Rehabilitation Guideline for the Management of Children with Cerebral Palsy

General Guideline

Humanity & Inclusion
2018
Rehabilitation Guideline for the Management of Children with Cerebral Palsy

| General Guideline |

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* The contents are the responsibility of Humanity & Inclusion and do not necessarily reflect the views of USAID or the United States Government
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 Dr Patricia Coker-Bolt and Prue Golland for their support in developing these guidelines. Their commitment towards strengthening medical and rehabilitation care in Vietnam is greatly appreciated.

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:

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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 SERVICE DELIVERY .............................................................................................................................. 9
  1.6. WHAT IS CP ...............................................................................................................................................................................10
  1.7. DESCRIBING CP .......................................................................................................................................................................11
  1.8. ASSOCIATED CONDITIONS ...................................................................................................................................................13
  1.9. CLASSIFICATION TOOLS .......................................................................................................................................................13
2. PATHWAYS AND PRINCIPLES OF REHABILITATION ..................................................................................................................19
  2.1. INTRODUCTION .......................................................................................................................................................................19
  2.2. REHABILITATION CYCLE .......................................................................................................................................................... 20
  2.3. ICF ..................................................................................................................................................................................................... 20
  2.4. PERSON CENTRED AND FAMILY CENTRED CARE ................................................................................................................ 22
  2.5. GENDER EQUALITY IN HEALTH ............................................................................................................................................ 24
  2.6. ORGANIZATION OF REHABILITATION SERVICES ................................................................................................................ 24
  2.7. MULTIDISCIPLINARY TEAMS AND INTERPROFESSIONAL TEAM APPROACH ..................................................................... 27
3. THE REHABILITATION CYCLE .........................................................................................................................................................30
  3.1. EVIDENCE-BASED PRACTICES IN CP ................................................................................................................................... 30
  3.2. NEUROPROTECTIVE AND PREVENTIVE STRATEGIES ......................................................................................................... 32
  3.3. DIAGNOSIS, ASSESSMENT, PROGNOSIS AND GOAL SETTING .............................................................................................. 34
  3.4. MANAGING THE MOTOR DISORDER ...................................................................................................................................... 42
  3.5. MAXIMISING FUNCTION AND ADLs ...................................................................................................................................... 50
  3.6. PRESCRIBING ADAPTIVE AND ASSISTIVE TECHNOLOGY (AAT) ............................................................................................ 51
  3.7. MANAGING COMMUNICATION IMPAIRMENTS .................................................................................................................... 53
  3.8. MANAGING OTHER CONDITIONS ASSOCIATED WITH CP ................................................................................................ 54
  3.9. REHABILITATION NEEDS ACROSS THE LIFESPAN ................................................................................................................ 82
  3.10. PARENT, FAMILY AND CAREGIVER SUPPORT .................................................................................................................... 84
4. SUPPORTING AND MONITORING THE IMPLEMENTATION OF THE GUIDELINES IN HOSPITALS ............................86
GLOSSARY ....................................................................................................................................................................................................87
REFERENCES ................................................................................................................................................................................................91
# List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAC</td>
<td>Augmentative and alternative communication</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of daily living</td>
</tr>
<tr>
<td>CBR</td>
<td>Community-based rehabilitation</td>
</tr>
<tr>
<td>CFCS</td>
<td>Communication Function Classification System</td>
</tr>
<tr>
<td>COPM</td>
<td>Canadian Occupational Performance Measure</td>
</tr>
<tr>
<td>CPAP</td>
<td>Continuous Positive Airway Pressure</td>
</tr>
<tr>
<td>CVI</td>
<td>Cortical visual impairment</td>
</tr>
<tr>
<td>EBP</td>
<td>Evidence-based practice</td>
</tr>
<tr>
<td>EDACS</td>
<td>Eating and Drinking Ability Classification System</td>
</tr>
<tr>
<td>FEES</td>
<td>Flexible endoscopic evaluation of swallowing</td>
</tr>
<tr>
<td>GMFCS</td>
<td>Gross Motor Function Classification System</td>
</tr>
<tr>
<td>GMFM</td>
<td>Gross Motor Function Measure</td>
</tr>
<tr>
<td>HIE</td>
<td>Hypoxic-ischaemic encephalopathy</td>
</tr>
<tr>
<td>HINE</td>
<td>Hammersmith Infant Neurological Examination</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Function</td>
</tr>
<tr>
<td>MACS</td>
<td>Manual Abilities Classification Scale</td>
</tr>
<tr>
<td>MP</td>
<td>Migration percentage</td>
</tr>
<tr>
<td>QUEST</td>
<td>Quality of Upper Extremity Skills Test</td>
</tr>
<tr>
<td>VFSS</td>
<td>Videofluoroscopic Swallow Study</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
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</table>
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 (this document), a technical guideline for physiotherapy and a technical guideline for occupational therapy. Collectively these documents make up a set of guidelines (known as ‘the guidelines’) for the holistic management of children with cerebral palsy. Specific technical guidelines for medical practitioners, nurses and speech pathologists are still to be developed.

The present General Rehabilitation Guideline for Cerebral Palsy provide general 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 guideline will be useful to any professional with an interest in rehabilitation for children with CP including doctors, neurologists, rehabilitation doctors, nurses, physiotherapists, occupational therapists, speech and language 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 occupational therapists (OT) and speech and language therapists (SALT) 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 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 CP 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, Principle 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 (range 1 month -13 years)
• CP type at diagnosis:
  o 66% spastic quadriplegia
  o 21% hemiplegia/monoplegia
  o 6.4% diplegia
• 1.5% had predominantly athetosis
• 54% the children had intellectual impairment and 12.7% had probable intellectual impairment
• Using the Gross Motor Function Classification System (GMFCS):
  o 16% had level V function
1.7. Describing CP

This section provides definitions of the motor types of CP. Assessments of spasticity, hypertonicity, dystonia, athetosis/choreoathetosis are provided in the Guidelines for Physiotherapy and Occupational Therapy.

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.

See section 5.2 Managing the Motor Disorder for information on assessing the motor disorder.

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.

*Figure 1: Image from Cerebral Palsy Diagnosis and Treatment infographic poster (www.worldcpday.org)*

In fig. 1: Hemiplegia includes children with monoplegia; quadriplegia includes children with triplegia
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.

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 15 will be unable to eat orally
- 1 in 25 will have a hearing impairment.
(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.

The focus is on determining which level best represents the child’s present abilities and limitations in gross motor function. Emphasis is on usual performance in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability). It is therefore important to classify current performance in gross motor function and not to include judgments about the quality of movement or prognosis for improvement. GMFCS level should be determined in conjunction with the child and family, not solely by a professional.

The CanChild website provides definitions/descriptors of the 5 GMFCS levels for different age groupings: Before 2nd birthday; Between 2nd and 4th birthday; Between 4th and 6th birthday; and Between 6th and 12th birthday. The GMFCS – E&R describes gross motor classification across the following age bands: 0-2 years; 2-4 years; 4-6 years; 6-12 years; and 12-18 years. The GMFCS emphasises the concepts inherent in the World Health Organization’s International Classification of Functioning, Disability and Health (ICF). The descriptions for the 6 to 12 year and 12 to 18 year age bands reflect the potential impact of environment factors (e.g., distances in school and community) and personal factors (e.g., energy demands and social preferences) on methods of mobility.

**Administration**

**Assessor:** Medical practitioners, physiotherapists, occupational therapists, nurses who are familiar with the child’s gross motor function in conjunction with a parent or caregiver.

**How:** Clinician asks questions of the child, parent or caregiver to determine functional mobility. Done either via parent/caregiver report and/or observation during regular appointment.

**Time:** N/A


**(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.
Administration
Assessor: Medical practitioners, physiotherapists, occupational therapists, nurses. Clinician asks questions of the child, parent or caregiver who is familiar with the child’s mobility (not direct observation).
How: questions asked during regular appointment.
Time: N/A

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:

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

(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:
<table>
<thead>
<tr>
<th>Group I - True Equinus</th>
<th>Ankle plantar flexion throughout stance with hips and knees extended</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group II - Jump gait</td>
<td>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.</td>
</tr>
<tr>
<td>Group III - Apparent Equinus</td>
<td>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.</td>
</tr>
<tr>
<td>Group IV - Crouch Gait</td>
<td>Excessive ankle dorsiflexion in combination with excessive flexion at the hip and knee.</td>
</tr>
<tr>
<td>Group V - Asymmetric Gait</td>
<td>A combination of any of the above two patterns.</td>
</tr>
</tbody>
</table>

1.9.3. Manual Ability

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

(Eliasson, Krumlinde Sundholm, Röslad, 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. MACS is based upon self-initiated manual ability, with particular emphasis on handling objects in an individual’s personal space (the space immediately close to one’s body, as distinct from objects that are not within reach). The focus of MACS is on determining which level best represents the child’s usual performance at home, school and in community settings. Distinctions between the levels are based on the child’s ability to handle objects and their need for assistance or adaptations to perform manual tasks in everyday life. MACS is not designed to classify best capacity and does not mean to distinguish different capacities between the two hands. MACS does not intend to explain the underlying reasons for limitations of performance or to classify types of CP.

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.

Administration

Assessor: Parent, caregiver or health professional who is familiar with the child’s hand function.

How: MACS level must be determined by asking someone who knows the child well and not by conducting a specific assessment (Eliasson, et.al.2005). Done either via parent/caregiver report and/or observation during regular appointment.

Time: N/A

Availability: A MACS training video is available as well as ‘The Supplementary MACS level identification chart’ to be used in conjunction with the MACS leaflet. Forms available for download from: www.macs.nu
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.

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Effective sender and receiver with familiar and unfamiliar partners</td>
</tr>
<tr>
<td>2</td>
<td>Effective but slow sender with familiar and unfamiliar partners</td>
</tr>
<tr>
<td>3</td>
<td>Effective sender and receiver with familiar partners</td>
</tr>
<tr>
<td>4</td>
<td>Inconsistent sender and/or receiver with familiar partners</td>
</tr>
<tr>
<td>5</td>
<td>Seldom effective sender and receiver even with familiar partners</td>
</tr>
</tbody>
</table>

**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: http://www.therapybc.ca/eLibrary/docs/Resources/CFCS_2008_11_03.pdf

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. It is complementary to the GMFCS, MACS and CFCS and its purpose is to be utilised both clinically and in research. 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.

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Eats and drinks safely and efficiently</td>
</tr>
<tr>
<td>II</td>
<td>Eats and drinks safely but with some limitations to efficiency</td>
</tr>
<tr>
<td>III</td>
<td>Eats and drinks with some limitations to safety; there may be limitations to efficiency</td>
</tr>
<tr>
<td>Level IV</td>
<td>Eats and drinks with significant limitations to safety</td>
</tr>
<tr>
<td>---------------</td>
<td>------------------------------------------------------</td>
</tr>
<tr>
<td>Level V</td>
<td>Unable to eat or drink safely, tube feeding may be considered to provide nutrition</td>
</tr>
</tbody>
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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.

**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](http://www.EDACS.org)

**Recommendations** -

> The classification systems for CP be adopted for use across Vietnam.
2. Pathways and Principles of Rehabilitation

2.1. Introduction

2.1.1. Rehabilitation

WHO describes rehabilitation as “a set of measures that assist individuals who experience, or are likely to experience, disability [resulting from impairment, regardless of when it occurred (congenital, early or late)] to achieve and maintain optimal functioning in interaction with their environments” “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 an infant with CP how to roll, sit unsupported, stand, and walk for the first time. It can also include teaching an older child with CP to ride a bicycle, hold a pencil and write, and catch/throw a ball for the first time.
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.

2.3. ICF

2.3.1. What is the ICF

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

WHO (2001). ICF Model
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.

For example:
- **Health Disorder**: Cerebral Palsy
- **Body Function/Structure Impairment**: Hypertonicity in upper extremity and lower extremity; spasticity
- **Activity Limitation**: Unable to put on a shirt or pants; unable to use a utensils (spoon/chopsticks) to feed self; unable walk
- **Participation Limitation**: Difficulty eating meals with family and out in the community; difficulty going to school; unable to play/socialize with same-aged children
- **Environment considerations**: physical access to community buildings, school
- **Personal factors**: age and gender of child; motivation of child

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

### 2.3.2. The ICF, Rehabilitation and CP

These guidelines have 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. Person Centred and Family Centred Care

2.4.1. Person-Centred Approach

Best practice service delivery when working with children with CP and their families is to adopt person-centred and family-centred approaches.

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 et al, 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.
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 paperwork and bureaucratic red tape.
- 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.

(Premises, Principles, and Elements of Family-Centred Service. Mary Law, Peter Rosenbaum, Gillian King, Susanne King, Jan Evans, 2003)

**Recommendation -**

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

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### 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 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

Rehabilitation is multi-sectoral (governmental agencies, health centres, educational institutions), which presents challenges related to prioritising needs, identifying available resources, and coordinating training among sectors, at all levels. There are several governmental agencies, associations, health care entities, non-governmental organisations and educational institutions which have roles in the training of rehabilitation specialists and provision of rehabilitation services. These include (but are not limited to):
- Ministry of Health (MoH) and its related departments
- Ministry of Labour, Invalids and Social Affairs (MOLISA)
- National, provincial and district hospitals (rehabilitation departments of the hospitals)
- Medical universities and schools
- Specialised Rehabilitation Centres (public and private)
- VINAREHA (Vietnam Association for Rehabilitation)
- Non-government organisations
- Community Based Rehabilitation

Under the MoH there are three levels of hospital - central, provincial and district levels. Not all provinces of Vietnam have a provincial rehabilitation hospital however most provincial hospitals have a Traditional Medicine department which provides rehabilitation services. Whilst most rehabilitation hospitals are under the MoH, some are run by private organisations and by other Ministries such as MOLISA.

Children with CP have access to medical insurance which covers rehabilitation services at government-run hospitals at the central, provincial and district level, as either an in-patient or out-patient. The type and extent of rehabilitation services may vary and are dependent on the child’s medical insurance, age of referral, and mechanism of referral for services.

**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).

**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 level, 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.
> Rehabilitation departments should establish and maintain strong links/relationships with other hospital departments especially maternal health, obstetrics/gynaecology, 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.

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.

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.

**2.7. Multidisciplinary Teams and Interprofessional Team Approach**

The gold standard approach for the management and treatment of children with CP requires a multidisciplinary team which utilises an interprofessional team approach.

Rehabilitation team members may include:

- Physician/Rehabilitation Specialist
- Nurse
- Physiotherapist
- Occupational Therapist
- Speech-Language Therapist
- Orthotist/P&O technician
- Nutritionist/Dietician
- Social Worker/Case Manager
- Psychologist

This approach focuses on all developmental aspects of the child (including conditions associated with CP) and on planning interventions in relation to the most important needs of the child and the family through team collaboration. Team collaboration is the process of forming partnerships among service providers, the family and child, and the community with the common goal of enhancing the child’s development and supporting the family.

In the 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. The role of each team member is defined and there is an emphasis on regular and on-going communication among team members. Common goals are developed in collaboration with the child and family.

In a multidisciplinary team approach, professionals still work independently and recognise and value contributions of other team members, however goals are developed in collaboration with the child and family by each individual team member (Effgen, 2006; Utley & Rapport, 2000).

**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.
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 et al., 1996). Decision making is also made with consideration to the organisational context (for example local policies, procedures and beliefs around approaches) (Figure 3).

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 one domain of the ICF. 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 (Table 1, Novak et al., 2013).

The intervention strategies outlined in these guidelines represent the current and highest level of evidence-based practice for the management of children with CP.
The following factors are important when reviewing the evidence-based for interventions for the management of children with CP.

- **Dosing** represents a critical and pressing aspect of intervention that is central for treatment efficacy and is defined as the frequency, intensity, time, and type of an intervention.
- **Frequency** refers to how often, such as the number of sessions for a given intervention per day, week, or month.
- **Intensity** refers to how hard the child works, the amount of effort, within the intervention session and is recorded as the number of repetitions per minute, day, or week or amount of work (eg, 75% of maximal heart rate).
- **Time** refers to the duration of the intervention.
- **Type** refers to the kind of intervention and can be focused at any of the dimensions of the *International Classification of Functioning, Disability and Health* (ICF): body functions and structures, activity, or participation. Within types, variation exists. For example, task practice can vary in the type of behavioural shaping (ie, structured versus unstructured training) and amount of feedback or reward (Kolobe et al., 2014).

Intervention studies must first demonstrate effectiveness in achieving a meaningful outcome then follow with carefully designed studies to determine the minimal dose required to elicit or maintain the same desired functional outcome.
To date, the minimum doses for changing structure and function, activity, and participation in children with CP are unknown and determining the effective dose of specific interventions is a focus of future intervention studies.

### 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)

Antenatal MgSO4 given to women at risk of preterm birth substantially reduces the risk of CP in their child. A guideline on the use of antenatal MgSO4 for neuroprotection of preterm infants have been developed and implemented across Australia (The Antenatal Magnesium Sulphate for Neuroprotection Guideline Development Panel, 2010).

The Australian guideline makes the following recommendations for use:

<table>
<thead>
<tr>
<th>The use of MgSO4 is recommended for neuroprotection of the foetus/infant/child:</th>
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<tbody>
<tr>
<td>▪ When women are at risk of imminent preterm birth before 30 weeks gestation</td>
</tr>
<tr>
<td>▪ When preterm birth before 30 weeks gestation is planned or definitely expected within 24 hours. (When birth is planned, commence magnesium sulphate as close to four hours before birth as possible)</td>
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**Dosage:**

- intravenously with a 4 gram loading dose (slowly over 20-30 minutes) and 1 gram per hour maintenance dose via IV route, with no immediate repeat doses. Continue regimen until birth or for 24 hours, whichever comes first

<table>
<thead>
<tr>
<th>The use of MgSO4 is recommended:</th>
</tr>
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<tbody>
<tr>
<td>▪ Regardless of the number of babies in utero</td>
</tr>
<tr>
<td>▪ Regardless of parity (number of previous births for the woman)</td>
</tr>
<tr>
<td>▪ Regardless of the anticipated mode of birth</td>
</tr>
<tr>
<td>▪ Whether or not antenatal corticosteroids have been given</td>
</tr>
</tbody>
</table>

Recommendations -

> Neuroprotection of preterm infants should be identified as an important strategy for reducing the impact of CP. Neuroprotection of preterm infants should be discussed with the appropriate Ministry of Health representatives and hospital departments (i.e. Maternity/Obstetrics and Gynaecology) and a national strategy developed.

> Where the capabilities exist, MgSO4 for neuroprotection of preterm infants should be made available to women at risk of preterm birth.

3.2.2. Therapeutic Hypothermia (Cooling)

Neonatal encephalopathy occurs in 1 to 3 per 1000 live births in high-income countries, and in up to 20 per 1000 live births in low and middle-income countries (Pauliah et al, 2013). Hypoxic ischaemic encephalopathy (HIE) is a form of neonatal encephalopathy caused by systemic hypoxaemia and/or reduced cerebral blood flow resulting from an acute peripartum or intrapartum event. HIE can be a clinical consequence of perinatal, birth and/or neonatal asphyxia. The prevalence of HIE in Vietnam is currently unknown.

In high-income countries, therapeutic hypothermia for infants has demonstrated improved survival and disability (including CP) after moderate-severe HIE (Davidson et al, 2015; Paula et al, 2013). Therapeutic hypothermia is now widely offered as standard treatment for HIE in high-income countries (Pauliah et al, 2013).

Current hypothermia protocols have consistently involved starting treatment within the first 6 hours of life, with systemic cooling to either $34.5 \pm 0.5^\circ C$ for head cooling, or $33.5 \pm 0.5^\circ C$ for whole-body cooling and continuing treatment for 48–72 hours (Davidson et al, 2015).

Many studies (in high-income countries) have shown that mild hypothermia stops brain damage and can promote healing. It is the only known treatment for HIE. It is the only single medical intervention that reduces brain damage, reduces the level of disability resulting from brain damage, and strongly improves an infant’s chance of survival.

Recommendation -

> Therapeutic hypothermia for infants with moderate-severe HIE should be identified as an important strategy for reducing the impact of CP. Therapeutic hypothermia should be discussed with the appropriate Ministry of Health representatives and hospital departments (i.e. Maternity/Obstetrics and Gynaecology) and a national strategy developed.
3.3. Diagnosis, Assessment, Prognosis and Goal Setting

3.3.1. Early Diagnosis of CP

(I) Why is early diagnosis needed

Early diagnosis is considered best practice because it enables timely access to diagnostic-specific early intervention when the greatest neuroplastic gains are possible, thus maximising the child’s developmental outcomes.

The average age at which children are given the description of CP is 19 months. This varies anywhere from 1 week to 3 years for children with severe motor impairment and from 1 week to 5 years for children with mild or moderate motor impairment (McIntyre et al, 2011).

Earlier detection of CP is both possible and accurate (McIntyre et al, 2011). The first 2 years of a child’s life are critical for cognitive and motor development as the brain is undergoing constant spontaneous plasticity (Morgan et al, 2013).

Children with CP reach approximately 90% of their gross motor potential by 5 years of age and even younger for those with more severe impairments (Hanna et al, 2009). It is vital that intensive, repetitive task-specific early intervention therapy commences as early as possible for infants with CP (McIntyre et al, 2011; Morgan et al, 2013).

Early diagnosis also enables parents and families to have access to the emotional supports that are crucial at such a vulnerable time.

(II) Diagnosing CP

Diagnostic best practice for CP involves a combination of:

- History taking and risk factors identification
- Neurological examination
- Standardised motor assessment:
  - Prechtl’s General Movement for infants <4 months corrected (assesses quality of spontaneous movements)
  - Developmental Assessment of Young Children for infants 6-12 months of age (parental questionnaire of volitional movements)
- Neuroimaging
- Ruling out of alternative diagnoses, including progressive disorders

CP 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).

Physiotherapists, occupational therapists, nurses or other health professionals may however be the first health professional to see a child because of concerns of the parents that the child is not
developing typically. Therefore it is important for other health professionals to be able to identify signs of CP and know when to refer children to a medical professional for further assessment and diagnosis.

**Risk factors**

History taking should include screening questions related to the mother’s health, pregnancy, birth and post-birth period. Risk factors for CP may be at the maternal or infant level.

Maternal risk factors include
- Thyroid condition
- Infection during pregnancy
- Pre-eclampsia
- Bleeds during the second or third trimester
- Multiple pregnancy (i.e. twins or greater)

Infant risk factors include:
- Prematurity
- Intrauterine growth restriction
- Low birth weight
- Acute intrapartum hypoxic event
- Moderate to severe encephalopathy
- Neonatal seizures
- Neonatal infection
- Hypoglycaemia
- Jaundice

Additional risk factors have been identified in children born at term (in high resource countries). These include (McIntyre et al, 2012):
- Placental abnormalities
- Birth defects
- Meconium aspiration
- Instrumental/emergency caesarean delivery
- Birth asphyxia
- Respiratory distress syndrome

A small percentage of children acquire CP after one month of age. This is generally a result of stroke, which may occur spontaneously or from complications associated with another condition or medical intervention (ACPR Group 2009). In Vietnam neurologic infections, especially meningitis, may cause CP in babies and infants.

**Neurological Assessment**

The Hammersmith Infant Neurological Examination (HINE) is a neurological assessment for infants between 2 and 24 months of age that includes items for cranial nerve function,
posture, movements, tone and reflexes. It can be reliably used to assess infants at neurological risk, both preterm and term born. The HINE identifies early signs of CP in infants with neonatal brain lesions.

Benefits of the HINE include:
- It is easily performed and accessible to all clinicians
- It has good inter-observer reliability, even in inexperienced staff
- It not only identifies children at risk of CP but also often provides additional information on the type and severity of the motor sequelae
  - Infants with global scores ≤56 at 3 months and ≤65 at 12 months showed a high (~90%) sensitivity and specificity for the development of CP
  - Scores <40 are associated with non-independently ambulatory CP (GMFCS III-V)
  - Scores between 40-60 are associated with independently ambulatory CP (GMFCS I-II)
- It often allows identification of early abnormal signs related to other aspects of neurological function such as cerebral visual impairment or feeding abnormalities (Romeo et al, 2008; Romeo et al, 2016)

The HINE can be conducted by a medical professional (e.g. general practitioner, paediatrician, paediatric neurologist), physiotherapist or occupational therapist. The HINE should be carried out by a medical professional for the purpose of diagnosis.

**Motor Assessment**
a) Prechtl’s Assessment of General Movements:
CP can be accurately identified as early as 3 months of age using the General Movements Assessment (GMs). The GMs is a video-based observation of an infant’s spontaneous movements, scored by a trained rater.

The GMs has been shown to be highly predictive of CP (Spittle et al, 2009):
- An abnormal score of “cramped synchronised” movements before 8 weeks corrected age followed by an abnormal score of “absent fidgety” movements at 10-20 weeks corrected age is 98% predictive of CP
- GMs (specifically “absent fidgety”) combined with MRI findings (specifically white matter injury) is 100% predictive of CP (Spittle et al, 2008).

Training in the GMs is carried out by the General Movements Trust [http://general-movements-trust.info](http://general-movements-trust.info)

The GMs can be conducted by any medical or allied health professional who has been trained in the assessment.
b) Developmental Assessment of Young Children (DAYC):
The DAYC is a simple questionnaire that does not require training, personnel or equipment. It is an individually administered, norm-referenced measure of early childhood development for children from birth through age 5 years 11 months.

Developmental domains addressed in the developmental screener are cognition, communication, social-emotional development, physical development, and adaptive behaviour.

A drop of two standard deviations in DAYC motor scores between 6-12 months of age is 83% predictive of CP (Novak, 2014).

Note: The norming of the DAYC was completed on a sample of children from the United States. The questionnaire is currently only available from the publisher in English.

c) Ages and Stages Questionnaire (ASQ):
The Ages and Stages Questionnaire (ASQ) is a parent-completed questionnaire that may be used as a general developmental screening tool.

Developmental domains addressed in the developmental screener are gross motor, fine motor, problem solving, personal-social and an overall section that addresses general parental concerns.

The ASQ can identify children who require further assessment however it is not known to be predictive of CP. It is available in Vietnamese (Singh et al, 2017).

Recommendation -
> The ASQ should be used by all healthcare providers to improve the early detection of infants at risk for CP. Infants who are identified as at-risk or delayed should be referred to a national, provincial or district hospital (rehabilitation departments of the hospitals) or a specialised Rehabilitation Centre (public and private) for neurologic and motor assessment specific to CP.

Neuroimaging
All children with a presumed or suspected brain injury should have magnetic resonance imaging (MRI). MRI is the gold-standard neuroimaging technique for determining the pathogenesis of CP - white matter damage of immaturity (WMDI) including periventricular leukomalacia, deep grey matter lesions, malformations, focal infarcts, and cortical and subcortical lesions (Rosenbaum et al, 2007). It should however be noted that 12-14% of children with CP will have a normal MRI (McIntyre et al, 2011) and a determination of CP should not depend solely on MRI.
Recommendations -

> Early diagnosis of CP should be identified as a key priority. Rehabilitation departments should establish and maintain strong links/relationships with other hospital departments especially maternal health, obstetrics/gynaecology, 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.

> To facilitate early diagnosis in infants under 4 months of age, Prechtl’s Assessment of General Movements and the Hammersmith Infant Neurological Examination should be adopted. Key medical and/or health professionals should be identified and trained in the GMs. Typically these professionals work in special care/neonatal intensive care nurseries and neonatology units.

> To facilitate early diagnosis in infants older than 4 months of age, the Hammersmith Infant Neurological Examination and the Developmental Assessment of Young Children should be adopted. The Ages and Stages Questionnaire could be considered as it is currently available in Vietnamese however the information obtained should always be accompanied by the HINE as the ASQ does not distinguish between developmental delay and CP.

3.3.2. Prognosis

The future for children with CP is rather bright. 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
- Disability increases with age
- 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
- Presence of severe dysphagia increases the risk of premature death

(III) Prognosis for walking
- Most children will walk - 60% will walk independently (GMFCS I-II), 10% will walk with a walking aid (GMFCS III) and 30% are wheelchair users (GMFCS IV-V)
- The more severe the child’s physical, functional or cognitive impairment, the greater the possibility of difficulties with walking
- If a child can sit at 2 years of age it is probable (but not certain) that they will be able to walk unaided by age 6
- If a child cannot sit but can roll at 2 years of age, there is a possibility that they may be able to walk unaided by age 6
- If a child cannot sit or roll at 2 years of age, they are unlikely to be able to walk unaided

**(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) Presence of associated conditions affect outcomes**
- CP is almost always accompanied by associated conditions (see 1.4)
- Screening for the presence of associated conditions should be routine and associated conditions managed if present

**(VI) Severity predictions**
- Under 2 years of age, severity predictions are incorrect 42% of the time - voluntary movement is still developing and hypertonia may still be evolving with myelination
- MRI may provide some information for predicting function - unilateral injuries usually result in milder presentations; periventricular white-matter lesions generally result in milder motor impairments (ie, usually ambulatory) but not always, whereas brain malformations, cortical, subcortical, and basal ganglia lesions generally result in more severe motor impairments (ie, non-ambulatory)

**(VII) Using MRI to predict prognosis**
- Do not rely on MRI alone for predicting prognosis in children with CP
- Consider the likely cause of CP and the findings from MRI (if performed) when discussing prognosis with the child or young person and their parents or carers
- Combine information obtained about risk factors, neuroimaging and assessment of motor function (especially the Hammersmith Infant Neurological Examination) to assist prediction of severity and therefore prognosis

(Novak, 2014; NICE, 2017)

**Recommendation** -
> All practitioners working with children with CP and their families should be familiar with these prognostic messages and be able to support families with this information.
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 (Bower, 2004). 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) **Canadian Occupational Performance Measure (COPM)**
(Law, Baptiste, Carswell, McColl, Polatajko & Pollock, 1990)

The Canadian Occupational Performance Measure (COPM) is an individualised measure that assesses an individual’s perceived occupational performance in the areas of self-care, productivity, and leisure. It is designed to detect change in a client’s self-perception of occupational performance over time. The COPM is used to identify problem areas and provide a rating of the client’s priorities in occupational performance, evaluate performance and satisfaction relative to those problem areas and measure changes in a client’s perception of his/her occupational performance over time.

**Administration**

**Assessor:** This tool can be conducted by any rehabilitation team member.

**How:** Ensure that the version used is the paediatric modified version. Select parent or child report as appropriate. The assessment involves a 5-step process nested within a semi-structured interview that focuses on identifying activities within each performance domain that the client wants, needs, or is expected to perform.

**Time:** 15-30 minutes, semi-structured interview.

**Note:** The COPM has been translated into 24 different languages. It is not currently available in Vietnamese however it is likely that a translation will be available.
(II) 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.

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 however it is typically used by physiotherapists and occupational therapists 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


Recommendations -
> GAS is an internationally recognised tool for setting and evaluating goals. Extensive experience and training is required. 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

3.4.1. Assessing the Motor Disorder

The motor types associated with CP are identified by physical assessment and clinical observation.

Points to remember:
- Hypertonia may still be evolving in the first two years of life with myelination
- Mixed presentations are common (spasticity/dystonia, dystonia/choreoathetosis)

(I) Assessing for spasticity

> Modified Tardieu Scale (MTS)
(http://www.rehabmeasures.org/Lists/RehabMeasures/PrintView.aspx?ID=1038)

The Modified Tardieu Scale is a scale for measuring spasticity that takes into account resistance to passive movement at both slow and fast speed. The scale originally began development in the 1950s and has gone through multiple revisions (reviewed in Haugh 2006). The Modified Tardieu Scale is an adaption of the original, more complex and time consuming assessment (the Tardieu Scale).

Administration

Assessor: The Modified Tardieu Scale is carried out by an occupational therapist, physiotherapist, neurologist or rehabilitation medicine specialist.

How: There are two parts to the assessment that are applied to each muscle group that is examined. In the first part of the assessment, the health professional slowly moves the person’s limb to observe the full range of their available movement (R2). In the second part of the assessment, the same limb is moved quickly (R1).

The R1 and R2 range of motion values are measured using a goniometer.

Individuals are positioned in sitting to test the upper extremities and supine to test the extremities according to standard protocols.

R1 is then subtracted from R2 and this represents the dynamic tone component of the muscle.

Muscles typically assessed in CP include:

<table>
<thead>
<tr>
<th>Upper Limbs</th>
<th>Lower Limbs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shoulder flexors</td>
<td>Hip flexors</td>
</tr>
<tr>
<td>Shoulder external rotators</td>
<td>Hip extensors</td>
</tr>
<tr>
<td>Elbow flexors</td>
<td>Hip abductors</td>
</tr>
<tr>
<td>Elbow extensors</td>
<td>Knee flexors</td>
</tr>
<tr>
<td>Wrist flexors</td>
<td>Knee extensors</td>
</tr>
<tr>
<td>--------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Wrist extensors</td>
<td>Ankle extensors (knee joint flexed)</td>
</tr>
<tr>
<td></td>
<td>Ankle extensors (knee joint fully extended)</td>
</tr>
</tbody>
</table>

**Time:** Varies depending on the number of muscle groups assessed.

> *Ashworth Scale and Modified Ashworth Scale*

(Ashworth, 1964; Bohannon & Smith, 1987)


The Modified Ashworth Scale (MAS), a modification to increase the sensitivity of the original Ashworth Scale (AS), measures spasticity and is applied manually to determine the resistance of the muscles to passive movement. There is no reference to the velocity of the movement therefore the response of stretch reflex to the increasing velocity is not examined. The reliability of the scales is poor and the literature recommends interpretation of scores be used with caution.

**Ashworth Scale**

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>0</td>
<td>No increase in tone</td>
</tr>
<tr>
<td>1</td>
<td>Slight increase in tone giving catch when the limb is moved in flexion and extension</td>
</tr>
<tr>
<td>2</td>
<td>More marked increase in tone, but limb is easily flexed</td>
</tr>
<tr>
<td>3</td>
<td>Considerable increases in tone, passive movement difficult</td>
</tr>
<tr>
<td>4</td>
<td>Limb rigid in flexion or extension</td>
</tr>
</tbody>
</table>

**Modified Ashworth Scale**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No increase in muscle tone</td>
</tr>
<tr>
<td>1</td>
<td>Slight increase in muscle tone, manifested by a catch and release or by minimal resistance at the end of the range of motion when the affected part(s) is(are) moved in flexion or extension.</td>
</tr>
<tr>
<td>1+</td>
<td>Slight increase in muscle tone, manifested by a catch followed by minimal resistance through the remainder of the range of motion but the affected part(s) is/are easily moved.</td>
</tr>
<tr>
<td>2</td>
<td>More marked increase in muscle tone through most of the range of movement, but the affected part(s) is easily moved.</td>
</tr>
<tr>
<td>3</td>
<td>Considerable increases in muscle tone, passive movement difficult.</td>
</tr>
<tr>
<td>4</td>
<td>Affected part(s) is(are) rigid in flexion or extension.</td>
</tr>
</tbody>
</table>

**Administration**

**Assessor:** This assessment is carried out by an occupational therapist, physiotherapist, neurologist or rehabilitation medicine specialist who assesses bilateral upper and lower limb muscles according to standard physical assessment protocol.

**How:** Place the patient in a supine position. If testing a muscle that primarily flexes a joint, place the joint in a maximally flexed position and move to a position of maximal extension over one second (count "one thousand one"). If testing a muscle that primarily extends a joint, place the
joint in a maximally extended position and move to a position of maximal flexion over one second (count “one thousand one”). Score based on the classification below.

**Time:** Varies depending on the number of muscle groups assessed

> **Hypertonicity Assessment Tool (HAT)**
(Jethwa et al, 2010)

The Hypertonia Assessment Tool (HAT) is a discriminative measure that assists the clinician to identify the specific types of hypertonia present and how to best manage the hypertonia. It is a six item tool (Knights, et al, 2013) developed for children between the ages of 4 to 19 years, whereby the assessor moves the child’s body part in a series of purposeful movements in order to observe movement, increased tone and/or resistance. The presence of at least 1 HAT item per hypertonia subgroup ie spasticity, dystonia, rigidity, confirms the presence of the subtype and the presence of items from more than one subgroup identifies the presence of mixed tone. The HAT is capable of discriminating hypertonia subtypes for both the upper and lower extremities.

The HAT was found to have good reliability and validity for identifying spasticity and the absence of rigidity (rigidity is rarely seen in paediatric population) and moderate findings for dystonia due to its variable nature. The HAT is stronger in identifying the presence of, rather than the absence of spasticity or dystonia and the reverse pattern was found for rigidity.

**Administration**

**Assessor:** This assessment is carried out by an occupational therapist, physiotherapist, neurologist or rehabilitation medicine specialist.

**How:** Clinician completes ALL 6 items on one extremity before moving to the next next extremity. It is recommended that all four limbs are assessed. Items are listed in the suggested order of administration in the HAT manual.


**Time:** Approximately 5 minutes to conduct per limb assessed

**II** Assessing for dystonia

To assess dystonia it is important to observe at rest and with voluntary movements as well as to measure and feel. There is usually variable resistance to movement, often in extensor groups but it can be both directions.

> **Hypertonicity Assessment Tool (HAT)**
See above.

> **Barry Albright Dystonia Scale (BAD)**
(Barry et al, 1999)
The Barry Albright Dystonia (BAD) Scale is a reliable and responsive five-point criterion based ordinal rating scale for quantifying secondary dystonia. It rates the severity of dystonia in eight body regions, including eyes, neck, mouth, trunk, upper limbs and lower limbs.

**Administration**

**Assessor:** This assessment is carried out by an occupational therapist, physiotherapist or physician experienced in secondary dystonia and CP.

**How:** Assess the patient for dystonia in each of the following regions: eyes, mouth, neck, trunk, each upper and lower extremity (8 body regions). Rate severity based only on dystonia as evidenced by abnormal movements or postures. When assessing functional limitations, do not score as dystonia-induced functional limitation if other factors, such as weakness, lack of motor control, cognitive deficits, persistent primitive reflexes, and/or other movement disorders are contributing to functional limitation.

**Eyes:** signs of dystonia of the eyes include: prolonged eyelid spasms and/or forced eye deviations

<p>| | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>0</td>
<td>Absent</td>
</tr>
<tr>
<td>1</td>
<td>Slight: dystonia less than 10% of the time and does not interfere with tracking</td>
</tr>
<tr>
<td>2</td>
<td>Mild: frequent blinking without prolonged spasms of eyelid closure, and/or eye movements less than 50% of the time</td>
</tr>
<tr>
<td>3</td>
<td>Moderate: prolonged spasms of eyelid closure, but eyes open most of the time, and/or eye movements more than 50% of the time that interfere with tracking, but able to resume tracking</td>
</tr>
<tr>
<td>4</td>
<td>Severe: Prolonged spasms of eyelid closure, with eyelids closed at least 30% of the time, and/or eye movements more than 50% of the time that prevent tracking</td>
</tr>
</tbody>
</table>

Unable to assess eye movements

**Mouth:** signs of dystonia of the mouth include grimacing, clenched or deviated jaw, forced open mouth, and/or forceful tongue thrusting

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<tbody>
<tr>
<td>0</td>
<td>Absent</td>
</tr>
<tr>
<td>1</td>
<td>Slight: dystonia less than 10% of the time and does not interfere with speech and/or feeding</td>
</tr>
<tr>
<td>2</td>
<td>Mild: dystonia less than 50% of the time and does not interfere with speech and/or feeding</td>
</tr>
<tr>
<td>3</td>
<td>Moderate: dystonia more than 50% of the time and/or dystonia that interferes with speech and/or feeding</td>
</tr>
<tr>
<td>4</td>
<td>Severe: dystonia more than 50% of the time and/or dystonia that prevents speech and/or feeding</td>
</tr>
</tbody>
</table>

Unable to assess mouth movements
**Neck:** signs of dystonia of the neck include pulling of the neck into any plane of motion: extension, flexion, lateral flexion or rotation

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Absent</td>
</tr>
<tr>
<td>1</td>
<td>Slight: pulling less than 10% of the time and does not interfere with lying, sitting, standing and/or walking</td>
</tr>
<tr>
<td>2</td>
<td>Mild: pulling less than 50% of the time and does not interfere with lying, sitting, standing and/or walking</td>
</tr>
<tr>
<td>3</td>
<td>Moderate: pulling more than 50% of the time and dystonia that interferes with lying, sitting, standing and/or walking</td>
</tr>
<tr>
<td>4</td>
<td>Severe: pulling more than 50% of the time and dystonia that prevents sitting in a standard wheelchair (e.g. requires special head rest), standing and/or walking</td>
</tr>
</tbody>
</table>

Unable to assess neck movements

**Trunk:** signs of dystonia of the trunk include pulling of the trunk into any plane of motion: extension, flexion, lateral flexion or rotation

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Absent</td>
</tr>
<tr>
<td>1</td>
<td>Slight: pulling less than 10% of the time and does not interfere with lying, sitting, standing and/or walking</td>
</tr>
<tr>
<td>2</td>
<td>Mild: pulling less than 50% of the time and does not interfere with lying, sitting, standing and/or walking</td>
</tr>
<tr>
<td>3</td>
<td>Moderate: pulling more than 50% of the time and dystonia that interferes with lying, sitting, standing and/or walking</td>
</tr>
<tr>
<td>4</td>
<td>Severe: pulling more than 50% of the time and dystonia that prevents sitting in a standard wheelchair (e.g. requires adapted seating system), standing and/or walking</td>
</tr>
</tbody>
</table>

Unable to assess trunk movements

**Upper extremities:** signs of dystonia of the upper extremities include sustained muscle contractions causing abnormal postures, score each limb separately

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Absent</td>
</tr>
<tr>
<td>1</td>
<td>Slight: dystonia less than 10% of the time and does not interfere with normal positioning and/or functional activities</td>
</tr>
<tr>
<td>2</td>
<td>Mild: dystonia less than 50% of the time and does not interfere with normal positioning and/or functional activities</td>
</tr>
<tr>
<td>3</td>
<td>Moderate: dystonia more than 50% of the time and/or dystonia that interferes with normal positioning and/or upper extremity function</td>
</tr>
<tr>
<td>4</td>
<td>Severe: dystonia more than 50% of the time and/or dystonia that prevents normal positioning and/or upper extremity function (e.g. arms restrained to prevent injury)</td>
</tr>
</tbody>
</table>

Unable to assess upper extremity movements

**Lower extremities:** signs of dystonia of the lower extremities include sustained muscle contractions causing abnormal postures, Score each limb separately

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Absent</td>
</tr>
<tr>
<td>1</td>
<td>Slight: dystonia less than 10% of the time and does not interfere with normal positioning and/or functional activities</td>
</tr>
<tr>
<td>2</td>
<td>Mild: dystonia less than 50% of the time and does not interfere with normal positioning and/or functional activities</td>
</tr>
</tbody>
</table>
| 3 | Moderate: dystonia more than 50% of the time and/or dystonia that interferes with
Severe: dystonia more than 50% of the time and/or dystonia that prevents normal positioning and/or lower extremity weight bearing and/or function

Unable to assess lower extremity movements

**Time:** Approximately 8 minutes of video (if used) plus time to score body segment movements.

### (III) Assessing for choreoathetosis
Assessment for chorea, athetosis and choreoathetosis is by observation of involuntary movements characterised by:

- Uncontrolled, slow and writhing movements (athetosis)
- An ongoing random-appearing sequence of one or more discrete involuntary movements or movement fragments (chorea)
- Both (choreoathetosis)

### 3.4.2. Medical Tone Management
The decision to treat the motor disorder needs to be based upon a comprehensive assessment and evaluation of the impact of the motor disorder on the attainment of identified goals. Treatment of the motor disorder may be necessary to reduce the negative impact of hypertonia on function and care/comfort. Caution needs to be exercised to ensure that if hypertonia is to be managed medically, that the hypertonia is not facilitating function (e.g. some children with hypertonia in certain muscle groups such as quadriceps, rely on their hypertonia to maintain knee extension in standing).

Medical tone management options include:

- Botulinum toxin A (BoNT-A) injections
- Medications
- Intrathecal baclofen (ITB)

---

This guideline outlines basic information relating to these options. Further detail, including recommended dosage and techniques for administration has to be retrieved from relevant guidelines for Medical Practitioners.

---

**(I) Botulinum toxin A (BoNT-A) injections**
BoNT-A is a neurotoxin injected into targeted muscles to treat localised spasticity and dystonia in children with CP. BoNT-A blocks the release of acetylcholine, one of the main neurotransmitters, at the neuromuscular junction and causes temporary muscle paralysis. This paralysis, or muscle weakness usually lasts between three and six months, when repeat injections may be indicated.

BoNT-A injections are considered with careful functional and/or carer goal identification and goal attainment and adverse events are closely monitored post injections. Current literature indicates there is strong evidence to support the use of BoNT-A injections for upper and lower limb spasticity management.
BoNT-A injections are considered a standard treatment option for managing hypertonia in children with CP in high-income countries. They are administered by rehabilitation specialists.

BoNT-A injections are currently available in Vietnam however they are not covered by medical insurance, meaning that families are required to pay for the cost of the injections. The cost of injections may be considered prohibitive for many families.

**Recommendation**

> The role of BoNT-A injections for the management of hypertonia in children with CP should be considered and strategies identified to improve access to BoNT-A injections across Vietnam

(II) Medications

A variety of oral medications are routinely prescribed for children with CP when a generalised reduction in spasticity and/or dystonia is the desired outcome.

Commonly prescribed medications used for generalised spasticity include:

- Baclofen
- Diazepam
- Dantrolene
- Tizanidine

Medications prescribed for the treatment of generalised dystonia include:

- Baclofen
- Haloperidol
- L dopa
- Tetrabenazine
- Benzhexol

Many of these medications can have side effects such as drowsiness, sedation and weakness. It is important to set specific goals when trialling medications and monitor ongoing medication use for continued benefits and/or adverse effects.

(III) Intrathecal baclofen (ITB)

Baclofen is a commonly trialled oral medication for children with generalised dystonia and spasticity. Its action on receptors in the spinal cord suppresses muscle spasms and reduces muscle tone. In oral form it does not cross the blood brain barrier easily which can necessitate higher doses which produce unwanted side effects.

Administered intrathecally, baclofen can be delivered directly to the site of action, allowing smaller doses and fewer side effects. An Intrathecal Baclofen pump, consisting of a programmable pump and intrathecal catheter, can be programmed to administer a continuous infusion plus/minus bolus doses of baclofen over a 24 hour period.
Protocols and eligibility for ITB vary from country to country. Due to the invasive nature of the intervention and the risks associated (such as pump malfunction, catheter breakage and wound care challenges), quick and easy access to the specialist medical team is often a pre-requisite for pump implantation.

3.4.3. Surgical Tone Management

(I) Selective Dorsal Rhizotomy (SDR)

Selective Dorsal Rhizotomy (SDR) is a neurosurgical spasticity-reducing intervention for children with spastic CP. The goal is to reduce the spasticity in the lower limbs permanently by interrupting the abnormal spinal reflex arc, in order to improve motor function.

The neurosurgeon divides the dorsal sensory spinal roots of L1/L2-S1 and stimulates each one with EMG. Sensory nerve rootlets with abnormal, excessive and contralateral (EMG) responses are surgically sectioned. In combination with physiotherapy, SDR has been reported to improve functional outcome in spastic diplegia (Josenby et al 2012).

It is suitable for a small selection of children with bilateral involvement, fulfilling the following criteria:

- GMFCS II/III
- Spasticity without any mixed presentation
- Strong
- Symmetrical
- Straight with no significant contractures
- Good selective motor control
- Supportive family environment and young (i.e. around 4-6 years of age)

The surgery will not correct existing contractures or deformities and does not cure the primary effects of CP, which include loss of motor control, weakness, balance problems and so on. For the majority of children, if they are to reach their optimal functional mobility, orthopaedic surgery may be needed some time after the SDR to correct persistent contractures and deformities of the bone.

Children undergoing a SDR will always require intensive physiotherapy following surgery to work on regaining and improving motor skills.

This guideline outlines basic information relating to SDR. Further detail, including recommended dosage and techniques for administration has to be retrieved from relevant guidelines for Medical Practitioners.
3.5. Maximising Function and ADLs

3.5.1. Assessment of Motor Function and ADLs
Assessments of motor function and ADLs are at the Activity and Participation level of the ICF. Assessments can be divided into assessments of capacity (refers to the child’s abilities as measured by assessments performed in a clinical setting i.e. hospital or clinic) and assessments of performance (refers to the child’s abilities as measured in naturalistic or everyday settings i.e. home, school or in the community). Capacity assessments identify the child’s ‘best’ ability under ideal test conditions whereas performance assessments identify the child’s typical ability in everyday life.

Assessments include:
- Task/activity analysis (Clinical observation of performance of a specific task)
- Gross Motor Function Measure
- Assessment of gait - 2D gait analysis
- Assessment of walking function - TUG
- Assessment of walking function - Timed Up and Down Stairs
- Assessment of walking function - 10MWT
- Assessment of walking function - timed walk test (1,2,6-minute walk tests)
- Assessment of upper extremity reach, grasp and release – Box and Block test
- Assessment of quality of unilateral hand or arm movement patterns – Quality of Upper Extremity Skills Test (QUEST)
- Assessment of ability to use hands in daily tasks – Pediatric Motor Activity Log (PMAL)
- Assessment of ability to manage routine tasks requiring both upper extremities – (ABILHAND Kids)

These assessments will be detailed in the technical guidelines for Physiotherapy and Occupational Therapy.

3.5.2. Interventions for Motor Function and ADLs

Interventions to maximise function and ADLs should be directed at the activities and participation domain of the ICF. Interventions that are directed at the body structures and function domain of the ICF have been shown to have an effect at the body structures and function level only and not at the activities and participation level.

Motor learning is the primary approach for learning motor skills.
Novak (2014) identifies that “therapy that is: (1) ‘done to the child’ for the purpose of gaining motor skills, where the child’s role predominantly is passive, and/or (2) involve nonspecific motor stimulation aimed at normalising movement—conflict with neuroplasticity evidence and for the most part have been proven ineffective or of very minimal benefit” (page 6).

Motor learning is defined as ‘a set of processes involving practice and exercise leading to a relatively stable change in motor behaviour’ (Schmidt 1988 in Shepherd 2014, page 20). Motor learning requires active participation and incorporates five key principles:

- Practice - intense and repeated
- Feedback - involves both intrinsic and extrinsic feedback
- Guidance - physical guidance that is reduced as performance increases
- Mental imagery - involves task visualisation and problem solving
- Task specificity and motivation

Motor learning theory considers the person, the environment and the task. It utilises cognitive strategies to learn and allows compensatory movements. Motor learning based approaches involve the establishment of a goal/s, setting up the regulatory stimulus conditions and utilise problem solving. For motor learning to be achieved (that is, for new motor skills to be learnt), motor learning approaches need to incorporate the principles of neuroplasticity. These include:

- Movement must be self-initiated (not passively done on behalf of the person)
- There must be mental and physical effort involved
- Training must be of sufficient intensity
- Training requires variability and must not be by rote
- Training and the movement must be meaningful to the patient.

**Recommendation**

> Child-active intervention approaches and motor learning should be adopted as the primary approach to maximising motor function and ADLs

Further detail regarding specific interventions will be outlined in the technical guidelines for Occupational Therapy, Physiotherapy and Speech Therapy.

### 3.6. 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). Assistive technology is any “item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities” (US Govt, 1988). Assistive technology is routinely prescribed to support individuals to achieve their movement, communication and participation goals as well as to reduce caregiver burden.
Having a clear understanding of each individual’s unique needs is essential when exploring, trialing and prescribing AAT. It is therefore necessary to ensure a thorough assessment has been completed to provide information about:

- The individual’s functional abilities
- The individual’s movement disorder
- The individual’s musculoskeletal status
- How the individual performs certain tasks and activities
- The environment in which the individual performs the tasks and activities

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

Examples of AAT include (but are not limited to):

- Wheelchairs and strollers
- Walking aids
- Standing frames
- Splints and orthoses (upper limb and lower limb)
- Bath/shower aids
- Positioning equipment including posture chairs, bed positioning
- Beds and mattresses
- Adaptive cutlery, bowels, plates, cups etc
- Transfer aids including hoists
- Ramps
- Low tech and high tech communication aids
- Accessible toys
- Gaming technology
- Robotic technology

Sources for adaptive and assistive technology include:

- Hospital workshops
- Private health-related workshops
- Local commercial workshops (wood work and iron work)
- Adaptive and assistive technology supply companies
- Non-governmental organisations (NGOs)
- Adaptations made by families
- School system workshops/trainings

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)

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

**Recommendation**

> 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.

### 3.7. Managing Communication Impairments

The production of speech, language, and gestures used for communication is often affected by CP. 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.

Language development from birth to 2 years presents multiple opportunities for therapeutic interventions during a critical window of language development. Speech sound differentiation, voice recognition, and word formation occur in the earliest phase of language development (Chorna, Hamm, Cummings, Fetters, & Maitre, 2017).

#### 3.7.1. Interventions for Early 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 and phonation** for improved production of sounds and words.

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

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

### 3.8. Managing other Conditions Associated with CP

#### 3.8.1. 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, Xie, Binepal, Switzer, & Fehlings, 2013).
- For some children, increased muscle tone, spasticity or dystonia can be an important contributing factor for pain. This type of pain, often referred to as musculoskeletal pain can be localised in the back, neck, foot/ankle, shoulder, knee, hip and arm.
- 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.
- Procedural pain, procedures identified as being potentially painful and often encountered by individuals with CP include needle injections.
Furthermore, many activities of daily living such as getting dressed, being lifted and daily assisted stretching can be painful.

Dental pain, caused by difficulties in maintaining good oral hygiene or gastro-esophageal reflux (causing erosions to the dental enamel and secondary caries) needs special consideration.

(I) Pain Management

The treatment may vary depending on the cause of pain.

- The first aim is to identify the cause and effect of the pain. Pain is classified as acute or chronic pain based on its duration.
- There are several different classes of oral drugs that can be used to alleviate pain.
- Non-pharmacological treatments can be warmth including a warm bath or cold such as an ice pack. Sometimes massage can help relieve tense muscles.
- For musculoskeletal pain, regular active movement and exercise is the key to strength and will often reduce pain.

Screening for pain

> Visual analogue scale (VAS)

VAS is a measurement instrument that helps to determine pain that a patient feels ranges across a continuum from none to an extreme amount of pain. It is validated in children 10 to 18 years of age.

Visual scales can be presented in several ways, including:

- Scales with a middle point, graduations or numbers (numerical rating scales),
- Meter-shaped scales (curvilinear analogue scales),
- "Box-scales" consisting of circles equidistant from each other (one of which the subject mark), and
- Scales with descriptive terms at intervals along a line (graphic rating scales or Likert scales)

Assessor: This scale is a child report of pain and the choice of terms is specific to the type of scale (Figure 4). The screening can be carried out by an occupational therapist, physiotherapist, nurse or medical practitioner.

How: The child is asked to rate his or her current pain based on the scale; “0” being no pain and “10” being extreme or severe pain.

Time: Approximately 5 minutes

Available:  
http://www.blackwellpublishing.com/specialarticles/jcn_10_706.pdf
Paediatric Pain Profile (PPP)

PPP is an outcome tool used to provide ongoing assessment and monitoring of pain in children with neurological disorders and can be used for children 1 to 18 years of age who are unable to communicate through speech or ACC.

**Assessor:** This is an observational and parent report outcome measure of child’s behaviours which can be carried out by an occupational therapist, physiotherapist, nurse or medical practitioner.

**How:** Each of the items of the PPP can be observed by the provider and parents can answer specific questions to rate their child’s behaviors or reaction during specific activities. The PPP is a 20-item behavioural response scale with each question scored from “0” (not at all) to “3” (a great deal), except for the first two questions in which the scoring is reversed. Responses to all questions are summed to give a total score between 0 and 60. Cut-off scores are used to determine pain severity: scores of 14/60 indicate clinically significant pain and can be additionally grouped into levels of severity mild (10-19), moderate (20-29), severe (30-39) and very severe (40 or greater).

**Time:** Approximately 20 minutes


(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.

- **Medical practitioners** - carry out holistic assessment of pain to determine potential causes of pain and prescription of specific medical interventions and medications based upon individual assessment findings. Referral to medical specialist to further assess causes of pain (e.g. dentist, orthopaedics for muscle and joint pain).

- **Physiotherapists** - carry out holistic assessment of pain based on symptoms, especially potential pain related to muscles or joints. Provide positioning interventions, physical activity interventions, referral to specialised medical practitioner (e.g. dentist, orthopaedics for muscle and joint pain).

- **Occupational therapists** - carry out holistic assessment of pain based on symptoms, provide positioning interventions, physical activity interventions, referral to specialised medical practitioner (e.g. dentist, orthopaedics for muscle and joint pain).

- **Speech-Language Pathologists** - carry out holistic assessment of pain based on symptoms and make referral to specialised medical practitioner (e.g. dentist, orthopaedics for muscle and joint pain).

- **Nurses** – participate in the assessment of potential causes of pain, education and training for families on potential ways to reduce pain symptoms, referral to specialised medical practitioner (e.g. dentist, orthopaedics for muscle and joint pain).
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

3.8.2. 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

The ASQ parent questionnaire is designed to screen children for developmental delays between one month and 5½ years and includes domains for problem solving, communication, and personal-social. Questions from these sections can provide an early indication of intellectual function in the context of social engagement with others and problem-solving during developmental play. (See section on Early Detection for more information about the ASQ).

Studies have found a connection between infants who reach motor milestones at an earlier age and achievement of higher levels of education in adolescence and adulthood (Batenburg-Eddes, 2013). Early intervention consisting of a combination of developmental stimulation, including trial-and-error learning in a challenging enriched environment, and support of parent–infant interaction, may be the best means to promoting motor and cognitive development of infants at risk for CP (Hadders-Algra, Boxum, Hielkema, & Hamer, 2017).

(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:

- **Medical practitioners** - carry out early and on-going assessment of intellectual abilities and determine impact on participation in daily activities and school performance. Refer to medical, school, or therapy specialists who can further evaluate intellectual disabilities through use of appropriate assessment tools.
Physiotherapists – evaluate and provide information on the child’s ability to perform and carry out daily activities which require decision making, problem solving, and social-cognitive skills. Refer to medical or school specialist who can further evaluate intellectual disabilities through use of appropriate assessment tools.

Occupational therapists - evaluate and provide information on the child’s ability to perform and carry out daily activities which require decision making, problem solving, and social-cognitive skills. Determine impact of intellectual abilities on child’s performance of basic self-care tasks (e.g. dressing, toileting). Refer to medical or school specialist who can further evaluate intellectual disabilities through use of appropriate assessment tools.

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 or school specialist who can further evaluate intellectual disabilities through use of appropriate assessment tools.

Nurses – participate in the assessment of intellectual abilities and administration of early screening tools (e.g. ASQ parent questionnaire) to identify early intellectual disabilities. Determine impact of intellectual abilities on child’s performance of basic self-care tasks (e.g. dressing, toileting).

3.8.3. Hip Displacement and Hip Dislocation

One in three children with CP will experience hip displacement (Novak et al, 2012). Hip displacement is directly related to GMFCS level with children at GMFCS IV and V at greatest risk. If left untreated, hip displacement can progress to hip dislocation.

Progressive displacement can lead to:

- Asymmetric pressure that may deform the femoral head and or acetabulum
- Degeneration of articular cartilage
- Hip dislocation
- Pain
- Problems with limited range of movement
- Negative impact on function
- Difficulties with positioning
- Difficulties with hygiene and personal care

(Wynter et al, 2014)

Hip dislocation is preventable through early identification and intervention

(I) Management of hip displacement and hip dislocation

The gold-standard management for hip displacement is hip surveillance. Hip surveillance is the process of identifying and monitoring the critical early indicators of progressive hip displacement.
Hip surveillance includes:

- Musculoskeletal assessment
  - Passive range of motion
  - Leg length
  - Spine
  - Pelvis
- Modified Tardieu Scale (specifically hamstrings and hip adductors)
- Modified Ashworth Scale (specifically hamstrings, hip adductors and hip flexors)
- Functional Mobility Scale (FMS)
- Pain around the hip
- Anteroposterior pelvic radiograph with a measure of migration percentage (MP)

Interventions that may be prescribed as part of hip surveillance and an individual management plan include:

- Medical tone management
- Non-operative orthopaedic management including postural systems, seating and standing systems and bracing
- Orthopaedic surgical interventions including preventive, reconstructive and salvage surgery (these include both soft tissue and bony procedures)

Hip surveillance guidelines have been developed in Australia and these should be adopted for use in Vietnam.


### (II) Inter-professional team responsibilities for hip surveillance

All practitioners who work with children with CP have a responsibility to be aware of the importance of hip surveillance and check in with families regarding ongoing hip surveillance.

- **Medical practitioners** - conduct musculoskeletal assessment, arrange pelvic radiograph and measure MP, make recommendations regarding individual interventions including referral to orthopaedics and prosthetics/orthotics. Management and oversight of the hips by an orthopaedic surgeon is recommended.
- **Physiotherapists** - conduct musculoskeletal assessment, refer to medical practitioner for pelvic radiograph, implement non-operative interventions (postural systems, seating and standing systems).
- **Occupational therapists** - may assist in conducting musculoskeletal assessment, refer to medical practitioner for pelvic radiograph, implement non-operative interventions (postural systems, seating and standing systems).
- **Speech-Language pathologist** – surveillance of musculoskeletal issues in order to refer to appropriate medical practitioner for further evaluation.
- **Nurses** - may assist medical practitioner with preparing child for pelvic radiograph, supporting implementation of individual interventions.
3.8.4. Dysphagia - Eating, Drinking, and Swallowing Difficulties

One in five children with CP have difficulty controlling saliva and secretions and one in fifteen children with CP will require alternative methods for nutrition (non-oral feeders).

(I) Common signs and symptoms of dysphagia

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

(II) Dysphagia management

Screening for dysphagia and feeding problems (Arvedson, 2013)

> Clinical feeding evaluation

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:

<table>
<thead>
<tr>
<th>Question</th>
<th>Potential areas of concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>How long does it take to feed your child?</td>
<td>Meal lasting longer than 30 minutes, on any regular basis</td>
</tr>
<tr>
<td>Are meal times stressful to child or parent?</td>
<td>Yes, if one or other, or both</td>
</tr>
<tr>
<td>Is your child gaining weight adequately?</td>
<td>Lack of weight gain over 2–3 months in young child, not just weight loss</td>
</tr>
<tr>
<td>Are there signs of respiratory problems?</td>
<td>Increased congestion at meal times, ‘gurgly’ voice, respiratory illnesses</td>
</tr>
</tbody>
</table>
> Instrumental evaluation of swallowing function
Each of the following examinations provides information during a ‘brief window in time’ and does not represent eating and swallowing during a full typical meal:

- A **Videofluoroscopic Swallow Study (VFSS)** is a radiographic exam completed in a typical eating position using liquid and food textures appropriate for the patient’s age. Barium sulfate is a metallic compound that shows up on X-rays and is used to help see abnormalities in the oral cavity and oesophagus. It helps with the evaluation of oral and pharyngeal phase swallowing disorders including penetration and aspiration.

- A **flexible endoscopic evaluation of swallowing (FEES)** allows direct visualisation of some aspects of the pharyngeal phase swallow. FEES is useful in selected instances, particularly with concerns related to possible upper airway obstruction and/or vocal fold paresis or paralysis. Advantages of FEES include the absence of radiation as well as the possibility to do bedside examinations, to evaluate handling of secretions and to do sensory testing. FEES does not always delineate aspiration events.

**Interventions for dysphagia**
Develop strategies and goals in partnership with the family and child for to determine the best intervention(s) to improve eating, drinking and swallowing.

- Create 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.

- Assess how the following could change or improve eating, drinking, and swallowing behaviours:
  - Postural management and positioning when eating
  - Modifying fluid and food textures
  - Use of specialised feeding techniques, such as pacing and spoon placement
  - Use of specialised feeding equipment and utensils
  - Changes to the mealtime environment (quiet, decreased distractions)
  - Strategies to develop oral motor skills such as biting and chewing
  - Communication strategies to allow child to pace meal
  - Accommodations for visual or other sensory impairments that affect eating, drinking and swallowing
  - Training of all individuals who play a role in feeding the child at mealtime

**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.

- **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.

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.

Speech-Language Pathologists – recognise signs and symptoms of dysphagia and may assist in the clinical assessment of feeding, eating, and swallowing. Provide specific guidance on pharyngeal 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.

Nurses - recognise signs and symptoms of dysphagia and assist in the clinical assessment of feeding, eating, and swallowing.

**Recommendation** -

> Dysphagia is complex and may greatly impact overall nutrition. A thorough evaluation with input from all team members will improve diagnosis and successful intervention of feeding, eating, and swallowing disorders

### 3.8.5. Sleep Disorders

One in five children with CP will experience a sleep disorder (Novak et al, 2012).

Sleep is one of the single most important activities every person participates in. Quality sleep assists brain development as well as physical growth and development. Inadequate sleep can lead to issues such as limited growth and development, anxiety, concentration and attention difficulties, general daytime functioning difficulties and mental health issues not only for the individual with the sleep disturbance but also their family (Wiggs, 2001).

Evidence also indicates that children with CP tend to have more difficulties with initiating sleep, maintaining sleep, sleep-wake transitions and sleep breathing (Newman et al, 2006; Wayte et al, 2012). In children with CP, young children with greater physical impairment (GMFCS IV-V) are more likely to have difficulties with sleep, whilst children with CP (GMFCS I-III) are more likely to experience pain which could impact on their sleep behaviours (Wong et al, 2012).

Issues that can impact sleep:

- Issues with positioning including difficulties maintaining postural position and alignment and comfort during rest times and sleep times
- Issues with respiration/ aspiration including difficulties with saliva management can impact on safe breathing and respiration during sleep
- Medical issues including vision impairments, seizures, sweating, jerks, incontinence, and waking affecting sleep
- Mental health can also have a significant impact on their sleep/wake cycle
- Inconsistent sleep behaviours and routines
- Pain

(I) Management of sleep disorders
Sleep disorders are complex making management difficult.

> Screening for sleep disturbances
Can be conducted using the Sleep Disturbance Scale for Children (SDSC). The SDSC is a 27-item inventory rated on a 5 point Likert-type scale. The instrument’s purpose is to categorise sleep disorders in children. As well as giving an overall score the instrument uses five subdomains: disorders of initiating and maintaining sleep, sleep breathing disorders, disorders of arousal, sleep-wake transition disorders, disorders of excessive somnolence, and sleep hyperhidrosis.

Administration
Assessor: This screening questionnaire is a parent-report questionnaire which can be carried out by an occupational therapist, physiotherapist, nurse or medical practitioner. How: The questionnaire can be given to a parent to complete independently or discussed as a semi-structured interview. The clinician should be responsible for calculating the scores and the information shared with the child’s medical practitioner. Time: Approximately 10-15 minutes
Available: http://www.midss.org/content/sleep-disturbance-scale-children-sdsc

> Assessment of sleep issues
A comprehensive sleep assessment should be considered which involves assessment of all the levels of the International Classification of Functioning and Disability Framework (ICF). Assessment of sleep issues should include a sleep diary which is completed by the family over the preceding week. This helps to identify trends in sleep patterns and possible causes of sleep issues.

> Interventions for sleep issues
Interventions will be dependent upon the identified issue or hypothesised cause of the sleep issue.

>> Positioning interventions
Consider night time positioning supports/equipment to support a client’s sleep position to promote postural alignment, or to manage client safety during sleep. Assessment and positioning interventions for sleep should be conducted in a child’s home environment.
Sleep positioning equipment should not be used in the following situations:
- When the client is unable to tolerate positioning equipment
- When the client’s need for positioning equipment is minimal
- When positioning equipment reduces the overall quality and length of sleep for an individual or their family or carers
- When the sleep system is being used as a restraint

>> Medical interventions:
Medical interventions may be introduced for the following reasons:
- To assist with pain management
- To help manage respiration/aspiration issues (e.g. introduction of a CPAP machine)
- To assist with skeletal alignment

Medications may be prescribed to:
- Manage pain or movement disorders
- To promote sleep/wake cycle e.g. melatonin
- Manage aspiration issues during sleep/rest times

>> Behaviour and sleep hygiene interventions:
- Psychoeducation - provides information on the environmental, physiological and behavioural factors and habits that promote sound sleep such as a better understanding of sleep, sleep stages, the circadian rhythm and healthy sleep practices
- Behavioural Interventions - includes techniques such as sleep training methods, cued crying, sleep/bed restrictions, and relaxation

>> Pain interventions:
- Medical interventions including pain medication and tone management interventions including baclofen and botulinum toxin-A injections can provide symptomatic relief of pain
- Physical activity can assist with managing chronic pain and should be encouraged under the principles of pacing and graded exposure. Physical activity programs should incorporate an educational component to help individuals understand their pain

(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 hygiene routines and behaviours, referral to medical practitioner.
- **Nurses** - behaviour and sleep hygiene interventions, referral to medical practitioner.

### 3.8.6. Epilepsy

One in four children with CP will be diagnosed with epilepsy. The seizure activity will resolve for 10-20% of children. Seizures are a fundamental part of an epilepsy diagnosis and are a symptom of abnormal brain function. Seizure classification depends on whether the seizure originates in a specific part of the brain (partial or focal) or involves both hemispheres from onset (generalised seizures). The international classification of seizures also includes a third category, unclassified seizures, for cases where sufficient evidence is lacking to categorise as partial or generalised. Epilepsy can have serious consequences on overall health (e.g. increased risk of unexpected falls, episodes of unconsciousness) and participation in daily life activities. Mortality rate for those diagnosed with epilepsy is 2-3 times that of the general population (Mac, et al., 2008; Zouganeli et al, 2016)

#### (I) Signs and symptoms of potential seizure activity
- “Blackouts” or sudden lack of consciousness, “dazed” behaviour, memory gaps, with no response to sensory stimuli
- Sudden and repeated falls, frequent stumbling or unusual clumsiness
- Repeated, unusual movements such as head nodding or rapid blinking
- Sudden stomach pain followed by confusion and sleepiness
- Unusual sleepiness and unexplained irritability when woken up
- Frequent complaints that things look, sound, taste, smell or feel "funny"
- Clusters of (repeated) and unexplained "jackknife" movements by infants who are sitting down

#### (II) Diagnosis of epilepsy

Diagnostic work-up for seizure activity requires access to neuroimaging (Computerised tomography - CT scans) and electroencephalogram (EEG).

#### (III) Treatment of epilepsy

Seizure activity is managed through pharmacological therapy, surgery, and diet to achieve seizure control:
- **Anti-epileptic drugs (AEDs)** are medications such as phenobarbital, phenytoin, carbamazepine, or diazepam. Per the Ministry of Health (MoH) and national programme for treatment of epilepsy, phenobarbital and phenytoin are provided free of charge to patients with epilepsy. Patient’s must have regular and frequent visits to their physician
for on-going medication management of seizures. The newer generation of medications may or may not be covered by the MoH (Mac et al., 2008).

- **Epilepsy surgery** is most commonly recommended when tests show that the seizure activity originates in a small, well-defined area of the brain that doesn't interfere with vital functions such as speech, language, motor function, vision or hearing. The surgery requires removal of the area of the brain where the seizure activity originates (subpial transections).

- **Ketogenic diet** is a high-fat, adequate-protein, low-carbohydrate diet that is used primarily to treat difficult-to-control (refractory) epilepsy. The diet forces the body to burn fats rather than carbohydrates. When there is very little carbohydrate in the diet, the liver converts fat into fatty acids and ketone bodies. The ketone bodies pass into the brain and replace glucose as an energy source. An elevated level of ketone bodies in the blood, a state known as ketosis, leads to a reduction in the frequency of epileptic seizures (Zouganeli et al, 2016).

(IV) **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.

- **Medical practitioners** - carry out holistic assessment of epilepsy and including referral for diagnostic exams such as EEG and CT scans. Prescribe appropriate seizure medication and monitor effects and benefits of medication over time. Consider alternatives to medications including epilepsy surgery and ketogenic diet.

- **Physiotherapists** – understand the signs and symptoms of seizures and monitor prevalence and duration of seizures, especially during therapy sessions. Make recommendations for safe positioning of child during active seizure. Referral to medical practitioner.

- **Occupational therapists** - understand the signs and symptoms of seizures and monitor prevalence and duration of seizures, especially during therapy sessions. Make recommendations for safe positioning of child during active seizure. Referral to medical practitioner.

- **Speech-Language pathologist** - understand the signs and symptoms of seizures, especially during therapy sessions. Support to families through education, referral to medical practitioner.

- **Nurses** – understand the signs and symptoms of seizures, support to families through education, referral to medical practitioner.

3.8.7. **Vision Impairment**
One in ten children with CP will have a visual impairment. Children with CP may be diagnosed with visual deficits that are of ocular or cerebral origin, or a combination of both (Denver et al, 2016; Ferzinger et al, 2011).
Visual impairments that result from damage to the brain may be referred to as cortical, cerebral, or neurological visual impairment. The visual abilities of a child with CP may be impacted by impairments at any point along the primary visual pathway (eye, optic nerves, thalami, optic radiations, and primary visual cortices), in the visual association areas, or the oculomotor system (Denver et al., 2016).

The causes of visual impairment in children with CP may include, but are not limited to, retinopathy of prematurity, congenital cataract, and cortical/cerebral visual impairment (CVI) (Denver et al., 2016).

Other visual impairments included refractive errors, myopia, permetropia, astigmatism, and strabismus, in addition to the reporting of children with ‘some impairment’ or ‘functional blindness’ (Denver et al, 2016).

Children with CP can also have a visual processing disorder which is a reduced ability to interpret information registered through the visual system (Ferzinger et al., 2011; McCullough et al., 2007).

(I) Clinical signs of visual dysfunction
- Complaints of severe, sudden eye pain
- Complaints of blurred or double vision
- Deconjugate eye gaze and poor eye teaming
- Decreased attention to tasks requiring sustained vision
- Easily distracted in busy visual environments at home and school
- Delays in the development of skills requiring vision (i.e. letter recognition, reading, writing)
- Unusually clumsy and frequently bumps into people and objects

(II) Screening for visual impairment
> Ophthalmological examination which focuses on visual acuity, refractive state of the eyes, ocular health, and, visual field assessments.

> Behavioural examination of functional vision focuses on how a child uses visual skills to complete everyday activities. This can include parent report of any difficulties the child is having when using vision during functional tasks.

(III) Assessment specific to visual impairments
> The CVI Questionnaire screens for or cortical visual impairment in children suspected of CVI (Ortibus et al, 2011).

Assessor: The CVI Questionnaire is a parent-report questionnaire which can be carried out by an occupational therapist, physiotherapist, nurse or medical practitioner.
How: The 47 questions can be given to a parent to complete independently or discussed as a semi-structured interview. CVI characteristics are rated as present/not present. The clinician should be responsible for calculating the sum scores and the information shared with the child’s medical practitioner.
> **Functional Visual Questionnaire** assesses daily visual performance in children with CP who are difficult to assess due to severe motor, cognitive, and communication impairments (Ferziger et al., 2011).

**Assessor:** The Functional Visual Questionnaire is a parent or teacher-report measure which can be carried out by an occupational therapist, physiotherapist, nurse or medical practitioner.

**How:** This 26-item questionnaire is divided into two sections. Section 1 (questions 1–12) is a general assessment of the participant’s use of visual motor skills in a classroom setting, in both regular- and low-light environments. Section 2 (questions 13–26) assesses the child’s visual skills in the following areas of function: communication, ADL, play and leisure, and mobility and orientation. The questionnaire can be given to a parent or teacher to complete independently or discussed as a semi-structured interview following a 2-week observation period and before the ophthalmological examination. Each question is rated on a 5-point ordinal scale reflecting the degree of performance from poor to very good. The clinician should be responsible for calculating the sum scores and the information shared with the child’s medical practitioner.

**Time:** Approximately 20 minutes


> **The Visual Skills Inventory (VSI)** evaluates visual skills and responses to familiar situations in children with neurological impairments (McCullough et al., 2007).

**Assessor:** The VSI is a parent-report measure which can be provided to the caregivers by an occupational therapist, physiotherapist, nurse or medical practitioner

**How:** This parent-report questionnaire has 22 questions which are scored yes/no for visual behaviours; additional scores for some items (e.g. distance for vision from 6 feet to <1 foot). The clinician should be responsible for reviewing the answers to the questionnaire and sharing information with the child’s medical practitioner.

**Time:** Approximately 10 minutes


(IV) **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.

**Medical practitioners** - carry out holistic assessment of visual skills and make appropriate referrals to specialist who can complete ophthalmological examination. Refer to low vision specialists and other therapists for training on functional use of visual skills.
Physiotherapists – understand the signs and symptoms of visual impairment, especially during functional movement and mobility. Complete functional visual assessments and administer appropriate parent questionnaires. Referral to medical practitioner.

Occupational therapists - understand the signs and symptoms of visual impairment, especially during activities of daily living, play, and school tasks. Complete functional visual assessments and administer appropriate parent questionnaires. Referral to medical practitioner.

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.

Nurses – understand the signs and symptoms of visual impairment and provide education for parents on identification of visual impairments over the lifespan. Complete functional visual assessments and administer appropriate parent questionnaires. Referral to medical practitioner.

Recommendation -

> Visual impairments can impact participation in home and school activities. Children should be screened early in life for visual impairments in order to initiate early therapy services which may impact overall visual processing abilities

3.8.8. Hearing Impairment

One in twenty-five children with CP will have a hearing impairment. The exact pathophysiological mechanisms for hearing loss remain unclear, but it is likely that hyperbilirubinemia, hypoxia, infection, and use of ototoxic drugs may all play a role (Marlow, Hunt, & Marlow, 2007).

- **Sensorineural Hearing Loss** – This type of hearing loss results from damage to the neural receptors of the inner ear, the nervous pathways to the brain, or the area of the brain that receives auditory stimuli. Hearing loss of this type can be congenital or acquired. Higher pitched or faint noises are often difficult to hear and children can also present with poor balance and reports of dizziness (Sano, Kaga, Kitazumi, & Kodama, 2005).

- **Conductive Hearing Loss** – This type of hearing loss affects the structures of the outer and middle ear. Conduction of sound through the outer and middle ear is disrupted, affecting hearing before the sound reaches the cochlea and the nerve receptors of the inner ear. Severe cases can be caused by malformation of the ear canal in utero (Reid, Modak, Berkowitz, & Reddihough, 2011).

- **Mixed hearing loss** occurs when symptoms of both types of hearing loss are present (Sano, Kaga, Kitazumi, & Kodama, 2005).

- 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, Modak, Berkowitz, & Reddihough, 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, Kaga, Kitazumi, & Kodama, 2005; Reid, Modak, Berkowitz, & Reddihough, 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.

- **Medical practitioners** - carry out holistic assessment of hearing abilities and make appropriate referrals to specialist who can complete behavioural and physiological audiological examinations. Refer to audiology and hearing specialists and other therapists training to compensate for hearing loss.
- **Physiotherapists** – understand the signs and symptoms of hearing impairments, especially during functional movement and mobility. Assessment of impact of hearing impairment on balance. Referral to medical practitioner.
- **Occupational therapists** - understand the signs and symptoms of hearing impairments, especially during activities of daily living, play, and school tasks. Referral to medical practitioner.
- **Speech-Language Pathologists** – understand the signs and symptoms of hearing impairments, especially impact on expressive and receptive language skills and functional communication. Referral to medical practitioner.
- **Nurses** – understand the signs and symptoms of hearing impairments and provide education for parents on identification of hearing impairments over the lifespan. Referral to medical practitioner.
**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.

### 3.8.9. 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).

Behavioural problems are more likely in children with CP who have:
- An intellectual disability
- Epilepsy (these children are also more likely to have an intellectual impairment)
- Severe pain

Children with CP and milder physical disability are more likely to have behavioural problems than children with severe physical disability.

Thorough assessment of behaviour is recommended. The assessment should involve:

> **Defining the behaviour**
  - What is it?

> **Analysing the behaviour**
  - Where is this behaviour happening?
  - Where is it not happening?
  - How often is the behaviour occurring?
  - Who is around when it occurs?
  - What tends to happen right before and right after the behaviour?
  - What is a more acceptable behaviour that can be used as a replacement?

An ABC chart is a tool that’s frequently used in this step. A stands for Antecedent (what happens before), B is for Behaviour (the action or reaction), and C is for Consequence (what happens after).

> **Hypothesise reasons for the behaviour**
  - Try to determine what the individual is escaping, avoiding or getting from the behaviour.
  - A pain assessment is also essential in the presence of behavioural problems, even for children with mild physical impairments. Pain control may remediate or minimise the behavioural problem.
  - Standard psychometric IQ assessment is also recommended in the presence of behavioural problems to enable the family to understand the prognosis of the behavioural problem.
Consider communication difficulties in relation to behaviour - frustration related to communication difficulties (particularly in children who are non-verbal) may be a driver behind certain behaviours.

(I) Management of behaviour disorders

Behaviour therapy
Positive behaviour support, behavioural interventions, and positive parenting are approaches that involve carers’ changing their interaction style with the child to promote positive adaptive behaviours in the child.

Cognitive behaviour therapy
Cognitive-behavioural therapy is an approach that involves identifying unhelpful thoughts and behaviours and teaching cognitive restructuring and self-management of constructive thinking and actions. The child actively participates in cognitive-behaviour therapy.

(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. All practitioners should check in with families regarding any concerns about behaviour.

- **Medical practitioners** - medical interventions to manage pain, carry out IQ assessments, referral to psychologist (if available).
- **Physiotherapists** - carry out behaviour assessments to help identify triggers, implement positive behaviour support strategies, referral to psychologist (if available), referral to medical practitioner.
- **Occupational therapists** - carry out behaviour assessments to help identify triggers, implement positive behaviour support strategies, referral to psychologist (if available), referral to medical practitioner.
- **Speech-Language pathologists** - carry out behaviour assessments to help identify triggers which may impact functional communication skills. Implement positive behaviour support strategies, referral to psychologist (if available), referral to medical practitioner.
- **Nurses** – support families with implementing behaviour plans, referral to medical practitioner.
- **Psychologists** – (if available) carry out IQ assessments, carry out behaviour assessments, implement full range of behaviour interventions including behaviour management plans.

Recommendation -
> Behaviour management can be complex. Psychologists and Behaviour Specialists are experts in supporting children and families with behaviours of concern. Rehabilitation departments would benefit from building their capabilities to respond to issues relating to behaviour management with the appropriate staffing.
3.8.10. 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.

- Medical practitioners – medical investigations, prescription of incontinence aids.
- Physiotherapists – support families with toilet training as appropriate, referral to medical practitioner.
- Occupational therapists – support families with toilet training as appropriate, referral to medical practitioner.
- Speech-Language pathologists – support families with toilet training as appropriate, referral to medical practitioner.
- Nurses – support families with toilet training as appropriate, referral to medical practitioner.
3.8.11. 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**

One of the most common surgical interventions for the treatment of GERD. 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, Koh, & Soo Lee, 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.
- **Physiotherapists** – understand the signs and symptoms of reflux and evaluation of positioning after mealtime which may reduce the incidence of reflux episodes. Referral to medical practitioner.
- **Occupational therapists** – understand the signs and symptoms of reflux and evaluation of mealtime behaviours and feeding interventions which may reduce the incidence of reflux episodes. Referral to medical practitioner.
- **Speech-Language pathologists** – understand the signs and symptoms of reflux and evaluation of mealtime behaviours and feeding interventions which may reduce the incidence of reflux episodes. Referral to medical practitioner.
- **Nurses** – understand the signs and symptoms of reflux and provide education for parents on signs of reflux, possible medical evaluations, and surgical interventions. Referral to medical practitioner.

**3.8.12. Constipation**

Chronic constipation is a common problem in children with CP. Chronic constipation is defined as a frequency of stool numbers less than 3 per week, or the need to use laxatives frequently to make stool (Sullivan, 2008). The prevalence of constipation in children with CP has been reported to be between 25 and over 75% (Giudice et al., 1999; Jiménez, Martin, García, & Treviño, 2010; Sullivan, 2008).

- There are multiple factors which may cause constipation including alterations in bowel motility associated with neurological lesions that affect the entire colon.
- Studies have shown proximal colon hypomotility in patients with constipation (Giudice et al., 1999; Park, Park, Cho, Na & Cho, 2004).
- Other factors that influence constipation are prolonged immobility, skeletal abnormalities, scoliosis, generalized hypotonia, dietary factors such as low fiber or liquid intake, and the use of anti-epileptic drugs (Jiménez, Martin, García, & Treviño, 2010; Sullivan, 2008).
- Chronic constipation can greatly impact overall quality of life and is associated with recurrent urinary tract infections and digestive disorders such as recurrent vomiting, early satiety, malnutrition, and chronic abdominal pain (Jiménez, Martin, García, & Treviño, 2010).

(I) Assessment of constipation
Clinical assessment should include a detailed history of feeding behaviours and bowel movements. Evaluation of colonic motility can also be measured through radiographic studies including abdominal x-ray and measure of colonic transit times.

Clinical signs of constipation
- Chronic nausea
- Anorexia
- Recurrent vomiting
- Chronic or recurrent abdominal pain
- Frequent urinary tract infections
- Incomplete voiding (defecation)
- Worsening episodes of reflux
- Infrequent history of voiding (defecation)
- Presence of hard stools palpable through the abdomen may suggest impaction

Radiographic studies
- Abdominal x-ray – can assess the degree of faecal loading and any spinal deformities which affect motility.
- Colonic Transit Times – use of radio-opaque markers (ingested/swallowed) can be viewed on x-ray to detect delayed or prolonged colonic transit times. Stimulant laxative should be considered in children with significantly delayed or prolonged transit times.

(II) Management of constipation
- Encourage foods that contain fibre. Soluble fibres found in fruits, vegetables and oats are the best source of fibre in the management or prevention of constipation. Encourage some of the following high-fibre foods on a daily basis:
  - Wholegrain cereals (e.g. porridge, wheat biscuits)
  - Whole meal pasta and rice (may be eaten whole or ground)
  - Fresh, stewed or canned fruits
  - All vegetables – raw, cooked, mashed or pureed (leave the skin on)
  - Baked beans, lentils, dried peas and beans
- Encourage a good intake of fluid.
  - Pear juice or prune juice may help with relieving constipation.
  - Good sources of fluid include: water, milk, juice, formula, ice, ice-blocks, jelly, yoghurt, custard, ice cream.
- Increase activity and limit periods of inactive sitting time
- Assist or encourage changes in body positions regularly to include lying in different positions, sitting and standing.
  - Stay on regular toileting program
    - Maintain a regular toileting schedule that includes sufficient time for child to sit on the toilet (up to 10 minutes).
    - For many children, the bowel is activated by eating or sitting in water. 15 minutes after a meal or straight after the bath can be a good time to encourage toileting.
    - Assure child is seated on a toilet with an appropriate sized seat and feet supported (e.g. on a small step or stool).

(III) 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.

- **Medical practitioners** – carry out holistic assessment of constipation and overall nutritional status and make appropriate referrals for further medical evaluation of constipation through radiographic studies. Prescribe appropriate medications if child has delayed or prolonged colonic transit times. Referral to therapists for further evaluation of overall mealt ime behaviours and causes of constipation.
- **Physiotherapists** – understand the signs and symptoms of constipation and determine frequency of positional changes which may reduce the incidence of constipation. Referral to medical practitioner.
- **Occupational therapists** – understand the signs and symptoms of constipation and evaluation of mealt ime behaviours and positional interventions which may reduce the incidence of constipation. Assist family with development of toileting routines. Referral to medical practitioner.
- **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.
- **Nurses** – understand the signs and symptoms of constipation and provide education for parents on signs of constipation possible medical evaluations and treatments. Referral to medical practitioner.

3.8.13. Osteoporosis
Children with CP are at risk for fragility fractures (osteoporosis) secondary to osteopenia from decreased weight-bearing. Osteopenia paired with trauma (e.g. falls) can lead to painful fragility fractures. Individuals with CP who are non-ambulatory have a 20% chance of having a fragility fracture. Frequently these involve the shaft of the long bones such as the distal femur (AACPDM, 2016).
The following are independent risk factors for low bone mineral density in children and young people with CP:

- Non-ambulant (GMFCS level IV or V)
- Vitamin D deficiency
- Presence of eating, drinking and swallowing difficulties or concerns about nutritional status
- Low weight for age (below the 2nd centile)
- History of low-impact fracture
- Use of anticonvulsant medication

(NICE, 2017)

(I) **Management of osteoporosis:**

**Prevention**
Inform children and young people with CP and their parents or carers if they are at an increased risk of low-impact fractures.

If a child and young person with CP has one or more risk factors for low bone mineral density:

- Assess their dietary intake of calcium and vitamin D and
- Consider the following laboratory investigations of calcium and vitamin D status:
  - Serum calcium, phosphate and alkaline phosphatase
  - Serum vitamin D
  - Urinary calcium/creatinine ratio

Create an individualised care plan for children and young people with CP who have one or more risk factors for low bone mineral density.

Consider the following as possible interventions to reduce the risk of reduced bone mineral density and low-impact fractures:

- An active movement programme
- Active weight bearing
- Dietetic interventions as appropriate, including nutritional support and calcium and vitamin D supplementation
- Minimising risks associated with movement and handling

**Treatment of fragility fractures**
If an individual with CP has a fragility fracture order additional investigations. These can include blood work (Ca, Phosphate, Parathyroid Hormone), an X-ray of the fracture site, and a DEXA scan to determine bone mineral density.

Ensure adequate nutrition, Ca and Vit D status. Consult with a paediatric orthopaedic surgeon for fracture management.
Bisphosphonates should also be considered in children although the long-term safety on growing bones is unknown. Bisphosphonates help to build bone density by suppressing bone resorption. Consultation with a bone specialist (endocrinologist, orthopaedic surgeon, physician with special interest in bone health) is recommended. In children, bisphosphonates are typically given intravenously three to four times per year rather than orally.

**II) Inter-professional team responsibilities for managing osteoporosis**

All practitioners who work with children with CP have a responsibility to be aware of the risk factors for osteoporosis and fragility fractures among children with CP and be able to support families with prognostic messaging.

- **Medical practitioners** – medical investigations, dietetic interventions, bisphosphonate therapy, referral to specialists.
- **Physiotherapists** – active movement and weight bearing programs, prescription and implementation of AAT for standing, parent/carer education regarding manual handling and transfers, referral to medical practitioner.
- **Occupational therapists** – active movement and weight bearing programs, prescription and implementation of AAT for standing, play, and daily activities, parent/caregiver education regarding manual handling and transfers, referral to medical practitioner.
- **Speech-Language pathologists** – assist with recommendations of AAT for standing, play, and daily activities as related to functional communication, referral to medical practitioner.
- **Nurses** – support families with information, support implementation of prescribed dietetic interventions, referral to medical practitioner.

### 3.8.14. Secondary Musculoskeletal Conditions

It is well established that children with CP experience progressive neuromusculoskeletal pathology which includes muscle shortening and contractures, bony torsion (particularly of long bones), joint instability and premature degenerative arthritis (Graham and Selber, 2003).

Four in five children with CP have contracture and children with spasticity are most at risk (Novak, 2014).

One in three children with CP have hip displacement and one in ten have hip dislocation without hip surveillance (Novak et al, 2012).

Severity of physical disability is associated with increased risk of hip abnormalities and associated spinal deformity (Novak et al, 2012).

Common musculoskeletal conditions seen in children with CP include:

- Hip deformities
- Spinal deformities
  - Scoliosis
- Kyphosis
- Lordosis
- Femoral anteversion
- Tibial torsion
- Joint instability
  - Hip subluxation
  - Mid-foot break
- Contractures
  - Hip adductors, hip flexors, hamstrings, gastrocnemius and soleus
  - Shoulder adductors, elbow flexors, wrist flexors, finger flexors
- Joint degeneration

Additional disorders include spinal cord compression and cervical myelopathy which typically present in adulthood and are due to degenerative changes in the spine. Individuals with dystonia are more at risk of these conditions.

Assessment of musculoskeletal conditions involves conducting both body structure and function assessments and activity and participation assessments to determine the goal limiting issues and identify appropriate intervention options. The following algorithm for musculoskeletal management in children and adolescents with CP has been proposed (Thomason et al, 2014).

Figure 5. Algorithm for musculoskeletal management in children and adolescents with CP
(I) Management of musculoskeletal conditions

Ankle-foot orthoses
Ankle-foot orthoses are an approach where a removable external device is worn over the ankle and foot designed to prevent or manage ankle contractures.

Casting
Casting is an approach, where plaster casts are applied to limbs in a stretched position to induce muscle lengthening. The amount of lengthening possible is substantially less than in a surgical approach and is best used in new contractures.

Hand splint/orthoses
Immobilisation hand splinting is an approach that uses custom-moulded thermoplastic or neoprene hand orthoses designed to hold the hand in a position of stretch to prevent or manage contractures.

Positioning
Positioning to promote or maintain musculoskeletal alignment is frequently used for children with CP. Positioning includes the use of standing frames, posture chairs, supine and prone positioning and positioning for sleep.

Orthopaedic surgery
Orthopaedic surgery is an approach involving surgical prevention or correction of musculoskeletal deformities, eg, muscle lengthening, tendon transfer, osteotomies. Upper limb, lower limb and spinal procedures are common in CP.

Single-event multilevel surgery
Single-event multilevel surgery is a specific orthopaedic surgery where a series of simultaneous orthopaedic procedures are carried out to manage contractures, optimise skeletal alignment, and prevent ambulation deterioration or postural deterioration secondary to musculoskeletal deformities. The advantage of this surgical approach is that multiple surgeries are avoided and outcomes are superior.

Recommendation -
> 3D gait analysis is part of the gold-standard assessment protocol to assist with decision making around orthopaedic surgery for ambulant children with CP. Where 3D gait analysis is not available, a thorough assessment comprised of 2D gait analysis, range of motion, muscle tone and spasticity and FMS and collaborative goal setting should be standard

Further detail relating to orthoses and casting will be outlined in the technical guidelines for Physiotherapy and Occupational Therapy.
Further detail relating to orthopaedic surgery has to be retrieved from relevant technical guidelines for Medical Practitioners.

(II) Inter-professional team responsibilities for managing musculoskeletal conditions

All practitioners who work with children with CP have a responsibility to be aware of the risk factors for secondary musculoskeletal conditions among children with CP and the progression of these conditions. All practitioners should be able to support families with prognostic messaging.

- **Medical practitioners** – medical investigations including x-ray, hip surveillance (see 6.3), referral to 3D gait analysis (if available), spasticity management (see 5.1), orthopaedic surgery, prescription of splints/orthoses, referral to specialists.

- **Physiotherapists** – physical assessments (range of motion, muscle tone), hip surveillance (see 6.3), casting interventions to increase muscle length, prescription and implementation of splints and orthoses, prescription and implementation of positioning devices and programs, child-active interventions to maximise functional abilities (including post-surgery), parent/carer education regarding musculoskeletal conditions, referral to medical practitioner.

- **Occupational therapists** – physical assessments (range of motion, muscle tone), hip surveillance (see 6.3), casting interventions to increase muscle length, prescription and implementation of splints and orthoses, prescription and implementation of positioning devices and programs, child-active interventions to maximise functional abilities (including post-surgery), parent/carer education regarding musculoskeletal conditions, referral to medical practitioner.

- **Speech-Language pathologists** – support families with information related to management of musculoskeletal conditions, referral to medical practitioner.

- **Nurses** – support families with information, support inpatient stay pre/post-surgical interventions, referral to medical practitioner.

### 3.9. 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.
3.9.1. Gait and Functional Decline

(I) Adolescence

Projections of motor function for children and adolescents with CP have been well documented. Gross motor curves for CP show the average rate of gross motor skill acquisition for children across the GMFCS levels. It shows a projected stability for GMFCS I-II and the average decline for GMFCS III-V, with decline occurring as early as 7 or 8 years of age. This trend is often referred to as the ‘natural history of CP’ (Hanna et al, 2009)

A small number of studies have looked at the stability of the GMFCS in adults over the age of 21 (Jahnsen, 2006; McCormick, 2007). These report functional decline even amongst GMFCS I and II, with fatigue, balance problems, fear of falling and chronic musculoskeletal pain among the reasons for changes in GMFCS level.

Prognosis of walking function

- A child’s walking ability at age 12 years is predictive of their walking ability as an adult
- Children who walk using aids or cannot walk lose walking function during adolescence
- Ability to walk further declines during later adulthood

Recommendations -

> Children who walk using aids and their families should be emotionally prepared for potential loss of motor function in adolescence
> Children who walk using aids require mobility assessments at the commencement of adolescence to enable prescription of appropriate mobility devices to accommodate declining motor function

(II) Adulthood

25% or more of adults with CP experience deterioration in gait and walking function. Those most at risk are adults classified GMFCS III and adults with bilateral CP.

Gait deterioration occurs at an earlier age for adults with CP compared with adults without a disability. Deterioration is strongly associated with inactivity with a lower risk of deterioration found amongst adults who engaged in regular physical activity. Age, increased pain, increased
fatigue, decreased balance and lack of opportunity to participate in adapted physical activity were also associated with gait decline (Morgan & McGinley, 2013).

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.

(III) 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.

**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
- Provide a named worker to facilitate timely and effective transition, and recognise the importance of continuity of care

3.10. 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 – page [23]*)

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.

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**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.

Chorea – A motor type of CP which presents as ongoing random-appearing sequence of one or more discrete involuntary movements or movement fragments.

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).

Contracture - a condition of shortening and hardening of muscles, tendons, or other tissue, often leading to deformity and rigidity of joints.

Cortical Visual Impairment (CVI) - defined as a bilateral loss of central visual function
(visual acuity) caused by neurological damage to the visual cortex and/or visual pathway structures. It most commonly results from hypoxic ischaemia causing periventricular leukomalacia in the preterm infant.

**CT** - A CT scan combines a series of X-ray images taken from different angles and uses computer processing to create cross-sectional images, or slices, of the brain. A CT scan may detect abnormalities in brain structures.

**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.

**EEG** - An EEG is a test that detects electrical activity in the brain using electrodes attached to the child’s scalp. The electrodes measure electrical impulses of the brain even when the child is asleep. This brain activity is displayed in an EEG recording.

**Equinus** - tightness in the calf and Achilles tendon which limits dorsiflexion (toes to shin) of the ankle.

**Foot drop** - is a gait abnormality in which the dropping of the forefoot happens due to muscular weakness.

**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.
**Gross Motor Functional Classification Scale (GMFCS)** – A classification system based on self-initiated movement, with emphasis on sitting, transfers, and mobility. A five-level classification system with distinctions based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement.

**Gross Motor Function Measure (GMFM)** – a clinical tool designed to evaluate change in gross motor function in children with CP. There are two versions of the GMFM - the original 88-item measure (GMFM-88) and the more recent 66-item GMFM (GMFM-66). Items on the GMFM-88 span the spectrum from activities in lying and rolling up to walking, running and jumping skills. The GMFM-66 is comprised of a subset of the 88 items identified (through Rasch analysis) as contributing to the measure of gross motor function in children with CP.

**Hypoxic Ischaemic Encephalopathy (HIE)** – brain injury caused by oxygen deprivation to the brain, also commonly known as intrapartum asphyxia.

**Hammersmith Infant Neurological Exam (HINE)** - a neurological assessment for infants between 2 and 24 months of age that includes items for cranial nerve function, posture, movements, tone and reflexes. It can be reliably used to assess infants at neurological risk, both preterm and term born. The HINE identifies early signs of CP in infants with neonatal brain lesions.

**Hip dislocation** – a hip dislocation occurs when the head of the femur comes out of the acetabulum in the pelvis

**Hip displacement** – a hip displacement occurs when head of the femurs migrates, or moves, out of acetabulum in the pelvis

**Hyperhydrosis** - a condition characterised by abnormally increased sweating, in excess of that required for regulation of body temperature.

**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.

**Likert scale** – a widely used scale for patient responses which provides choice of five to seven pre-coded responses with the neutral point being neither agree nor disagree. It is used to allow the individual to express how much they agree or disagree with a particular statement.
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.

Migration percentage – a commonly used measure for subluxation (dysplasia) of the hip.

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.

Quality of Upper Extremity Skills Test (QUEST) - an outcome measure that evaluates movement patterns and hand function in children with CP. The four domains evaluated by the QUEST include: dissociated movement, grasp, protective extension, and weight bearing.

Recurvatum - Genu recurvatum is a deformity in the knee joint, so that the knee has excessive backwards motion. In this deformity, excessive extension occurs in the tibiofemoral joint.

Scoliosis - abnormal lateral curvature of the spine.

Spasticity - 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.

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


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.

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