor acts such as head turning, vocalizations, gesture, and facial expressions (Sandberg &

Liliedahl, 2008). Visual and motor impairments will affect the development of these skills and therefore overall language development.

The most effective intervention strategies will enhance the child's use of intentional communication signals, building the foundation for later language acquisition (Ogletree & Pierce, 2009). This may include working on cause and effect understanding, making choices and training caregivers in interpreting their child's communication attempts and developing contingent responses. Early intervention should aim to construct situations to teach children that they can control people and objects in their environment to encourage intentional communication and avoid learned helplessness (Beukelman & Mirenda, 1998).

Attention

Joint attention is the state in which the attention of a child and a communication partner is coordinated, focusing on the same object or activity (looking, listening, touching, smelling). Joint attention is critical to the development of intentional preverbal communication and is highly correlated with the development of later language skills. Joint attention behaviours fall into two main categories; responding to joint attention (RJA) and initiating joint attention (IJA).

An infant with CP is at risk for delays and impairment in the development of joint attention due to disturbances in muscle tone, posture, and visual differences. Caregivers often have difficulty assessing where the child's attention is focused, making it difficult to respond to the child's attempts at joint attention. Children with CP are less likely to initiate eye contact (i.e. IJA) with parents than typically developing peers (Hanzlik, 1990). This may be influenced by the child's difficulty in shifting positions and grasping objects, making them more restricted to the activity that is presented by the parent.

Gesture

Gestures are one of the most consistent early indicators of intentionality, providing a means for a child to communicate information before they develop oral speech and language. Gestures can be expressed using the fingers, hands, and arms, and may also include facial features and body motions.

Impairment in the timing and planning of coordinated gross and fine motor movement may often result in inconsistent gestures that are difficult to interpret. Due to the presence of primitive or atypical reflexes, gestures may be counterintuitive or unintentional at times.

(II) Managing Receptive and Expressive Language

Assessment and intervention to improve receptive and expressive language skills for children who can speak with CP can follow the same procedures as any child with a language delay, however assessment and therapy activities must be adapted to the child's motor and sensory abilities.

(III) Managing Speech

Approximately 20% of children with CP are unable to produce intelligible speech. The speech impairment related to CP is dysarthria. Dysarthria is caused by neurological impairment, resulting in weak, imprecise and poorly coordinated speech of varying levels of severity. Anarthria is the term used when the child is not able to produce speech due to the severity of impairment across the speech subsystems. Control of all or some of the speech subsystems may be impaired: respiration, phonation, resonance, articulation and prosody. The speech systems may be differentially affected, for example respiration may be insufficient to support clear speech but articulation of a range of consonants may be possible (Pennington et al. 2013). Severe dysarthria is not linked with impaired cognition.

The motor disorders of cerebral palsy may affect the:

- Speed
- Range
- Strength
- Coordination
- Accuracy

of movements of the vocal tract, leading to the motor speech disorder dysarthria (Duffy, 2005).

Assessment of Dysarthria

See section 1.9.4 for a description of the Viking Speech Scale, which is a classification tool for the intelligibility of the child's speech.

Assessment of dysarthric speech should include observation and investigation into the speech subsystems. This may include assessment of duration and quality of single vowel production, consonant production in isolation, single words and phrase and sentence level speech in a variety of tasks. It may also include a basic oro-motor assessment and examination.

Rating scales can be used to assess intelligibility and the impact of the speech impairment on activity and participation. The Intelligibility in Context Scale (McLeod, Harrison and McCormack, 2012) and the Speech Participation and Activity Assessment of Children: Vietnamese (McLeod, 2004) are available in Vietnamese.

Treatment of Dysarthria

Children with dysarthria often have shallow, irregular breathing and speak on small, residual pockets of air. They have low pitched, harsh voices, nasalised speech and very poor articulation. Speech and language therapy aims to help children to control the movements for breathing and speech and so become more intelligible.

Small, observational studies have suggested that for some children, therapy might have been associated with positive changes in intelligibility and clarity of children's voices.

A systems approach that targets the components of the vocal tract controlling breathing, phonation, nasal resonance, articulation and intonation is commonly advocated, and is similar to intervention for adults with acquired dysarthria. Treatment may focus on regulating breathing to support speech across short phrases. Intervention also involves slowing children's speech rate, to allow more precise movement of muscles in the oral tract. It may also work on increasing respiratory effort and focusing on maximizing jaw movements in speech to increase oral cavity volume and, thereby, increase loudness and decrease excess nasality.

Articulation treatment is only advised when other aspects of speech production have been or are being addressed, because imprecise speech sounds are usually due to problems in controlling respiration, phonation, and the velopharynx, rather than solely the lips and tongue. More precise articulation and improved intelligibility are achieved through developing control of breathing for speech, increasing respiratory effort, and slowing speech rate.

Treatment for overall speech naturalness (prosody) comprises exercises aimed at controlling speaking rate, appropriateness of pauses used between words, loudness and, where necessary, pitch variation (Pennington et al, 2016; Pennington, 2009).

Treatment of Anarthria

If the child in anarthric it is unlikely they will develop intelligible speech in the near future; therefore intervention must focus on AAC and communication strategies. If child can imitate vocalisations including speech sounds, extending this may be one target of intervention.

(IV) Non Speech Oral Motor Exercises

Non speech oral motor exercises such as blowing, sucking, whistling, stretching and massage have not been shown to improve speech production (Novak et al., 2013).

(V) Augmentative and Alternative Communication (AAC)

It is important to target communicative forms that are within the child's zone of proximal development, which may not always be oral speech (Yoder and Warren, 2002). AAC refers to any form of communication which supports or replaces speech and/or writing. It includes signing, gesture, eye pointing and body language (unaided). It also includes methods that require extra equipment (aided), which may be paper based (low tech) or technology based (high tech). AAC may be sign or symbol based. It is usually implemented as part of a Total Communication approach, whereby all forms of available communication are accepted and encouraged.

Children with CP may have a diverse range of neurodevelopmental impairments alongside their primary physical difficulties, with complex profiles of health, motor, sensory, learning, behavioural and communication needs. Severe motor impairments will limit potential for sign, so focus for these children should be symbol use through high tech and/or low tech aids.

Assessment and implementation of AAC requires an MDT approach - SLTs collaborating in particular with OTs.

Components of AAC assessment are as follows:

- **Body Structure and Function**
  - oro-motor examination
  - sensory functions: vision and hearing
  - motor ability
  - cognitive ability and language understanding
- **Environmental Factors**
  - Family and school factors that may facilitate or be barriers to AAC implementation
- **Participation**
  - Establish child's current profile of communicative participation in life situations

3.6.2 Communication Training Approaches

Studies show that the more severely the child is physically and/or cognitively impaired, the less responsive and more directive parents are towards them.

Children with CP are often placed in respondent roles during conversations, have fewer turns, and are more compliant to parent directives (McConachie, 1999). This pattern of interaction is a natural result of a child that is slow to initiate, has inconsistent and unconventional communication signals, and is often slow to respond when it is their turn.

Intervention should focus not only on the children, teaching them how to use their augmentative systems and to produce a full range of conversation skills, but also should focus on their carers.

Training for carers aims to increase their interaction skills, teaching them how to facilitate and expand children's communication skills. There are a number of established communication training programmes, including 'Hanen; It takes two to talk' and 'Prelinguistic Milieu Teaching'.

Insufficient evidence and research has been carried out to evaluate the effectiveness of communication training approaches in the CP population (Novak et al, 2013).

Recommendations -

> Assessment and treatment of speech in CP should follow a subsystems approach, focussing on respiration, phonation, resonance, articulation and prosody.

> Children with little to no intelligible speech should be given access to an appropriate AAC system to communicate.

> AAC systems should be designed and implemented specifically for each child and their individual needs and abilities.

> There is a need to develop high tech AAC in the Vietnamese language which is sensitive to the cultural context.

> Oro motor exercises should be used with caution and not as the primary focus of intervention due to research evidence that does not support their effectiveness in improving speech outcomes.

> Research is needed to evaluate the effectiveness of communication training approaches for children with CP in Vietnam.

3.7. Managing other Conditions which affect Communication

3.7.1. Hearing Impairment

One in twenty-five children with CP will have a hearing impairment.

- Hearing impairment can have a profound impact on a child with CP and can lead to delays in language, speech, and social development (Reid, Modak, Berkowitz, & Reddihough, 2011).

(I) Signs of a hearing impairment

- Does not startle easily at loud noises or wake to noise
- Does not calm by parent's voice
- Pays closer attention to a person's face while listening or speaking to others (e.g. looking for facial cues)
- Frequently requires parent to repeat directions
- Does not consistently respond when name is called or does not follow verbal directions well
- Poor attention to music, singing, or being read a story

(II) Screening for hearing impairments

- Most CP registries record hearing status, classifying hearing into broad categories based on information gained during behavioural or physiological audiological testing (Reid, Modak, Berkowitz, & Reddihough, 2011).
- Pure tone audiometry is the key behavioural test used to identify hearing threshold levels in typically developing children (Sano, Kaga, Kitazumi, & Kodama, 2005; Reid et al, 2011).
- Test results are plotted on audiograms, which show the difference, measured in decibels (dB), between the hearing threshold and a reference threshold of 0dB hearing loss at each frequency (Sano et al, 2005; Reid et al, 2011).

(III) Inter-professional team responsibilities for managing hearing impairments

All practitioners who work with children with CP have a responsibility to be aware of symptoms of hearing impairment and potential interventions.

.

- **Speech and Language Therapists** – understand the signs and symptoms of hearing impairments, especially impact on expressive and receptive language skills and functional communication. Referral to medical practitioner/audiologist.

Recommendation -

> Hearing impairments can impact participation in home and school activities. Children should be screened early in life for hearing impairments in order to initiate early therapy services which may impact overall language, speech, and social development.

3.7.2. Vision Impairment

One in ten children with CP will have a visual impairment. See general guidelines for further details on visual impairment.

For details on Clinical signs, Screening and Assessment specific to visual impairments: see General Guideline on management of CP.

Inter-professional team responsibilities for managing visual impairments

All practitioners who work with children with CP have a responsibility to be aware of symptoms of visual impairment and potential interventions.

Speech-Language pathologist - understand the signs and symptoms of visual impairment and impact on functional communication, especially the use of assistive technology such as augmentative communication devices. Referral to medical practitioner.

Recommendation -

> Strategies should be identified for increasing access to speech-language therapies for children with CP

3.7.3. Intellectual Impairment

One in two children with CP will have an intellectual impairment and children with an intellectual disability have a poorer prognosis for ambulation and developing continence (Hadders-Algra, Boxum, Hielkema, & Hamer, 2017).

- Children with an intellectual disability will have limitations in both cognitive functioning (the thinking skills that lead to knowledge) and adaptive behaviour (the ability to adapt to the environment and function in daily life activities).
- Intellectual disabilities can be categorised as mild, moderate or severe based on tests of cognitive abilities. Children with intellectual disabilities may require specialised school program which can provide adaptive learning strategies.
- Social participation may be significantly affected in children with intellectual impairments due to limitations in social communication skills.

(I) Early detection of intellectual impairment and early intervention

For details: see General Guideline on management of CP.

(II) Inter-professional team responsibilities for management of intellectual impairments

All practitioners who work with children with CP have a responsibility to be aware or intellectual disabilities and potential impact on participation in daily activities:

- **Speech-Language pathologist** - evaluate and provide information on the child's cognitive abilities, especially related to language skill. Determine impact of intellectual abilities on child's ability to use functional communication (i.e. verbal, gestures, augmentative communication). Refer to medical, psychologist school specialist who can further evaluate intellectual disabilities through use of appropriate assessment tools.

3.7.4. Behaviour Disorders

One in four children with CP have a behaviour disorder and the rate of abnormal behaviour in children with CP is 2 to 4 times higher than the population (Novak et al, 2012).

(I) Management of behaviour disorders

For details: see General Guideline on management of CP.

(II) Interprofessional team responsibilities for managing behaviour disorders

All practitioners who work with children with CP have a responsibility to be aware of the prevalence of behaviour disorders among children with CP.

Speech and Language Therapists - observe behaviour and gather information from parents/ carers to help identify triggers which may impact functional communication skills and mealtime participation. Implement positive behaviour support strategies, referral to psychologist (if available), referral to medical practitioner.

3.8. Managing Dysphagia - Eating, Drinking, Swallowing and Drooling Difficulties

Oropharyngeal dysphagia (OPD) is characterized by impairments in oral preparatory, oral propulsive, and/or pharyngeal phases of swallowing associated with eating, drinking, and controlling saliva (Benfer et al., 2013, Matsuo and Palmer, 2008). The prevalence of OPD in children with cerebral palsy is unclear, but it is estimated to range from 19% to 99%, depending on the definitions and tools used (Benfer et al., 2013, Calis et al., 2008; Parkes, Hill, Platt, & Donnelly, 2010; Reilly and Skuse, 1992, Wilson and Hustad, 2009).

One in fifteen children with CP will require alternative methods for nutrition and will be non-oral feeders.

One in five children with CP have difficulty controlling saliva and secretions and the potential health impacts and social consequence of drooling are serious and significant (Reid, McCutcheon, Reddihough, Johnson, 2012). The Drooling Quotient (Van Hulst, Lindeboom, Van Der Burg, Jongerius, 2012) and The Drooling Impact Scale (Reid, Johnson, Reddihough,2010) are internationally recognised tools to assess drooling and to assess the effect of interventions on drooling.

(I) Common signs and symptoms of dysphagia

- Inability to swallow
- Gagging, choking, and/or coughing when attempting to swallow
- Delayed (or sometimes absent) swallowing reflex
- Regurgitation
- Unusual weight loss
- Poor weight gain
- Hoarse cry, voice
- Excessive drooling or inability to manage secretions
- Change in colour while eating or drinking
- Recurrent chest infection/aspiration pneumonia
- Prolonged meal duration.
- Food refusal
- Oral aversion
- Families report that mealtimes are stressful or distressing for the child

(II) Dysphagia management

Dysphagia is complex and may greatly impact overall nutrition. Eating and drinking occur within many different social environments which may include family members, friends, teachers and other caregivers.

SLTs who manage feeding, eating, and swallowing issues must collaborate and work closely with family members and caregivers who take part in mealtimes. They must also collaborate with PTs and OTs to maximise success at mealtimes. In addition, SLTs must consider psychosocial, cultural, and environmental factors which may strongly influence feeding behaviours.

- Feeding – describes the act of giving food / supplying nourishment to an individual. It can include self-feeding.
- Eating – the ability to keep and manipulate food or fluid in the mouth and swallow it.
- Swallowing – involves a complex act in which food, fluid, medication, or saliva is moved from the mouth through the pharynx and oesophagus into the stomach.

3.8.1 Screening and assessment

(I) Clinical Feeding Evaluation

Screening

There are no validated and published dysphagia screening tools (SPA Dysphagia Clinical Guideline, 2012; Stewart, 2003). Many clinicians will develop own screening tool specific to the clinical setting.

Screening should investigate both symptoms of dysphagia e.g. coughing, throat clearing, gurgly voice quality and also the risk factors which are less obvious. Factors contributing to dysphagia in children with CP include bite reflexes, slowness of oral intake, poor trunk control and inability to feed independently (Waterman, 1992). The presence of tongue thrusting; presence of drooling; severity of cerebral palsy, poor head control, severity of ID, seizures and speech disorders are all positively correlated with dysphagia in CP.

Providers should ask specific questions to the child and parent pertaining to feeding and mealtime behaviours. In addition, when possible, providers should observe the child drinking liquids and eating foods of various textures.

Specific questions during the clinical evaluation may include (Arvedeson, 2013):

Question	Potential areas of concern
How long does it take to feed your child?	Meal lasting longer than 30 minutes, on any regular basis
Are meal times stressful to child or parent?	Yes, if one or other, or both
Has your child lost weight or failed to gain weight over the last 3 months (where child is under 18 years)?	Lack of weight gain over 2–3 months in young child, not just weight loss
Are there signs of respiratory problems?	Increased congestion at meal times, ‘gurgly’ voice, respiratory illnesses
Does your child get constipated?	Constipation may indicate dehydration.
Is your child receiving tube feeds? If so, does your child also receive food or drink through the mouth?	Child may not be safe to feed orally

Additionally, specific questionnaires can be used as screening tools:

The Montreal Children's Hospital Feeding Scale (MCH:Feeding Scale)

(Ramsay, 2011)

The Montreal Children's Hospital: Feeding Scale is a valid and reliable screening tool for quick detection of feeding problems in children from 6 months to 6 years of age.

Administration

Assessor: Carer

How: The questionnaire can be self administered by the carer or the health professional can record the carer's answers.

Time: N/A

Availability: The MCH-Feeding Scale, scoring package and template are available in Appendix 1 (page e16) and Appendix 2 (page e17). Ramsay, M., Martel, C., Porporino, M., Zygmuntowiez, C. (2011) The Montreal Children's Hospital Feeding Scale: A brief bilingual screening tool for identifying feeding problems. *Paediatric Child Health,* 16,3, 147-151, e16-17.

Mealtime Assessment

The clinical assessment must investigate areas that are reflected in the ICF framework and should include:

- **Medical diagnosis and background**: complexity of condition; current nutritional status and immediate nutritional needs; cultural educational + vocational background
- **Immediate observations:** level of awareness + orientation; client's ability to participate, carer/ child interaction
- **Communication, cognition + behaviour:** ability to follow instructions need for communication device; paediatric age appropriate to developmental motor skill level
- **Oropharyngeal Assessment**
- **Oral Trial/ Feeding Assessment**
- **Referral for Other Assessments**
- **Overall impression/ Diagnosis**
- **Management Plan**

Many published assessment measures of oropharyngeal dysfunction do not provide adequate information on how the measure purported to detect change i.e. the measure's responsiveness . Most assessment tools are observation measures. However, The Dysphagia Disorders Survey (DDS requires training and certification to use) and The Schedule for Oral-Motor Assessment Scale (SOMA) have the strongest clinical utility to support decision making (Benfer, 2012).

The Schedule for Oral-Motor Assessment Scale (SOMA)

(Reilly, 2000)

The SOMA is a reliable and valid assessment tool developed to record oral motor skills objectively in infants between ages 8 and 24 mths postnatally. It aims to identify areas of dysfunction that could contribute to feeding difficulties

Administration

Assessor: SLT

How: A range of tastes and texture are presented to the infant in order to elicit a full range of oral motor behaviours. These specific behaviours are rated for each oral motor challenge category(ranging from liquid through to chewable solids). The SOMA distinguish those infants with normal oral motor function from those with oral motor dysfunction.

Time: 20 minutes and intended to be rated largely from a videorecording of a structured feeding session.

Recommendations –

> A thorough evaluation with input from all team members will improve diagnosis and successful intervention of feeding, eating, and swallowing disorders.

> Introduce use of parent questionnaires to assist with detection of feeding problems.

>Introduce observation measure assessment tools to provide a baseline assessment.

(II) Clinical Drooling Evaluation

The potential health impacts and the significant social consequence of drooling are serious and significant. The Drooling Quotient and The Drooling Impact Scale are internationally recognised tools to assess drooling and to assess the effect of interventions on drooling.

The Drooling Quotient (DQ5) (van Hulst, 2012)

The drooling quotient represents a semiquantitative, direct observational method that evaluates drooling by measuring leaked saliva from the mouth (anterior drooling). It assesses the problem of anterior drooling and to ultimately evaluate effects of treatment, a combination of measures is recommended focusing on (1) severity and frequency of drooling and (2) impact of drooling on the child and the family. Severity of drooling is assessed by a 5 minute standardised observation during the performance of an activity resulting in a Drooling Quotient.

Administration

Assessor: Medical practitioners, physiotherapists, occupational therapists, SLTs, nurses. The health professional observes drooling during two trials of 5 minutes.

How: The observation must be performed under standardised conditions

- (At least) one hour after a mealtime
- While the child is sitting
- The mouth is empty and clean before the start of the observation and saliva is wiped off the chin.

Time: 10 minutes

Availability: https://www.aacpdm.org/UserFiles/file/drooling-quotient-instructions.pdf

The Drooling Impact Scale (Reid, 2010)

The Drooling Impact Scale is a useful evaluative tool to assess the effect of saliva-control interventions on drooling in children with developmental disabilities. It is a valid and reliable subjective measure that is responsive to change (Reid 2010).

Administration

Assessor: Carer or medical practitioners, physiotherapists, occupational therapists, SLTs, nurses.
How: The questionnaire can be self administered by the carer or the health professional can record the carer's answers. The same carer is required to rate the drooling on successive administrations.
Time: N/A
Availability: https://www.aacpdm.org/UserFiles/file/Drooling-Impact-Scale-DMCN.pdf

Recommendation -

> The Rehabilitation team should engage in using tools to improve their assessment and to measure the outcomes of their intervention with children who have drooling problems.

(III) Instrumental Evaluation of Swallowing Function

The following instrumental assessments provide information during a 'brief window in time' and may not represent eating and swallowing during a "typical" meal. Both Fibreoptic Endoscopic Evaluation of Swallowing (FEES) and Videofluoroscopic Swallow Studies (VFSS) are instrumental assessments of dysphagia which provide video images of the internal structures of swallowing. They are commonly regarded as 'gold-standard' assessments; however, there is no consensus regarding a gold-standard measure to analyse the video recordings that they produce. (Swan, Cordier, Brown & Speyer, 2018)

- A **Videofluoroscopic Swallow Study (VFSS)** is a dynamic radiographic study completed in a typical but simulated feeding position using liquid and food textures appropriate for the patient's developmental age and /or motor skills. Barium sulfate is the metallic compound contrast mixed with food/liquids to enable observation of structural and functional abnormalities during the oral, pharyngeal and upper oesophageal phases of the swallow including penetration and aspiration. Ability to visualise all phases of swallowing makes the study comprehensive (Arvedson , 2013).

  VFSS is indicated if there is
  - Risk of aspiration by observation or history
  - Prior aspiration pneumonia
  - Suspicion of a pharyngeal or laryngeal problem (breathy or husky voice)
  - a "gurgly" voice quality (Arvedson, 2013)

  VFSS assists in determining
  - the presence of aspiration
  - the safest consistencies to swallow & bolus flow rate

- presence of nasopharyngeal regurgitation & pharyngeal residue, delayed swallow initiation.

- **The Fibreoptic Endoscopic Evaluation of Swallowing (FEES])** allows for visualisation of events occurring immediately before and immediately after the pharyngeal swallow and was developed as an adjunct to VFSS and clinical examination. It allows evaluation of the swallowing process and the handling of secretions by assessing areas surrounding the larynx (upper airway obstruction & vocal fold paralysis). Advantages of FEES include the absence of radiation as well as the possibility to do bedside examinations, and can be safely performed with premature infants.

- **Cervical Auscultation** is the technique of listening to the sounds of swallowing using a stethoscope on the larynx. It assumes that the normal biological sounds will be different from the abnormal biological sounds but there is no normative data to support this. With clinical feeding assessment, it does improve sensitivity of predicting aspiration, but not in isolation (Frakking, Chang, O'Grady, David, Walker-Smith, Weir, 2016)

Recommendations -

> The SLT assessment should include the use of instrumental assessment.

> The SLT must liaise with Diagnostic Imaging (X-Ray) Department and /or Ear Nose & Throat Department (ENT) re equipment needed.

> SLTs require specific training in any instrumental procedures available and in interpreting information gained from the studies. Cervical auscultation should never be used in isolation.

3.8.2. Management and intervention

(I) Clinical Intervention for Dysphagia

Strategies and goals in partnership with the family and child need to be developed to determine the best intervention(s) to improve eating, drinking and swallowing.

Information gathered from the assessment will inform how eating, drinking, and swallowing behaviours can be changed or improved

SLT interventions for the comprehensive management of oral motor, eating, feeding, and swallowing disorders include:

1) Creating an individualised plan for managing eating, drinking, and swallowing taking into account the understanding, knowledge and skills of family and any other person involved in feeding the child.
2) Use of specialised feeding equipment and utensils.
3) Use of specialised feeding techniques, such as pacing and spoon placement
4) Postural and positioning problems which may impact feeding, eating, and swallowing e.g. poor head control and inability to hold head at midline can impact functional and safe swallowing.
5) Intervention for oral motor and mechanical issues which impact the child's ability to chew and manage food or liquid during the oral phase of eating. Children with CP need strategies to develop oral motor skills such as opportunities to experience biting and chewing. CP children with abnormal oral-facial muscle tone

may require external assistance/support**.** There is **no** evidence for oral motor exercises for hypo or hypertonicity of oral-facial muscles.

6) Accommodation and intervention for sensory issues which impact desire or ability to eat (e.g. oral sensory defensiveness, visual problems).
7) Intervention for behaviourally based feeding disorders (e.g. refusal to eat).
8) Communication strategies to allow child to pace meal.
9) Changes to the mealtime environment (quiet, decreased distractions)
10) Training of all individuals who play a role in feeding the child at mealtimes including in the use of adaptive feeding equipment to facilitate oral feeding skills (e.g. modified teat and bottle, modified cup or spoon.
11) **Texture modification** of fluid and food textures. Firmer textured foods may be easier to handle in the oral and pharyngeal phase of swallowing for cerebral palsy children with reduced oral motor control. Some foods tend to stimulate saliva production.

Recommendations -

> Utilise intervention strategies and develop goals in partnership with the child with CP and their parents, carers and other family members to use these interventions in the child's environment.

> Comprehensive and consistent intervention can be established if the use of standardised texture guidelines are implemented collaboratively with the dietician to ensure nutrition and hydration requirements are met.

Refer International Dysphagia Diet Standardisation Initiative www.iidsi.com

---

(II) Management of children with long term non oral tube feeding

1 in 15 children with cerebral palsy are unable to take food through their mouth and need to be fed through a feeding tube. In Vietnam, children may be fed via a nasogastic tube for unlimited lengths of time.

Recommendations -

> Family, child and rehabilitation team (especially doctor, gastroenterologist, dietician and SLT) should review and consider the consequences of long term naso-gastric tube feeding on both the child and the family.

> Family, child and rehabilitation team (especially doctor, gastroenterologist, dietician and SLT) should review and consider the advantages and disadvantages of feeding via a percutaneous endoscopic gastrostomy tube (PEG)

(III) Drooling Management

Drooling may be improved when

- better eating patterns are developed
- posture is improved
- behaviour modification program is implemented
- medication is prescribed
- surgery is recommended

However positioning, medication history, reflux, eating, dental issues and implementation of a behaviour modification program must be considered before trialling medication or recommending surgery (NICE 2017). Anticholinergic medication may reduce the severity and frequency of drooling in children and young people with cerebral palsy and may be considered.

Recommendation -

> The Rehabilitation team should use drooling assessment tools to measure the outcomes of their intervention with children who have drooling problems.

Inter-professional team responsibilities for dysphagia management

All practitioners who work with children with CP have a responsibility to be aware difficulties with feeding and swallowing and dysphagia management.

- **Speech & Language Therapists** – recognise signs and symptoms of dysphagia and may assist in the clinical assessment of feeding, eating, and swallowing. Provide specific guidance on oropharyngeal phase swallowing disorders and techniques/treatment to provide safe and effective swallow. These techniques/treatments may include recommendations for safe consistency or texture of food (e.g. thin liquid, soft solids, hard solids) or positioning of head and neck to promote safe swallow.
- **Medical practitioners** - conduct clinical feeding evaluation and determine need for evaluation of swallow function through a VFSS or FEES. Provide recommendations to family regarding nutrition and hydration, growth patterns, allergies or food sensitivities that could impact safe and efficient feeding, eating, and swallowing.
- **Physiotherapists** – recognise signs and symptoms of dysphagia and may assist in the clinical assessment of feeding, eating, and swallowing. Provide specific guidance for proper seating and positioning to improve feeding, eating, and swallowing performance.
- **Occupational therapists** - recognise signs and symptoms of dysphagia and may assist in the clinical assessment of feeding, eating, and swallowing. Provide specific guidance for proper seating and positioning to improve feeding, eating, and swallowing performance. Provide specific recommendations for adaptive feeding utensils and changes to environment to enhance performance at mealtime.
- **Nurses** - recognise signs and symptoms of dysphagia and assist in the clinical assessment of feeding, eating, and swallowing.

3.9 Managing other Conditions Associated with CP

3.9.1. Gastro-Oesophageal Reflux Disease

Gastro-oesophageal reflux refers to retrograde passage of gastric contents to the oesophagus, pharynx, or oral cavity (Kim, Koh, & Soo Lee, 2017).

- Chronic and severe reflux is called gastro-oesophageal reflux disease (GORD) and can cause pain symptoms or complications which impair participation and quality of life (Sherman et al., 2009).

- GORD is more prevalent in children with CP than in the typical population, and it can be a significant obstacle to ensuring adequate nutrition (Trinick, Johnston, Dalzell, & McNamara, 2012).
- Absence or relaxation of lower oesophageal sphincter muscle tone is considered the main mechanism for reflux. Delayed gastric emptying and decreased gastroduodenal motor function have also been suggested as other mechanisms for reflux (Kim, Koh, & Soo Lee, 2017).

(I) Signs and symptoms of GORD

- Recurrent aspiration pneumonia
- Grunting after meals
- Frequent regurgitation or vomiting
- Complaints of chest pain and "heart burn" only at meal time
- Unexplained food refusal
- Increased irritability at mealtime; food refusal
- Tonic posture or stiff posture following meals
- Change in voice quality; hoarse voice

(II) Medical examinations and interventions for GORD

PH-probe

A pH-monitoring catheter probe is inserted through the child's nose to the distal oesophagus for 24-hours to record acidic episodes of reflux. An acidic reflux index is recorded; this is the percentage of the time during the trial in which the pH value is less than four. For infants and children, more than 12% and 6%, respectively, is considered a pathologic sign of acidic reflux disease (Kim, Koh, & Soo Lee, 2017).

Multichannel intraluminal impedance probe

An impedance monitoring catheter probe is inserted through the child's nose to the distal oesophagus for 24-hours to record acidic and non-acidic episodes of reflux. Abnormal results for impedance probe has been defined by infant data available in the current literature with normal values defined as 70 reflux events in a 24-hour period, of which 25% are acidic and 73% are non-acidic. However, the pH and MII studies are poor indicators of pathologic reflux in infants and do not adequately discern which patients will benefit from fundoplication (Fike et al, 2012).

Nissen fundoplication

This is one of the most common surgical interventions for the treatment of GORD. The laparoscopic surgery involves wrapping of the upper curve of the stomach (the fundus) around the lower oesophagus. The fundus is sewn into place so that the lower portion of the oesophagus passes through a small tunnel of stomach muscle (Kim, 2017)

(III) Inter-professional team responsibilities for managing GORD

All practitioners who work with children with CP have a responsibility to be aware of symptoms of GORD and potential interventions.

- **Medical practitioners** – carry out holistic assessment of GORD and overall nutritional status and make appropriate referrals for further medical evaluation of acidic and non-acidic reflux. Referral to gastrointestinal specialist to evaluate for surgeries, such as a nissen fundoplication. Referral to therapists for further evaluation of overall feeding and mealtime behaviours.
- **Speech & Language Therapists** – are aware of GORD symptoms through case history feeding information, observation of behaviours around mealtimes and evaluation of behaviours and skills during mealtimes. Some feeding interventions which may reduce the incidence of reflux episodes but a referral to a doctor and dietician is recommended.

Recommendation -

> Gastro-oesophageal reflux disease can impact participation in feeding and mealtimes at home. Infants and children should be referred early in life for medical assessment and management if GORD is suspected and referral to dietician and SLT is recommended in order to minimise the impact GORD may have on participation.

3.9.3. Pain

Pain is one of the most common problems experienced by individuals with CP and as many as 75% of children with CP experience chronic pain.

- Children with CP might, like any other person, have problems with headache, periodic pain and other commonly encountered causes of pain. Pain emerging from muscles, joints and the skeleton are common.
- Acute pain is the sudden onset, is felt immediately following injury, can be severe in intensity, and is usually short lasting. Acute pain generally last less than 30 days and may be caused by medical procedures, illness, and trauma (Penner, Xie, Binepal, Switzer, & Fehlings, 2013).
- Chronic pain typically persists past the time of normal healing and typically lasts greater than 30 days. Chronic pain may also be the result of disease, trauma, repeated noxious stimuli, or difficulty healing after injury (Penner et al 2013).
- Gastro-intestinal pain often caused by gastro-oesophageal reflux secondary to changed muscular function in the oesophagus or lower oesophageal sphincter and spinal deformity (scoliosis) is another source to chronic pain. In addition, problems with gastrostomy tube can cause pain.
- Dental pain, caused by difficulties in maintaining good oral hygiene or gastro-oesophageal reflux (causing erosions to the dental enamel and secondary caries) needs special consideration.

(I) Pain Management Check General

See for details: General Guideline on the management of CP.

(II) Inter-professional team responsibilities for pain management

All practitioners who work with children with CP have a responsibility to be aware pain and pain symptoms and should check in with families regarding pain symptoms and management. Practitioners should make referrals to specialised medical practitioner (e.g. dentist, orthopaedics for muscle and joint pain) when further management is needed.

Recommendation -

> All healthcare providers should be aware of signs and symptoms of pain and use pain screening tools to help monitor pain, especially increase or decrease in pain in response to new medical and therapy interventions.

3.9.5. Sleep Disorders

(II) Inter-professional team responsibilities for managing sleep disorders

All practitioners who work with children with CP have a responsibility to be aware of the importance of sleep on learning and development and the prevalence of sleep disorders among children with CP. All practitioners should check in with families regarding sleep.

- **Medical practitioners** - carry out holistic assessment of sleep, prescription of specific medical interventions and medications based upon individual assessment findings, referral to sleep specialist (if available).
- **Physiotherapists** - carry out holistic assessment of sleep, positioning interventions, behaviour and sleep hygiene interventions, physical activity interventions, referral to medical practitioner.
- **Occupational therapists** - carry out holistic assessment of sleep, positioning interventions, behaviour and sleep hygiene interventions, physical activity interventions, referral to medical practitioner.
- **Speech-Language pathologists** – surveillance of sleep routines and behaviours as they may impact on mealtime routines and require referral to medical practitioner.
- **Nurses** - behaviour and sleep hygiene interventions, referral to medical practitioner.

3.9.6. Epilepsy

One in four children with CP will be diagnosed with epilepsy. The seizure activity will resolve for 10-20% of children.

Refer to General CP Guidelines for further information on signs and symptoms of potential seizure activity, diagnosis and treatment of epilepsy

Inter-professional team responsibilities for managing epilepsy

All practitioners who work with children with CP have a responsibility to be aware of epilepsy and signs and symptoms of seizures.

.

- **Speech-Language pathologist** - understand the signs and symptoms of seizures, especially during assessment and therapy sessions. Be aware of protocol for keeping a child safe during a seizure. Support to families through education, referral to medical practitioner.

3.9.9. Incontinence

One in four children with CP do not have bladder control and the rate of bladder control problems in children with CP, 4 years old is 2 to 3 times higher than the population (Novak et al, 2012).

The risk of bladder and bowel control problems increases with severity of physical disability. Children with CP who are unable to walk or have an ID are most at risk for bladder and bowel control problems.

Continence can be affected by changes in mobility. Individuals who experience a decrease in mobility function may experience difficulties in reaching a toilet and therefore for some, incontinence may be experienced as a result.

(I) Management of incontinence

Assessment

Medical investigations are warranted as abnormal anatomic findings are common.

Toilet training

Children with CP should be offered standard toilet training but over a longer period of time.

Incontinence aids

Prescription of incontinence aids will be required for 1 in 3-4 children and this will be for longer periods of time than children without physical disabilities.

(II) Inter-professional team responsibilities for managing incontinence issues

All practitioners who work with children with CP have a responsibility to be aware of the prevalence of incontinence issues among children with CP and be able to support families with prognostic messaging.

- **Speech-Language pathologists** – support families with toilet training as appropriate, referral to medical practitioner.

3.9.10. Constipation

Chronic constipation is a common problem in children with CP.

Refer to General CP Guidelines for further information on assessment and management of constipation.

Inter-professional team responsibilities for managing constipation

All practitioners who work with children with CP have a responsibility to be aware of symptoms of constipation and potential interventions.

- **Speech-Language pathologists** – understand the signs and symptoms of constipation and determine frequency of positional changes which may reduce the incidence of constipation. Referral to medical practitioner and dietician.

3.9.11. Dental Health & Oral Hygiene

Oral health is increasingly recognized as a foundation for general wellbeing. Children with CP have a higher risk of dental problems creating significant morbidity that can further affect their wellbeing and can negatively impact their quality of life as well as their family's. (Jan & Jan, 2016). The more severe the neurological insult in children with CP, the higher is the risk of dental disease which results from multiple factors including motor and coordination difficulties as well as limited oral care and hygiene (Sehrawat, Marwaha, Bansal & Chopra, 2014).

(I) Assessment

The ability to access appropriate dental care is an issue for people who have disabilities. (Dharmani,2018). Dentists should be alert to early signs of dental disease in cerebral palsy patients.

(II) Management

Dentists should be integral members of teams of professionals involved in optimizing the health of individuals who have CP. and provide appropriate education, preventive therapy, intervention or refer to the MD team. Home dental care and hygiene should be promoted.

Management of dental problems in children with cerebral palsy consists of

- Pain relief and infection control
- Treatment or elimination of existing untreated disease
- Planning for prevention of further disease.

(III) Inter-professional team responsibilities

As with all members of the multidisciplinary team, dentists should have a thorough knowledge of the medical, cognitive, and rehabilitative issues associated with CP so that the best possible health care can be provided. (Doherty, 2009)

Recommendations -

> Children's dental health and oral hygiene should be promoted by the MDT and monitored by a paediatric dentist to provide both primary and comprehensive, preventive and therapeutic oral health care to children with cerebral palsy.

>Families and caregivers of children with CP should be educated about home dental care and oral hygiene as early as possible, to become competent in home oral health practices.

3.10. Rehabilitation Needs across the Lifespan

CP is a permanent but not unchanging condition. Musculoskeletal status, functional abilities and cognitive function can and do change over time. Skills attained during childhood can deteriorate secondary to musculoskeletal changes, the impact of puberty and early onset ageing. Individuals with CP require monitoring and may benefit from repeat rehabilitation sessions over time particularly at key growth points. Monitoring is particularly important at natural transition points such as the onset of puberty, late adolescence and throughout adulthood.

3.10.1. Functional Decline

(I) Adulthood

25% or more of adults with CP experience deterioration in gait and walking function.
In addition to gait decline, declines in the performance of activities of daily living, eating and drinking, and cognitive functioning are common in people with CP.

(II) Transition

Transitioning between paediatric and adult rehabilitation services is an important aspect of the care of individuals with CP.
The following overarching principles should guide transition planning (NICE, 2017)

- Recognise that challenges for young people with CP continue into adulthood, and ensure that their individual developmental, social and health needs, particularly those relating to learning and communication, are addressed when planning and delivering transition.
- Recognise that for young people with CP there may be more than one transition period in health and social care settings; for example, college, resident educational and adult home settings.

See PT and OT Guidelines for further information on Section 3.10.1.

Recommendations for transition planning -

> Develop clear pathways for transition that involve: the young person's medical practitioners and clinicians in adults' services, both locally and regionally, who have an interest in the management of CP

> Ensure that professionals involved in providing future care for young people with CP have sufficient training in order to address all their health and social care needs

> As a minimum standard of care, ensure that the young person has access to adults' services both locally and regionally that include healthcare professionals with an understanding of managing CP

> Ensure that all relevant information is communicated at each point of transition

> Recognise that functional challenges (including those involving eating, drinking and swallowing, communication and mobility) and physical problems (including pain and discomfort) may change over time for people with CP, and take this into account in transition planning.

3.11. Parent, Family and Caregiver Support

CP impacts the entire family in a manner that is long-term, complex and multifactorial. In studies on parent experiences and expectations, many families expressed the desire for their child with CP to be able to live independently in the future. Parents often report a need for information on what would be realistic to expect for their child's future. Parents often experienced disappointments about their child's progress (Darrah, Wiart, Magill-Evans, Ray, & Andersen, 2014; Kruijsen-Terpstra, et al., 2016).

- Families whose child is diagnosed with CP experience complex care responsibilities, financial hardship, limits to occupational attainments, relationship distress, grief and social isolation. They may experience significant stress and anxiety about the future and a lack of understanding from the broader community.
- Parents of children with CP need to be proactive, skilled and conscious of their parenting choices to provide their children with optimal developmental support.
- Parenting a child with CP, and optimising their development, involves forward thinking, a commitment to long-term support, patience, compassion, behavioural management skills and effort above and beyond the parenting of typically developing children. Further, all of this requires a strong and loving emotional bond and parental psychological resilience.

(I) Recommendations for ways to empower and support families

(See also section 2.4.3. Parent Empowerment)

No one empowerment approach can be applied to all families of children with CP and providers must assess each families' individual needs to determine the most beneficial approach:

- Encourage parental involvement in **community support groups** to connect families who have children with CP.
- Develop **family training programs** to educate and support parents on specific health needs (e.g. parent training on feeding and nutrition issues).
- Refer parents to international parent support organisations which can connect families through the internet, social media, and e-mail Listservs (e.g. Children's Hemiplegia and Stroke Association (CHASA), Hemi-Kids)
- Collaborate with families to develop home programs and goals for therapy.

Recommendation -

> Practitioners should be educated on the process of parent empowerment and learn ways to enhance family support and community involvement

---

4. Supporting and Monitoring the Implementation of the Guidelines in Hospitals

The development of a monitoring and evaluation committee which comprises staff from medical, nursing and allied health professions within each health service is recommended. The committee can complete trimonthly (or as regularly as is achievable) reviews of set key performance indicators (KPIs).

Key performance indicators should be specific and realistic given the context of each health service. KPI’s related to staff to CP children ratio, the number of interventions provided per person, the amount of MDT meetings held monthly and changes in FIM/Barthel Index scores could be potential KPI’s used in evaluation. Gender-sensitive data may help to identify gender norms and inequalities affecting access to and use of health services, determinants of risk behaviours and whether health program approaches contribute to gender equality or exacerbate gender disparities.

In order to evaluate practice, teams should agree on a means of recording activities for analysis. This may be simple as ticking a box on a chart located at the nursing station to make recording of activities accessible and timely.

Glossary

Aspiration – when food or liquids passes into the laryngeal space during pharyngeal phase swallowing, past the level of the vocal cords, depositing food or liquids into the lungs.

Ataxia – A motor type of CP which affects the sense of balance and depth perception. Children with ataxia may have poor coordination; walk unsteadily with a wide-based gait, and experience difficulty when attempting quick or precise movements, such as writing or buttoning a shirt.

Athetosis – A motor type of CP characterised by uncontrolled, slow, writhing movements.

Augmentative and alternative communication (AAC) - AAC includes all forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas. Special augmentative aids, such as picture and symbol communication boards and electronic devices, are available to help children and adults with CP express themselves. This may increase social interaction, school performance, and feelings of self-worth.

Behaviour disorder – a pattern of disruptive behaviours which may involve inattention, hyperactivity, Impulsivity, and defiant behaviours.

Canadian Occupational Performance Measure (COPM) - an individualised measure that assesses an person's perceived occupational performance in the areas of self-care, productivity, and leisure.

Cerebral palsy (CP) - a term used to describe a group of chronic conditions affecting body movement and muscle coordination. It is caused by damage to one or more specific areas of the brain, usually occurring during foetal development; before, during, or shortly after birth; or during infancy.

Communication and function classification system (CFCS) - A classification system used to categorise the everyday communication performance of an individual into one of five levels. The CFCS focuses on activity and participation levels as described in the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF).

Dyskinesia - refers to an increase in muscular activity that can result in excessive abnormal movements, excessive normal movements, or a combination of both.

Dysphagia – difficulty with swallowing which may impact a child's ability to eat.

Dystonia - a movement disorder in which involuntary sustained or intermittent muscle contractions cause slow twisting and repetitive movements, abnormal postures, or both that are triggered by attempts to move.

Eating and Drinking Ability Classification Scale (EDACS) – A classification system which categorises how individuals with children with CP eat and drink in everyday life using distinctions that are meaningful. EDACS provides a systematic way of describing an individual's eating and drinking in five different levels of ability.

Fundoplication - a Nissen fundoplication, or laparoscopic Nissen fundoplication is a surgical procedure to treat gastro-oesophageal reflux disease (GERD) and hiatal hernia. During fundoplication surgery, the upper curve of the stomach (the fundus) is wrapped around the oesophagus and sewn into place so that the lower portion of the oesophagus passes through a small tunnel of stomach muscle.

Gastrostomy - an opening into the stomach from the abdominal wall, made surgically for nutritional support or gastric decompression.

International Classification of Function, Disability, and Health (ICF) - a classification of health and health-related domains. As the functioning and disability of an individual occurs in a context, ICF also includes a list of environmental factors. The ICF is the World Health Organization's framework for measuring health and disability at both individual and population levels.

Interprofessional team approach - providers work independently, but recognise and value contributions of other team members. This approach requires interaction among the team members for the evaluation, assessment, and development of the intervention plan.

Manual Abilities Classification Scale (MACS) - A classification system which describes how children with CP use their hands to handle objects in daily activities. MACS describes five
Levels or categories which are based on the children's self-initiated ability to handle objects with both hand and their need for assistance or adaptation p to perform manual activities in everyday life.

Multidisciplinary team - a group of health care workers who are members of different disciplines (e.g. physicians, nurses, therapists, social workers, etc.), each providing specific services to the patient.

Osteoporosis - a medical condition in which the bones become brittle and fragile from loss of tissue, typically due to hormonal changes, or deficiency of calcium or vitamin D.

Penetration - when food or liquids passes into the laryngeal space during pharyngeal phase swallowing but does not move past the level of the vocal cords. The food or liquid is typically expelled from the laryngeal space through a forceful cough.

Telerehabilitation – a means of delivering of rehabilitation services over telecommunication networks and the internet.

References

Arvedson, J.C. (2013) Feeding children with cerebral palsy and swallowing difficulties *European Journal of Clinical Nutrition* 67; S9–S12 Macmillan Publishers Limited.

Australian Cerebral Palsy Register Group (ACPR) (2016). Australian Cerebral Palsy Register Report 2016.
Retrieved July 2018 https://www.cpregister.com/pubs/pdf/ACPR-Report_Web_2016.pdf

Barty, E., Caynes, K. and Johnston, L. (2016). Development and reliability of the Functional Communication Classification System for children with cerebral palsy. *Developmental Medicine & Child Neurology*, 58(10), pp.1036-1041.

Benfer, K.A., Weir, K.L., Boyd. R.N. (2012). Clinimetrics of measures of oropharyngeal dysphagia for preschool children with cerebral palsy and neurodevelopmental disabilities: a systematic review. *Developmental Medicine & Child Neurology*, 54(9); 784-795.

Benfer, K.A. Weir, K.L. Bell, R.S. Ware, P.S. Davies, P.S.W., Boyd, N. (2013) Oropharyngeal dysphagia and gross motor skills in children with cerebral palsy. *Pediatrics*, 131, E1553-1562.

Benfer, K.A., Weir, K.A., Bell, K.L., Ware, R.S., Davies, P.S.W., Boyd, N.(2015) Clinical signs suggestive of pharyngeal dysphagia in preschool children with cerebral palsy. *Research in Developmental Disabilities*, 38; 192-201.

Benfer, K.A. Weir, K.L. Bell, R.S. Ware, P.S. Davies, R.N. Boyd (2017).The eating and drinking ability classification system in a population-based sample of preschool children with cerebral palsy. *Developmental Medicine & Child Neurology*, 59 (6); 647-654.

Beukelman, D. R., & Mirenda, P. (1998). Augmentative and alternative communication: Management of severe communication disorders in children and adults (2nd ed.). Baltimore: Paul H. Brookes.

Calis, E.A., Veugelers,R., Sheppard, J.J., Tibboel, D., Evenhuis, H.M., Penning C. (2008). Dysphagia in children with severe generalized cerebral palsy and intellectual disability *Developmental Medicine & Child Neurology,* 50; 625-630.

Chorna, O., Hamm, E., Cummings, C., Fetters, A. and Maitre, N. (2016). Speech and language interventions for infants aged 0 to 2 years at high risk for cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology*, 59(4), pp.355-360.

Crais, E., Douglas, D. and Campbell, C. (2004). The Intersection of the Development of Gestures and Intentionality. *Journal of Speech Language and Hearing Research*, 47(3), p.678.

Darrah, J., Law, M., Pollock, N., Wilson, B., Russell, D., Walter, S., Rosenbaum, P., Galuppi, B. (2011). Context therapy: a new intervention approach for children with cerebral palsy. *Developmental Medicine and Child Neurology, 53*(7); 615-620.

Denver, B., Froude, E., Rosenbaum, P., Wilkes-Gillan, S., & Imms, C. (2016). Measurement of visual ability in children with cerebral palsy: a systematic review. *Developmental Medicine and Child Neurology, 58;* 1016–1029.

Dharmani, C. K. Management of children with special health care needs (SHCN) in the dental office. (2018). *J Med Soc,* 32:1-6.

Dougherty, N.J. (2009). A review of cerebral palsy for the oral health professional. *Dental Clinics in North Am*erica, 53(2):329-38.

Drooling Quotient Instructions. Retrieved June 2018
https://www.aacpdm.org/UserFiles/file/drooling-quotient-instructions.pdf

Duffy, J. (2005). *Motor speech disorders*. St. Louis, Mo.: Elsevier Mosby.

Eating and Drinking Ability Classification System for Individuals with Cerebral Palsy (EDACS RetrievedJune2018 https://www.sussexcommunity.nhs.uk/get-involved/research/chailey-research/eating-drinking-classification.htm.

Eliasson, A.C, Krumlinde Sundholm, L., Rösblad, B., Beckung, E., Arner, M., Öhrvall, A.M., & Rosenbaum, P. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: Scale development and evidence of validity and reliability. *Developmental Medicine & Child Neurology, 48: 549-554.*

Fike, F., Pettiford, J., St. Peter, S., Cocjin, J., Laituri, C. & Ostlie, D. (2012). Utility of pH/Multichannel Intraluminal impedance probe in identifying operative patients in infants with gastroesophageal reflux disease. *Journal of Laparoendoscopic & Advanced Surgical Techniques, 22*(5); 518-520.

Frakking, T.T, Chang, A. B., O'Grady, K.F., David, M., Walker-Smith, K., Weir, K.A. (2016). The use of cervical auscultation to predict oropharyngeal aspiration in Children: a randomised controlled trial. Dysphagia, 31(6);738–748.

Goh, Y., Choi, J.Y., Kim, S.A., Park, P., Park, E.S (2018).Comparisons of severity classification systems for oropharyngeal dysfunction in children with cerebral palsy: Relations with other functional profiles. Research in Developmental Disabilities,72; 248-256.

Graham, H.K., Harvey, A., Rodda, J., Nattras, G.R. & Pirpiris, M. (2004). The functional mobility scale (FMS). *Journal of Paediatric Orthopaedics, 24(5): 514-520.*

Hadders-Algra, M., Boxum, A.G., Hielkema, T., & Hamer, E.G. (2017) Effect of early intervention in infants at very high risk of cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology,* 59:3,246-258

Hanzlik, J. (1990). Interactions Between Mothers and Their Infants with Developmental Disabilities:. *Physical & Occupational Therapy In Pediatrics*, 9(4), pp.33-49.

Hanzlik, J., & Stevenson, M. (1986). Interaction of Mothers with Their Infants Who Are Mentally Retarded, Retarded with Cerebral Palsy, or Nonretarded. *American Journal of Mental Deficiency*, 90(5), p.513-20.

Harty, H., Griesel, M., & van der Merwe, A. (2011). The ICF as a common language for rehabilitation goal-setting: comparing client and professional priorities, Health and Quality of Life Outcomes, 9; 87.

Health Innovation Network. Retrieved July, 2018 https://healthinnovationnetwork.com/system/ckeditor_assets/attachments/41/what_is_person-centred_care_and_why_is_it_important.pdf.

Hidecker, M.J., Paneth, N., Rosenbaum, P.L., Kent, R.D., Lillie, J., Eulenberg, J.B., Chester, Jr. K., Johnson, B., Michalsen, L., Evatt, M.& Taylor, K. (2011). Developing and validating the Communication Function Classification System for individuals with cerebral. *Developmental Medicine & Child Neurology, 53; 799-805.*

Hurn J., Kneebone, I., Cropley, M. (2006) Goal setting as an outcome measure: a systematic review. Clinical Rehabilitation, 20 (9); 756-772

International Diet Standardisation Initiative (IDDSI) Framework, (2016) Retrieved June 1, 2018 http//iddsi.org.framework/

Iverson, J. and Goldin-Meadow, S. (2005). Gesture Paves the Way for Language Development. *Psychological Science*, 16(5), pp.367-371.

Jan, B.M., Jan,M.M. (2016) Dental health of children with cerebral palsy. *Neurosciences*, 21 (4): 314-318.

Khandaker G, Van Bang N, D ng TQ, Giang NTH, Chau CM, Van Anh NT, Van Thuong N, Badawi N, Elliott EJ. Protocol for hospital based-surveillance of cerebral palsy (CP) in Hanoi using the Paediatric Active Enhanced Disease Surveillance mechanism (PAEDS-Vietnam): a study towards developing hospital-based disease surveillance in Vietnam. BMJ Open. 2017 Nov 9;7(11):e017742

Kim, J.S., Han, Z.A., Song, D.H., Oh, H.M., Chung, M.E., (2013). Characteristics of dysphagia in children with cerebral palsy: Related to gross motor function. American Journal of Physical Medicine and Rehabilitation, 92; 912-919

Kim, S., Koh,H., & Soo Lee, J. (2017). Gastroesophageal Reflux in Neurologically Impaired Children: What Are the Risk Factors? *Gut and Liver, (11)* 2; 232-236.

Kruijsen-Terpstra, A., Verschuren, O., Ketelaar, M., Riedijk, L., Gorter, J., Jongmans, M., & Boeije H. (2016). Parents' experiences and needs regarding physical and occupational therapy for their young children with cerebral palsy. Research on Developmental Disabilities, 53-54; 314-22. doi: 10.1016/j.ridd.2016.02.012.

Lane, M., Russell, D., Rosenbaum, P. & Avery, L. (2007). Gross Motor Function Measure: (GMFM-66 and GMFM-88) User's Manual. MacKeith Press.

Law, M., Rosenbaum, P., King, G., King, S., Evans, J. Premises, Principles, and Elements of Family-Centred Service. 2003 - CanChild Centre for Childhood Disability Research, McMaster University.

Matsuo,K., Palmer, J.B. (2008).Anatomy and physiology of feeding and swallowing: Normal and abnormal. Physical Medicine and Rehabilitation Clinics of North America, 19; 691-707

McConachie, L. (1999). Mother-child interaction revisited: communication with non-speaking physically disabled children. *International Journal of Language & Communication Disorders*, 34(4), pp.391-416.

McDougall, J. and King, G. (2007) Goal Attainment Scaling: Description, Utility, and Applications in Pediatric Therapy Services. (2nd ed.). London, ON: Thames Valley Children's Centre.

McLeod, S. (2004). Speech pathologists' application of the ICF to children with speech impairment. *Advances in Speech Language Pathology*, 6(1), pp.75-81.

McLeod, S., Harrison, L. and McCormack, J. (2012). The Intelligibility in Context Scale: Validity and Reliability of a Subjective Rating Measure. *Journal of Speech Language and Hearing Research*, 55(2), p.648.

National Institute for Health & Care Excellence (2017) Retrieved June, 2018. https://www.nice.org.uk/guidance/NG62/chapter/Recommendations#ftn.footnote_1.

Novak, I., Hines, M., Goldsmith, S., Barclay, R. (2012) Clinical prognostic measures from a systematic review on cerebral palsy. Paediatrics 130 (5): e1285-1312.

Novak, I., McIntyre.S., Morgan, C., Campbell, I., Dark, L., Morton, N., Stumbles, E., Wilson, A., Goldsmith, S. (2013) A systematic review of interventions for children with cerebral palsy:state of the evidence. *Developmental Medicine & Child Neurology*, 55; 885-910.

Novak, I. (2014). Evidenced-based diagnosis, health care and rehabilitation for children with cerebral palsy. Journal of Child Neurology, 29; 1141-1156.
Ogletree, B. and Pierce, H. (2009). AAC for Individuals with Severe Intellectual Disabilities: Ideas for Nonsymbolic Communicators. *Journal of Developmental and Physical Disabilities*, 22(3), pp.273-287.

Palisano, R., Rosenbaum, P. Walter, S., Russell, D., Wood, E. & galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine & Child Neurology, 39(4): 214-223.*

Palisano, R., Rosenbaum, P., Bartlett, D., Livingston, M. (2008). Content validity of the expanded and revised Gross Motor Function Classification System. *Developmental Medicine & Child Neurology, 50 (10); 744-50.*

Parkes, J., Hill, N., . Platt, M.J., Donnelly, C. (2010). Oromotor dysfunction and communication impairments in children with cerebral palsy: A register study. Developmental Medicine & Child Neurology, 52, 1113-1119

Penner, M., Xie, W., Binepal, N., Switzer, L, & Fehlings, D. (2013). Characteristics of pain in children and youth with cerebral palsy. *Pediatrics, 132*(2); e407-413.

Pennington, L. (2009). Effects of It Takes Two to Talk—The Hanen Program for Parents of Preschool Children With Cerebral Palsy: Findings From an Exploratory Study. *Journal of Speech Language and Hearing Research*, 52(5), p.1121.

Pennington, L., Parker, N., Kelly, H. and Miller, N. (2016). Speech therapy for children with dysarthria acquired before three years of age. *Cochrane Database of Systematic Reviews*.

Pennington, L., Virella, D., Mjøen, T., da Graça Andrada, M., Murray, J., Colver, A., Himmelmann, K., Rackauskaite, G., Greitane, A., Prasauskiene, A., Andersen, G. and de la Cruz, J. (2013). Development of The Viking Speech Scale to classify the speech of children with cerebral palsy. *Research in Developmental Disabilities*, 34(10), pp.3202-3210.

Pirila, S., van der Meere, J., Pentikainen, T., Ruusu-Niemi, P., Korpela, R., Kilpinen, J. and Nieminen, P. (2007). Language and motor speech skills in children with cerebral palsy. *Journal of Communication Disorders*, 40(2), pp.116-128.

Ramsay, M., Martel, C., Porporino, M., Zygmuntowiez, C. (2011). The Montreal Children's Hospital Feeding Scale: A brief bilingual screening tool for identifying feeding problems. *Paediatric Child Health,* 16 (3); 147-151, e16-17.

Reid, S.M., Johnson, H.M., Reddihough, D.S. (2010) The Drooling Impact Scale: a measure of the impact on drooling in children with developmental disabilities. *Developmental Medicine and Child Neurology.*52, e23-e28.

Reid, S.M., McCutcheon, J., Reddihough, D.S.,Johnson, H.M. (2012) Prevalence and predictors of drooling in 7- to 14-year-old children with cerebral palsy: a population study. *Developmental Medicine & Child Neurology,* 54(11); 1032-1036

Reid, S.M., Modak, M.B., Berkowitz, R.G. & Reddihough, D.S. (2011).A population based study and systematic review of hearing loss in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 53(11);1038-1045

Reilly, S., Skuse.D. (1992). Characteristics and management of feeding problems of young children with cerebral palsy. *Developmental Medicine & Child Neurology*, 34; 379-388.

Reilly S, Skuse D, Wolke D.(2000) *Schedule for oral motor assessment.* London: Whurr Publishers.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M. and Bax, M. (2007). A report: the definition and classification of cerebral palsy. *Developmental Medicine & Child Neurology, Supplement, 109; 8-14.*

Rosenbaum, P. and Stewart, D. (2004). The World Health Organization International Classification of Functioning, Disability, and Health: A Model to Guide Clinical Thinking, Practice and Research in the Field of Cerebral Palsy. *Seminars in Pediatric Neurology, 11(1); 5-10.*

Sackett, D.L., Rosenberg, W.M.C., Gray, J.A.M., Haynes, R.B., Richardson, W.S. (1996) Evidence based medicine: what it is and what it isn't. *BMJ*, 312:71.

Sandberg, A. and Liliedahl, M. (2008). Patterns in early interaction between young preschool children with severe speech and physical impairments and their parents. *Child Language Teaching and Therapy*, 24(1), pp.9-30.

Sanger, T.D., Delgado, M.R., Gaebler-Spira, D., Hallett, M. & Mink, J.W. (2003). Task force on childhood motor disorders. Classification and definition of disorders causing hypertonia in childhood. *Pediatrics, 111: e89-97.*

Sanger, T.D., Chen et.al (2010). Definition and classification of hyperkinetic movements in childhood. *Movement Disorders*, *25(11);1538-1549.*

Sano, M., Kaga, K., Kitazumi, E. & Kodama, K. (2005) Sensorineural hearing loss in patients with cerebral palsy after asphyxia and hyperbilirubinemia. *International Journal of Pediatric Otorhinolaryngology,* 69 (9); 1211-1217.

Sellers, D., Mandy, A., Pennington, L., Hankins, M. & Morris, C. (2014). Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Developmental Medicine & Child Neurology, 56(3); 245-51.*

Sellier, E., Platt, M.J., Andersen, G., Krageloh-Mann, I., De La Cruz, J. and Cans, C. (2015). Decreasing prevalence in cerebral palsy: a multi-site European population-based study, 1980 to 2003. *Developmental Medicine & Child Neurology, 58: 85–92.*

Sherman, P.M., Hassall, E., Fagundes-Neto, U., Gold, B.D., Kato, S., Koletzo,S., Orenstein, S., Rudolph, C., Vakil, N. & Vandenplas,Y. (2009) A global, evidence-based consensus on the definition of gastroesophageal reflux disease in the pediatric population*. The American Journal of Gastroenterology* 104; 1278–1295.

Sigurdardottir, S. and Vik, T. (2010). Speech, expressive language, and verbal cognition of preschool children with cerebral palsy in Iceland. *Developmental Medicine & Child Neurology*, 53(1), pp.74-80.

Simces Z. (2003). Exploring the link between public involvement/citizen engagement and quality health care. A review and analysis of the current literature. *Health Canada.*Ottawa

Slonims, V. and McConachie, H. (2006). Analysis of Mother–Infant Interaction in Infants With Down Syndrome and Typically Developing Infants. *American Journal on Mental Retardation*, 111(4), p.273.

Speech Pathology Australia (2012). Charter & Scope of Practice. Retrieved: July 20, 2018. www.speechpathologyaustralia.org/SPAweb/About_us/SPA_Documents

Speech Pathology Australia (2012). Dysphagia Clinical Guideline. Retrieved: July 20, 2018. www.speechpathologyaustralia.org

Stewart, L. (2003) Development of the Nutrition and Swallowing Checklist, a screening tool for nutrition risk and swallowing risk in people with intellectual disability. *Journal of Intellectual & Developmental Disability,* 28:2, 171-187.

Swan, K., Cordier, R. Brown, T., Speyer, R. (2018) Psychometric Properties of Visuoperceptual Measures of Videofluoroscopic and Fibre-Endoscopic Evaluations of Swallowing: A Systematic Review. *Dysphagia* doi: 10.1007/s00455-018-9918-3. [Epub ahead of print]

Trinick, R., Johnston, N., Dalzell, A.M, & McNamara, P.S (2012). Reflux aspiration in children with neurodisability—a significant problem, but can we measure it? *Journal of Paediatric Surgery*, 47(2);291-298.

Turner-Stokes, L. (2009) "Goal Attainment Scaling (GAS) in rehabilitation: a practical guide." *Clinical Rehabilitation*, 23, 4, 362-370.

Van Hulst, K., Lindeboom, R., van der Burg, J., Jongerius, P. (2012) Accurate assessment of drooling severity with the 5 minute drooling quotient in children with developmental disabilities. *Developmental Medicine and Child Neurology,* 54 (12); 1121-1126.

UNICEF Retrieved July, 2018 https://www.unicef.org

Van Hulst, K.V., Lindeboom, R., Van Der Burg, J., Jongerius, P. (2012) Accurate assessment of drooling severity with the 5- minute drooling quotient in children with developmental disabilities. *Developmental Medicine & Child Neurology,* 54, 1121-1126
https://www.aacpdm.org/UserFiles/file/drooling-quotient-instructions.pdf

Waterman, E.T., Koltai. P.J., Downey. J.C., Anthony T., Cacace, A.T.(1992)Swallowing disorders in a population of children with cerebral palsy. *International Journal of Pediatric Otorhinolaryngology,2*4, 1, 63-71

Wilson, E.M., Hustad,K.C. (2009). Early feeding abilities in children with cerebral palsy: A parental report study. *Journal of Medical Speech-Language Pathology* 1-16.

World Health Organization. (2001). International classification of functioning, disability and health. Geneva: Author.

World Health Organization. (2006). Constitution of the World Health Organization (45th ed.).Retrieved from http://www.afro.who.int/index.php?option=com_docman&task=doc_download&gid=19&Itemid=2111WHO 2006

World Health Organization. (2017). Rehabilitation 2030: A Call for Action. Retrieved from: https://www.who.int/disabilities/care/Rehab2030MeetingReport_plain_text_version.pdf?ua=1

Yoder, P. and Warren, S. (2002). Effects of Prelinguistic Milieu Teaching and Parent Responsivity Education on Dyads Involving Children With Intellectual Disabilities. *Journal of Speech Language and Hearing Research*, 45(6), p.1158.

Disclaimer

Healthcare professionals are expected to take the present clinical guidelines fully into account when exercising their clinical judgment. However, the guidance does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of each patient, in consultation with the patient and/or their guardian or carer.

Copyright