

Management Of Cerebral Palsy In Children: A Guide For Allied Health Professionals

Summary The Management of Cerebral Palsy in Children - A Guide for Allied Health Professionals Guideline provides information to support clinical decision making of allied health professionals for the management of children with cerebral palsy.

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MANAGEMENT OF CEREBRAL PALSY IN CHILDREN - A GUIDE FOR ALLIED HEALTH PROFESSIONALS

PURPOSE

Management of Cerebral Palsy in Children - A Guide for Allied Health Professionals provides recommendations, information and guidance to support the clinical decision making of allied health professionals regarding the management of children with cerebral palsy. The guideline was prepared for the NSW Ministry of Health by an expert clinical reference group and is aimed at achieving the best possible paediatric care in all parts of the state.

KEY PRINCIPLES

The guideline reflects what is currently regarded as a safe and appropriate approach to the management of children with cerebral palsy. However, as in any clinical situation there may be factors which cannot be covered by a single set of guidelines. This document should be used as a guide, rather than as a complete authoritative statement of procedures to be followed in respect of each individual presentation. **It does not replace the need for the application of clinical judgement to each individual presentation.**

As in any clinical situation and due to the heterogeneous nature of cerebral palsy, there are factors that cannot be covered by a single guide. Clinicians and clients need to develop individual treatment plans that are tailored to the specific needs and circumstances of the client. This guideline should be read in conjunction with other relevant guidelines, position papers, codes of conduct, and policies and procedures, at professional, organisational and Local Health District levels.

USE OF THE GUIDELINE

Chief Executives must ensure:

- This guideline is adopted or local protocols are developed based on *Management of Cerebral Palsy in Children - A Guide for Allied Health Professionals*
- Local protocols are in place in all hospitals and facilities likely to be required to care for children with cerebral palsy
- Ensure that all staff treating paediatric patients are educated and supported in the use of the locally developed paediatric protocols.

Directors of Clinical Governance are required to inform relevant clinical staff treating paediatric patients of this revised guideline.

REVISION HISTORY

Version	Approved by	Amendment notes
March 2018 (GL2018_006)	Deputy Secretary, Strategy and Resources	New guideline.

ATTACHMENTS

1. Management of Cerebral Palsy in Children - A Guide for Allied Health Professionals: Guideline.

MANAGEMENT OF CEREBRAL PALSY IN CHILDREN

A guide for allied health professionals



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MANAGEMENT OF CEREBRAL PALSY IN CHILDREN



INTRODUCTION

1. INTRODUCTION

1.1 PURPOSE

The purpose of this guide is to provide support for allied health professionals in the assessment and management of children diagnosed with cerebral palsy (CP). This guide aims to support individuals with cerebral palsy to achieve their goals and to improve their participation in everyday activities and quality of life by providing clinicians with evidenced-based information about assessment and treatment options.

1.2 DEVELOPMENT OF THE GUIDE

The guide was initiated in response to survey results obtained from NSW Health allied health professionals who work with children, requesting further education and guidance with regards to the management of children diagnosed with cerebral palsy across NSW Health healthcare facilities.

The Cerebral Palsy Clinical Practice Guideline Working Party was established to facilitate the development of an evidence-based clinical practice guide focusing on the management of children diagnosed with cerebral palsy, as an initiative of NSW Children's Healthcare Network Allied to Kids: allied health education and clinical support. Members of the working party were initially identified through an expression of interest process, with additional members invited to join the group as required. Group membership included dietitians, occupational therapists, physiotherapists and speech pathologists from the NSW tertiary children's hospitals, non-tertiary hospitals and healthcare facilities, NSW Department of Ageing, Disability and Home Care, Cerebral Palsy Alliance and a private practice. The working group was chaired and provided secretariat support by the NSW Children's Healthcare Network, Allied Health Educators. For further information regarding the composition of the working party please refer to Appendix One.

The scope of the guide was determined by the working group. Initially, a search was undertaken to identify any existing evidence-based guidelines which could be adapted for local use.

It is intended that this guide is updated every five years in order to reflect any changes in evidence related to the assessment and management of children diagnosed with cerebral palsy.

1.3 OBJECTIVES OF THE GUIDE

1. To provide recommendations that reflect what is currently recognised as best practice in line with available research evidence, consensus clinical practice and values from clients and their families regarding management of children with cerebral palsy
2. To provide resources and contacts for clinicians working with this population.

1.4 INSTRUCTIONS TO USERS

This guide seeks to support allied health professionals in providing optimal, evidence-based care for children with cerebral palsy. Health professionals who may utilise this guide include (but are not limited to):

- Clinical psychologists
- Community health workers
- Dietitians
- Occupational therapists
- Orthotists
- Physiotherapists
- Social workers
- Speech pathologists.

This guide is applicable to healthcare settings in metropolitan, regional, rural, and remote areas of NSW.

The recommendations provided within this guide reflect what is currently regarded as a safe and appropriate approach to assessment and management of individuals with cerebral palsy. The assessments listed in this guide are in order of relevance. Key references listed for each of the assessment tools provide information about reliability and validity or contain the assessment. As in any clinical situation and due to the heterogeneous nature of cerebral palsy, there may be factors which cannot be covered by a single set of guidelines. This clinical practice guide is one component of good clinical decision making, which takes into account clients' preferences and values, clinicians' values and experience, current available research and the available resources. Responsible clinical reasoning regarding the management of patients remains paramount. Clinicians and clients need to develop individual treatment plans that are tailored to the specific needs and circumstances of the client.

Each local health service or organisation is responsible for ensuring local protocols based on this guide are developed. Local Health Districts should also make sure staff working with paediatric clients who have cerebral palsy are educated in the use of locally developed guidelines and protocols.

In the interest of optimal patient care, it is critical that timely, accurate and complete documentation is maintained during the course of individual client management.

MANAGEMENT OF CEREBRAL PALSY IN CHILDREN

2

IMPORTANT CONSIDERATIONS

2. IMPORTANT CONSIDERATIONS

2.1 INTERNATIONAL CLASSIFICATION OF FUNCTIONING (ICF)

This guide was developed using the *International Classification of Functioning, Disability and Health (ICF)*¹ to guide clinical thinking and the delivery of services to children with cerebral palsy and their families. The ICF is a classification system developed by the World Health Organisation that encompasses all aspects of health and describes them in terms of health domains and health-related domains. It is an integrated bio-psychosocial model of health, where the individual's functioning is determined by the complex interaction of the impairment, activities, and participation within the environmental and personal context. In other words, children with cerebral palsy should be assessed and have interventions provided within their different life domains including (but not limited to) home, child care centres, schools, recreational or other settings, in order to have a full understanding of the child's functional abilities in different environments and facilitate full integration to their community living.

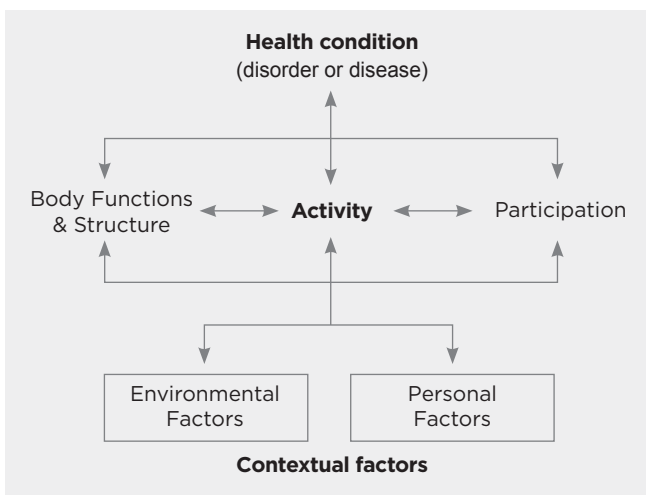


Figure 1: World Health Organisation: International Classification of Functioning, Disability and Health¹

The use of the ICF as a framework for clinical practice provides healthcare workers with a guide to the selection of measurement tools, to inform goal setting and decision making processes and determine outcomes meaningful to the children with cerebral palsy and their families.² Use of the ICF in the management of cerebral palsy 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”.^{2 p.8}

2.2 CHILD PROTECTION

Child protection is a key issue for consideration when working with families that have complex needs. The role of the professional is to ensure the service is child-focused, with the safety and wellbeing of the child being of paramount concern. Health workers are uniquely placed to support families and communities and to promote the development of a safe and healthy environment for all children and young people. It is therefore, essential for allied health professionals to work collaboratively within multidisciplinary teams for the safety, welfare and wellbeing of children, young people and their carers.

Further information can be obtained by visiting the NSW Government ‘Keep Them Safe’ website at <http://www.keepthemsafe.nsw.gov.au/>.³ NSW Health’s *Child Wellbeing and Child Protection Policies and Procedures for NSW Health* can be obtained by visiting http://www0.health.nsw.gov.au/policies/pd/2013/PD2013_007.html.⁴ *The Child Wellbeing and Child Protection – NSW Interagency Guidelines* can be obtained by visiting <http://www.community.nsw.gov.au/kts/>.⁵

2.3 FAMILY-CENTRED PRACTICE

When working with children who have cerebral palsy, a person/family-centred approach to therapy plays an integral role in supporting the individual with cerebral palsy to realise their plans, hopes and vision for the future. A person/family-centred approach to practice recognises the need to actively listen to the individual and their family to identify, respect and value what is important to them and for them.⁶

A family-centred approach to practice primarily relates to working with children where the child is at the centre and the child’s goals and/or aspirations are reflected through practice. It is important that there is a balance between the child’s goals, and strengthening and supporting the family and their role in the child’s life.⁷

Principles of family-centred practice include:

- The family deciding on their own level of involvement in decision making
- The family having ultimate responsibility for the child's care
- The family being treated with respect
- Considering the needs of all family members and encouraging the involvement of all family members.

Existing research evidence, although limited, investigating the psychological adjustment of the child, psychosocial wellbeing of the parents and satisfaction with the service providers, all pointed to positive outcomes from the family-centred service approach.⁸

2.4 TEAM APPROACH

A multiple disciplinary team approach (whether in a format of multidisciplinary, interdisciplinary or transdisciplinary)⁹, is considered best practice when working with children with complex needs. Research evidence supporting the effectiveness of a multiple disciplinary team approach is however, limited and shows conflicting results.¹⁰ Although a multiple disciplinary team approach may not be feasible in all settings, due to geographical, financial, organisational and time restraints, where possible, it is recommended that all disciplines involved with the child work together in a family-centred model to meet the needs and goals of the child and their family. Where clinicians may not work directly with, or have access to, other disciplines, they are encouraged to seek multidisciplinary support from other disciplines within their organisation or geographical area, or from tertiary institutions or specialist services to facilitate the provision of a holistic service. Care must be taken to ensure that all professionals involved in a child's care are included and this may include child care professionals and/or teachers. Particular attention should be focused on times of transition with early forward planning being essential for positive outcomes.

2.5 EARLY PLANNING FOR TRANSITION PERIODS

It is widely acknowledged in the literature on provision of support services for children with cerebral palsy that families of children at life transition points require a greater level of support than at other times across their lifespans. Major transition periods may include:

- Commencing childcare/preschool
- Attending primary school
- Attending high school
- Adulthood.

It is essential that at major transition periods we ensure that appropriate services are identified and secured at the correct time for children with cerebral palsy.

The Australian Institute of Health and Welfare¹¹ states that:

As the child with cerebral palsy approaches school age, the emphasis of therapy shifts to promoting independence by preparing the child for school and helping them to access their classroom, curriculum and extra-curricular activities, and master activities of daily living such as dressing, bathing, and eating.^{11 p.44}

Research evidence demonstrates that transition to school can be more demanding for children with disabilities when compared to children without a disability.¹²

The *Transition To School Resource* website, www.transitiontoschoolresource.org.au¹³, was developed by the Early Childhood Intervention Australia (ECIA) NSW Chapter Incorporated and funded by Ageing, Disability and Home Care (ADHC) NSW. The website provides extensive and current information on useful practices and potential barriers to support a child with a disability and his or her family to transition to school. The website states that useful practices include interagency collaboration, timeliness of service provision, training, active parent involvement, family-centred practice and ongoing evaluation.

Transitioning into adulthood for children with cerebral palsy should focus on assisting children with cerebral palsy to enter the workforce, access further education and live independently. For further information on transitioning into adulthood please refer to:

www.cerebralpalsy.org.au/services¹⁴

www.cerebralpalsy.org/the-journey/transition¹⁵

2.6 CLINICAL MEASUREMENT PRACTICAL GUIDELINES FOR SERVICE PROVIDERS

(Hanna, Russell, Bartlett, Kertoy, Rosenbaum & Swinton 2005)

Clinical Measurement Practical Guidelines for Service Providers is available from CanChild at:

<https://www.canchild.ca/en/resources/29-clinical-measurement-practical-guidelines-for-service-providers>.¹⁶

This is recommended as a guide for clinicians reviewing the measurements used in their clinical practice. Topics in the document include:

- Why is accurate clinical measurement important?
- What are the purposes of clinical measurement?
- I see the measurement terms often: what do they mean?^{16 p.3}

2.7 CULTURAL CONSIDERATIONS

A culture incorporates the collection of beliefs and traditions associated with a specific group. It can guide the family's interactions with health professionals, their views of health issues and also their views on assessment and intervention. Clinicians should respect individual family dynamics, child-rearing practices and community beliefs. It is vital to gain an understanding of these influences before attempting to initiate any assessments or interventions with children or their families.

MANAGEMENT OF CEREBRAL PALSY IN CHILDREN

3

BACKGROUND

3. BACKGROUND

3.1 DEFINITION

Cerebral palsy is “an umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of development”.^{17 p.549} In other words, it describes a group of developmental disorders affecting movements and postures, causing activity restriction or disability.¹⁸ 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”.^{19 p.9}

3.2 PREVALENCE/INCIDENCE/AETIOLOGY

Cerebral palsy is the most common physical disability in childhood. In Australia, approximately one in every 500 children is affected by cerebral palsy.²⁰

It is widely accepted that cerebral palsy does not result from a single cause but rather from a series of ‘causal pathways’ that can result in or accelerate injury to the developing brain. The cause of cerebral palsy in the majority of babies is still unknown. A recent systematic review of risk factors for cerebral palsy in children born at term in developing countries found 10 risk factors that were consistently reported as statistically significant predictors of cerebral palsy.²¹ The 10 consistent risk factors identified include:

- Placental abnormalities
- Birth defects
- Low birth weight
- Meconium aspiration
- Instrumental/emergency caesarean delivery
- Birth asphyxia
- Neonatal seizures
- Respiratory distress syndrome
- Hypoglycaemia
- Neonatal infection.^{21 p.499}

Risk factors alone are not the cause of cerebral palsy but their presence may lead to an increased chance of a child being born with cerebral palsy. A small percentage of children acquire cerebral palsy 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.²²

3.3 HOW IS CEREBRAL PALSY CLASSIFIED?

Cerebral palsy can be classified by motor types, topographical distribution and functional motor ability.¹⁹

3.3.1 Motor Type

Spastic cerebral palsy is the most common motor type of cerebral palsy. 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.

Dyskinetic cerebral palsy is characterised by abnormalities of tone and various movement disorders including dystonia and athetosis. Dystonia is characterised by sustained or intermittent muscle contractions causing repetitive or twisting movements. Athetosis is characterised by uncontrolled, slow and writhing movements.

Ataxic cerebral palsy is the least common motor disorder. It is characterised by shaky movements and affects a person’s coordination and balance.

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

3.3.2 Topographical Distribution

Unilateral:

- **Monoplegia:** used as a description when one upper or lower limb is affected; this is very rare.
- **Hemiplegia:** used as a description when the arm and leg on one side of a person’s body are affected.

Bilateral:

- **Diplegia:** the predominant problem is the lower limbs but signs are usually also present in the upper limbs. In asymmetrical diplegia, one side is more affected than the other.
- **Quadriplegia:** head, trunk and both upper and lower limbs are affected (also referred to as tetraplegia). The extent to which each limb is affected may vary.

3.3.3 Functional Motor Ability

Gross Motor Function Classification System (GMFCS):

Provides information about the severity of the functional limitation based on the child's motor abilities and their need for wheelchairs, walking frames and other mobility devices.

The five levels within the GMFCS are:

Gross Motor Function Classification System (GMFCS) Levels

- I Walk independently
- II Walk independently with limitations
- III Use assistive devices such as elbow crutches or walking frames
- IV Require a wheelchair but may have some form of independent mobility such as a powered wheelchair or may assist with transfers
- V Require a wheelchair and are fully dependent in their mobility

Communication Function Classification System (CFCS):

Used to classify everyday communication performance of an individual with cerebral palsy. There are five levels within the CFCS:

Communication Function Classification System (CFCS) Levels

- I Effective sender and/or receiver with familiar and unfamiliar partners
- II Effective but slower paced sender and/or receiver with familiar and unfamiliar partners
- III Effective sender and/or receiver with familiar partners
- IV Inconsistent sender and/or receiver with familiar partners
- V Seldom effective sender and/or receiver even with familiar partners

Manual Abilities Classification System (MACS): Valid in children over the age of 4, MACS is a similar classification system to the GMFCS that is used to describe how children with cerebral palsy use their hands to handle objects in daily activities. There are five levels within the MACS:

Manual Ability Classification System (MACS) Levels

- I Handles objects easily
- II Handle most objects but with reduced speed and/or quality
- III Have some difficulty and need help to modify or prepare activities
- IV Handle a limited selection of easily managed objects in adapted settings
- V Do not handle objects

MANAGEMENT OF CEREBRAL PALSY IN CHILDREN

4

ASSESSMENT OF CEREBRAL PALSY IN CHILDREN

4. ASSESSMENT OF CEREBRAL PALSY IN CHILDREN

Thorough and accurate assessment of children with cerebral palsy by a multidisciplinary team is essential to ensure chosen interventions meet the child's needs. Most assessments measure a particular aspect of the child's life. The World Health Organisation's International Classification of Functioning, Disability and Health (ICF) has been used to guide assessment. The ICF domains include body function and structure, participation, activity and personal and environmental factors. Standardised assessments and outcome measures may be relevant to one or more domains of the ICF. A significant number of assessments are available and it is often necessary to use a combination of these. Selection of assessment tools should be based on purpose, psychometrics and those most relevant to the area/s of difficulty. The functional motor ability classification scales should be used to guide assessment and intervention with all children diagnosed with cerebral palsy to facilitate communication and goal setting. Further assessment should occur to ensure realistic goal setting, provide a baseline for therapy and for evaluation of therapy programs.

5

GOAL SETTING

5. GOAL SETTING

Assessment Tool		Section
Goal Setting	Canadian Occupational Performance Measure (COPM)	5.1
	Goal Attainment Scaling (GAS)	5.2

A goal can be defined as a specific and measurable objective. It is essential that goals are specific, measurable, attainable, realistic and timely.²³ The main purpose of therapy is goal attainment and goals are set to reduce limitations in activity and participation.²⁴ In person/family-centred practice, goals are determined with the child and family and realistic levels of attainment, within an allocated time frame, are set. Goals can be used in all areas of therapy with children with cerebral palsy, whether it be a specific upper limb intervention, orthopaedic surgery outcomes, Botulinum Toxin injections, independent functional self-care tasks or ease of cares for a caregiver. It is important to include all members of the treating team when considering goals (see Appendix Two).

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.

5.1 CANADIAN OCCUPATIONAL PERFORMANCE MEASURE (COPM)

(Law, Baptiste, Carswell-Opzoomer, McColl, Polatajko & Pollock 1991)

The Canadian Occupational Performance Measure (COPM) is an individualised measure 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

Ensure that the version used is the paediatric modified version. Select parent or child report as appropriate.

Assessor: Allied health professionals.

Time Allocated: 15 to 30 minutes, semi-structured interview. Complete cover page with family and child. Record any additional information on the back page.

Availability: Can be purchased at:

<https://www.caot.ca/store/SearchResults.aspx?searchterm=copm&searchoption=ALL>.

Contact: The COPM authors can be contacted at <http://www.thecopm.ca/contact/>.

Key References

- Cusick, A., Lannin, N. A. & Lowe, K. (2007). Adapting the Canadian Occupational Performance Measure for use in a paediatric clinical trial. *Disability & Rehabilitation*, 29(10): 761-766.
- Sakzewski, L., Boyd, R. & Ziviani, J. (2007). Clinimetric Properties of Participation Measures for 5-to-13-year old Children with Cerebral Palsy: A Systematic Review. *Developmental Medicine & Child Neurology*, 49: 232-240.
- Cusick, A., McIntyre, S., Novak, I., Lannin, N. & Lowe, K. (2006). A comparison of goal attainment scaling and the Canadian Occupational Performance Measure for paediatric rehabilitation research. *Paediatric Rehabilitation*, 9(2): 149-157.
- Dedding, C., Cardol, M., Eyssen, I.C., Dekker, J. & Beelen, A. (2004). Validity of the Canadian Occupational Performance Measure: a client-centred outcome measurement. *Clinical Rehabilitation*, 18(6): 660-667.
- Law, M., Baptiste, S., Carswell-Opzoomer, A., McColl, M.A., Polatajko, H., & Pollock, N. (1991). *Canadian Occupational Performance Measure*. Toronto, ON: CAOT Publications ACE.
- Law, M., Baptiste, S., McColl, M.A., Opzoomer, A., Polatajko, H. & Pollock, N. (1990). The Canadian Occupational Performance Measure: An outcome measure for occupational therapy. *Canadian Journal of Occupational Therapy*, 57(2): 82-87.

5.2 GOAL ATTAINMENT SCALING (GAS)

(Kiresuk & Sherman 1968)

Goal Attainment Scaling (GAS) is used to evaluate services or an individualised program based on the attainment of individualised goals. 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.

Administration

Assessor: Allied health professionals.

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

Availability: Freely available from McDougall & King (2007) & Turner-Stokes (2009).

Key References

Steenbeek, D., Ketelaar, M., Lindeman, E., Galama, K. & Gorter, J.W. (2010). Interrater reliability of goal attainment scaling in rehabilitation of children with cerebral palsy. *Archives of Physical Medicine & Rehabilitation*, 91(3): 429-435.

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

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

Palisano, R.J. (1993). Validity of Goal Attainment Scaling in Infants with Motor Delays. *Physical Therapy*, 73(10): 651-660.

Palisano, R.J., Haley, S.M. & Brown, D.A. (1992). Goal attainment scaling as a measure of change in infants with motor delays. *Physical Therapy*, 72(6): 432-437.

Kiresuk, T.J. & Sherman, R.E. (1968). Goal attainment scaling: a general method for evaluating community mental health programs. *Community Mental Health Journal*, 4: 443-453.

6

CLASSIFICATION TOOLS

6. CLASSIFICATION TOOLS

Assessment Tool	Section
Functional Motor Ability	6.1
Gross Motor Function Classification System (GMFCS)	6.1.1
Functional Mobility Scale (FMS)	6.1.2
Gait Classifications	6.2
Classification of Gait Patterns: Hemiplegic Gait	6.2.1
Classification of Gait Patterns: Diplegic Gait	6.2.2
Upper Limb Classifications	6.3
Manual Ability Classification System (MACS)	6.3.1
House Thumb Classification	6.3.2
The Zancolli Scale	6.3.3
Neurological Hand Deformity Classification (NHDC)	6.3.4
Communication Classification	6.4
Communication Function Classification System (CFCS)	6.4.1
Functional Communication Classification System (FCCS)	6.4.2
Eating and Drinking Classification	6.5
Eating and Drinking Ability Classification System (EDACS)	6.5.1

A variety of well established classification tools are utilised with children with cerebral palsy to describe motor ability, gait and upper limb deformity. The assessment of functional motor ability in the areas of gross motor, hand function and communication provide a broad overview of the functional level of each child with cerebral palsy and can be used as a guide for intervention and therapy.²⁵ The GMFCS, MACS and increasingly the CFCS provide an international language to describe the functional level of a child with cerebral palsy.

6.1 FUNCTIONAL MOTOR ABILITY

6.1.1 Gross Motor Function Classification System (GMFCS)

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

The Gross Motor Function Classification System (GMFCS) is a five level classification that describes the gross motor function of children with cerebral palsy 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 five levels of the GMFCS are:

Gross Motor Function Classification System (GMFCS) Levels

- I Walk independently
- II Walk independently with limitations
- III Use assistive devices such as elbow crutches or walking frames
- IV Require a wheelchair but may have some form of independent mobility such as a powered wheelchair or may assist with transfers
- V Require a wheelchair and are fully dependent in their mobility

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 five GMFCS levels for different age groupings:

- Before 2nd birthday
- Between 2nd and 4th birthday
- Between 4th and 6th birthday
- Between 6th and 12th birthday.

The GMFCS – Expanded and Revised (2007) describes gross motor classification across the following age bands:

- 0 and 2 years
- 2 and 4 years
- 4 and 6 years
- 6 and 12 years
- 12 and 18 years.

The GMFCS emphasises the concepts inherent in the World Health Organisation'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: Professionals who are familiar with the client's gross motor function in conjunction with a parent or caregiver.

Time Allocated: N/A - done either via parent/caregiver report and/or observation during regular client appointment.

Availability: The GMFCS – Expanded and Revised (2007) can be sourced freely online by visiting the CanChild website at <https://canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r>

Contact: For further information contact canchild@mcmaster.ca

Key References

- Imms, C., Carlin, J. & Eliasson, A. (2010). Stability of caregiver-reported manual ability and gross motor function classifications of cerebral palsy. *Developmental Medicine & Child Neurology*, 52: 153-159.
- Palisano, R., Rosenbaum, P., Bartlett, D. & Livingston, M. (2008). Content validity of the expanded and revised Gross Motor Function Classification System. *Developmental Medicine & Child Neurology*, 50(10): 744-750.
- Palisano, R.J., Hanna, S.E., Rosenbaum, P.L., Russell, D.J., Walter, S.D., Wood, E.P., Raina, P.S. & Galuppi, B.E. (2000). Validation of a model of gross motor function for children with cerebral palsy. *Physical Therapy*, 80(10): 974-985.
- Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E. & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 39(4): 214-223.

6.1.2 Functional Mobility Scale (FMS)

(Graham, Harvey, Rodda, Natras & Pirpiris 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: five 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: Clinician asks questions of the child, parent or caregiver who is familiar with the child's mobility (not direct observation).

Time Allocated: N/A – questions asked during regular appointment.

Availability: Download of forms available from: <http://www.rch.org.au/emplibrary/ortho/MOBILITYSCALE.pdf>

Contact: Contact details for the Hugh Williamson Gait Laboratory can be found at http://www.rch.org.au/gait/contact_us/Contact_Hugh_Williamson_Gait_Laboratory/

Key References

Harvey, A., Morris, M.E., Graham, H.K., Wolfe, R. & Baker, R. (2010). Reliability of the Functional Mobility Scale for children with cerebral palsy. *Physical & Occupational Therapy in Pediatrics*, 30(2): 139-149.

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

6.2 GAIT CLASSIFICATIONS

Classifications of common gait patterns in children with hemiplegia and diplegia have been developed. For further information and diagrams of common gait patterns refer to Rodda & Graham ²⁶ or the Australian Hip Surveillance Guidelines in section 11.2.

6.2.1 Classification of Gait Patterns: Hemiplegic Gait

(Winters, Gage & Hicks 1987)

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

Winters, Gage and Hicks (1987) Gait Pattern Types

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

Administration

Assessor: Physiotherapist.

Time Allocated: N/A – part of total assessment.

Availability: The classification scale can be found in Winters, Gage & Hicks (1987).

Key References

Winters, T.F., Gage, J.R. & Hicks, R. (1987). Gait patterns in spastic hemiplegia in children and young adults. *Journal of Bone & Joint Surgery (American)*, 69(3): 437-441.

6.2.2 Classification of Gait Patterns: Diplegic Gait

(Rodda & Graham 2001)

The classification of common gait patterns seen in children with spastic diplegia have been developed by Rodda & Graham and Rodda, Graham, Carson, Galea & Wolfe. Diplegic gait patterns include:

Rodda & Graham²⁶ and Rodda et al.²⁷ Gait Pattern Groups

- I True Equinus – ankle plantar flexion throughout stance with hips and knees extended
- II Jump Gait – ankle in equinus, the hip and knee in flexion, anterior pelvis tilt and an increased lumbar lordosis. Often a stiff knee due to rectus femoris activity in the swing phase of gait
- III Apparent Equinus – walking on toes, however equinus is apparent rather than real with sagittal plane kinematics showing ankle has normal range of dorsiflexion but the hip and knee are in excessive flexion throughout stance phase of gait
- IV Crouch Gait – excessive ankle dorsiflexion in combination with excessive flexion at the hip and knee
- V Asymmetric Gait – a combination of any of the above two patterns

Administration

Assessor: Physiotherapist.

Time Allocated: N/A – part of total assessment.

Availability: The classification scale can be found in Rodda & Graham (2001).

Key References

Rodda, J.M., Graham, H.K., Carson, L., Galea, M.P. & Wolfe, R. (2004). Sagittal gait patterns in spastic diplegia. *The Bone and Joint Journal*, 86(2): 251-258.

Rodda, J.M. & Graham, H.K. (2001). Classification of gait patterns in spastic hemiplegia and diplegia: a basis for a management algorithm. *European Journal of Neurology*, 8(5): 98-108.

6.3 UPPER LIMB CLASSIFICATIONS

6.3.1 Manual Ability Classification System (MACS)

(Eliasson, Krumlinde Sundholm, Rösblad, Beckung, Arner, Öhrvall & Rosenbaum 2006)

The Manual Ability Classification System (MACS) provides a systematic method of classifying how children with cerebral palsy, 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 cerebral palsy.

There are five levels within the MACS:

Manual Ability Classification System (MACS) Levels

- I Handles objects easily
- II Handles most objects but with reduced speed and/or quality
- III Has some difficulty and needs help to modify or prepare activities
- IV Handles a limited selection of easily managed objects in adapted settings
- V Does not handle objects

Administration

Assessor: Parent, caregiver or professional who is familiar with the client's hand function. MACS level must be determined by asking someone who knows the child well and not by conducting a specific assessment.²⁸

Time Allocated: N/A – completed either via parent/caregiver report and/or observation during regular client appointment.

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. Download of forms available from www.macs.nu.

Contact: Further information can be obtained by contacting Ann-Christin Eliasson, one of the developers of the MACS, by email at Ann-Christin.eliasson@ki.se.

Key References

Imms, C., Carlin, J. & Eliasson, A. (2010). Stability of caregiver-reported manual ability and gross motor function classifications of cerebral palsy. *Developmental Medicine & Child Neurology*, 52(2): 153-159.

Öhrvall, A. & Eliasson, A. (2010). Parents' and therapists' perceptions of the content of the Manual Ability Classification System, MACS. *Scandinavian Journal of Occupational Therapy*, 17(3): 209-216.

Plasschaert, V., Ketelaar, M., Nijnius, M., Enkelaar, L. & Gorter, J. (2008). Classification of manual abilities in children with cerebral palsy under 5 years of age: How reliable is the Manual Ability Classification System? *Clinical Rehabilitation*, 23(2): 164-170.

Eliasson, A.C, Krumlinde Sundholm, L., Rösblad, B., Beckung, E., Arner, M., Öhrvall, A.M. & Rosenbaum, P. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. *Developmental Medicine & Child Neurology*, 48(7): 549-554.

6.3.2 House Thumb Classification

(House, Gwathmey & Fidler 1981)

Thumb deformities, seen in cerebral palsy, are the result of an imbalance of intrinsic or extrinsic thumb muscles or both. The House Thumb Classification describes the position of the thumb in the child with cerebral palsy using four classifications.

Table 1: House Thumb Classifications²⁹

	Type 1: spasticity and contracture of adductor pollicis, 1 st interosseus, secondary contracture of skin in thumb web space
	Type 2: contracture of flexor pollicis brevis, inter phalangeal joint often immobile
	Type 3: compensatory efforts of extensor pollicis longus and extensor pollicis brevis acting across the hyperextended metacarpal phalangeal joint and no flexor pollicis longus spasticity
	Type 4: most severe deformity. Either spasticity in flexor longus pollicis or spasticity and contracture in flexor pollicis longus and intrinsic thumb muscles

Administration

Assessor: Occupational therapists, physiotherapists and physicians.

Time Allocated: N/A – part of total assessment.

Availability: The classification scale can be found in House, Gwathmey & Fidler (1981).

Key References

House, J.H., Gwathmey, F.W. & Fidler, M.O. (1981). A dynamic approach to the thumb-in-palm deformity in cerebral palsy. *Journal of Bone and Joint Surgery*, 63(2): 216-225.

6.3.3 The Zancolli Scale

(Zancolli & Zancolli 1981)

The Zancolli Scale describes wrist deformity in children with cerebral palsy using four classifications to describe the positioning of the affected hand.

Administration

Assessor: Occupational therapists, physiotherapists and physicians.

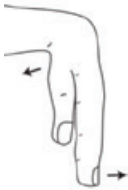
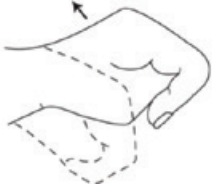
Time Allocated: N/A – part of total assessment.

Availability: The classification scale can be found in Zancolli & Zancolli (1981).

Key References

Zancolli, E.A. & Zancolli, E.R. (1981). Surgical management of the hemiplegic spastic hand in cerebral palsy. *Surgical Clinics of North America*, 61(2): 395-406.

Table 2: Zancolli Scale Classifications³⁰

	Group 1: mild spasticity, primarily in flexor carpi ulnaris
	Group 2a: spasticity in finger flexors
	Group 2b: spasticity/weakness in wrist extensors
	Group 3: severe limitations, spasticity in wrist flexors and pronators and weakness in wrist extensors and supinator muscles

6.3.4 Neurological Hand Deformity Classification (NHDC)

(Wilton 2003 & 2004; Georgiades, Elliott, Wilton, Blair, Blackmore & Garbellini 2014)

The Neurological Hand Deformity Classification (NHDC) was developed based on the Zancolli (1981) wrist and House (1981) thumb surgical classifications. The NHDC provides a description of common deformities from an anatomical and biomechanical perspective as well as providing a framework for intervention options. The NHDC includes four flexion type deformities (F1 to F4) and two extension type deformities (E1 and E2). The classification table details the deformity at the wrist, associated thumb deformities and associated finger patterns.³¹ This classification system also details where spasticity is located, where contracture may be present and what functional deficits may be present with each of the six classifications.

Administration

Assessor: Occupational therapist.

Time Allocated: N/A – completed either via observation during regular client appointment or from prerecorded sessions.

Availability: The classification scale can be found in Georgiades et al. (2014).

Key References

Georgiades, M., Elliott, C., Wilton, J., Blair, E., Blackmore, M. & Garbellini, S. (2014). The Neurological Hand Deformity Classification for children with cerebral palsy. *Australian Occupational Therapy Journal*, 61(6): 394-402.

Wilton, J. (2004). Splinting and casting in the presence of neurological dysfunction. *Hand Splinting: principles of design and fabrication* (pp. 168-197). Perth, WA: Success Print.

Wilton, J. (2003). Casting, splinting and physical and occupational therapy of hand deformity and dysfunction in cerebral palsy. *Hand Clinics*, 19(4): 573-584.

6.4 COMMUNICATION CLASSIFICATION

6.4.1 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 five descriptive levels:

Communication Function Classification System (CFCS) Levels

- I Effective sender and/or receiver with familiar and unfamiliar partners
- II Effective but slower paced sender and/or receiver with familiar and unfamiliar partners
- III Effective sender and/or receiver with familiar partners
- IV Inconsistent sender and/or receiver with familiar partners
- V Seldom effective sender and/or receiver even with familiar partners

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.

Administration

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

Time Allocated: N/A – completed either via parent/caregiver report and/or observation during regular client appointment.

Availability: Can be accessed at:

http://cfcs.us/wp-content/uploads/2014/02/CFCS_English_2011_09_01.pdf.

Contact: Contact details for the authors of the CFCS can be found at http://cfcs.us/?page_id=6.

Key References

Hidecker, M.J., Paneth, N., Rosenbaum, P.L., Kent, R.D., Lillie, J., Eulenberg, J.B., Chester, Jr.K., Johnson, B., Michalsen, L., Evatt, M. & Taylor, K. (2011). Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Developmental Medicine & Child Neurology*, 53(8): 704-710.

6.4.2 Functional Communication Classification System (FCCS)

(Barty & Caynes 2009)

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

Administration

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

Time Allocated: N/A – completed via report or observation.

Availability: Can be accessed at <http://www.cpl.org.au/docs/position-descriptions/fccs.pdf?sfvrsn=0>.

Contact: The Centre for Cerebral Palsy and Cerebral Palsy League of Queensland, info@cplqld.org.au.

Key References

Barty, E., Caynes, K. & Johnston, L.M. (2016). Development and reliability of the Functional Communication Classification System for children with cerebral palsy. *Developmental Medicine & Child Neurology*, *Epub ahead of print*.

Caynes, K., Burmester, D., Barty, E. & Johnston, L.M. (2014). Concurrent validity of the Functional Communication Classification System for cerebral palsy with the CELF-4 pragmatic profile. *Developmental Medicine & Child Neurology*, 56(2): 45-46.

Barty, E. & Caynes, K. (2009). Development of the Functional Communication Classification Scale. Paper presented at the 3rd International Cerebral Palsy Conference, Sydney, Australia.

Functional Communication Classification System (FCCS) Levels

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

6.5 EATING AND DRINKING CLASSIFICATION

6.5.1 Eating and Drinking Ability Classification System (EDACS)

(Sellers, Mandy, Pennington, Hankins & Morris 2013)

The Eating and Drinking Ability Classification System (EDACS) is a newly developed system for classifying eating and drinking ability in children with cerebral palsy 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.

Eating and Drinking Classification System (EDACS) Levels

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

An additional classification of degree of help required during mealtimes can be used to further supplement EDACS. This includes: independent (Ind), requires assistance (RA) or totally dependent (TD). It classifies usual rather than best performance.

Administration

Assessor: Parent, caregiver or professional who is familiar with the client's eating and drinking ability.

Time Allocated: N/A - completed either via parent/caregiver report and/or observation.

Availability: Can be accessed at:

<http://www.sussexcommunity.nhs.uk/get-involved/research/chailey-research/eating-drinking-classification.htm>

Contact: For further information please contact Diane Sellers at diane.sellers@nhs.net.

Key References

Sellers, D., Mandy, A., Pennington, L., Hankins, M. & Morris, C. (2013). Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Developmental Medicine & Child Neurology*, 56(3): 245-251.

MANAGEMENT OF CEREBRAL PALSY IN CHILDREN



BODY STRUCTURE AND FUNCTION ASSESSMENT

7. BODY STRUCTURE AND FUNCTION ASSESSMENT

Assessment Tool		Section
Physical Assessment		7.1
	Range of Motion (ROM)	7.1.1
	Measurement of Spasticity	7.1.2
	• Tardieu Scale and Modified Tardieu Scale	7.1.2.1
	• The Ashworth Scale (AS) and Modified Ashworth Scale (MAS)	7.1.2.2
	• Australian Spasticity Assessment Scale (ASAS)	7.1.2.3
	Measurement of Tone	7.1.3
	• Hypertonia Assessment Tool (HAT)	7.1.3.1
	Measurement of Dystonia	7.1.4
	• Barry-Albright Dystonia Scale (BAD)	7.1.4.1
	Strength	7.1.5
	Selective Motor Control	7.1.6
	• Selective Control Assessment of the Lower Extremity (SCALE)	7.1.6.1
	• Boyd and Graham Selective Motor Control Scale (SMC)	7.1.6.2
Functional Eating and Drinking Assessment		7.2
	Dysphagia Disorder Survey (DDS)	7.2.1
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7.1 PHYSICAL ASSESSMENT

The physical assessment of children with cerebral palsy should be routinely completed as a baseline and to determine the effects of intervention. The minimal physical assessment should include assessment of range of motion, passive and active (if relevant). In addition assessment and measurement of a child's spasticity and dystonia can be completed along with measures of strength, selective motor control and sensation.

7.1.1 Range of Motion (ROM)

Range of motion (ROM) can be assessed informally via observation of a child's functional activity and formally via goniometric measurement. Most occupational therapy and physiotherapy reference text books contain chapters regarding accurate goniometric measurement. A prior knowledge of passive (clinician moves child's body part) and active (child independently moves body part) range of motion is essential. In children with cerebral palsy joint range will often be restricted by hypertonia and muscle and/or bony contracture.

Administration

Assessor: Physiotherapist or occupational therapist.

Equipment: Goniometer (small size for use in paediatrics). This is more reliable than visual estimates. Inter-rater reliability measurements are as variable as 10-15 degrees, intra-rater reliability are better. An angle finder may also be used. This has as an inclination needle and is particularly useful for rotational movements (e.g. hip), only requires one hand but has unknown reliability.

The same clinician should perform all measures to increase reliability.

Key References

Herrero, P., Carrera, P., García, E., Gómez-Trullén, E. & Oliván-Blázquez, B. (2011). Reliability of goniometric measurements in children with cerebral palsy: A comparative analysis of universal goniometer and electronic inclinometer. A pilot study. *BMC Musculoskeletal Disorders*, 12: 155-163.

McWhirk, L. & Glanzman, A. (2006) Within-Session Inter-Rater Reliability of Goniometric Measures in Patients with Spastic Cerebral Palsy. *Pediatric Physical Therapy* 18(4): 262-265.

Menadue, C., Raymond, J., Kilbreath, S., Refshauge, K. & Adams, R. (2006). Reliability of two goniometric methods of measuring active inversion and eversion range of motion at the ankle. *BMC Musculoskeletal Disorders* 7: 60-68.

Kilgour, G., McNair, P. & Stott, S. (2003) Intrarater reliability of lower limb sagittal range-of-motion measures in children with spastic diplegia. *Developmental Medicine & Child Neurology*; 45(6): 391-399.

McDowell, B., Hewitt, V., Nurse, A., Weston, T. & Baker, R. (2000). The variability of goniometric measurements in ambulatory children with spastic cerebral palsy. *Gait and Posture*, 12(2): 114-121.

7.1.2 Measurement of Spasticity

The most commonly used definition of spasticity is that of Lance, who defined spasticity as: “a motor disorder characterised by a velocity-dependent increase in tonic stretch reflexes (muscle tone) with exaggerated tendon jerks resulting from hyperexcitability of the stretch reflex as one component of upper motor neuron syndrome”.^{32 p.485} The measurement of spasticity is difficult due to the complexity of factors involved and the use of the various ordinal scales lack reliability.

7.1.2.1 Tardieu Scale and Modified Tardieu Scales

(Gracies, Marosszeky, Renton, Sandanam, Gandevia & Burke 2000)

The Tardieu Scale, named after Tardieu's work from the 1950s to 1980s by Professor Jean-Michel Gracies, quantifies muscle tone through the measurement of the muscles reaction to specific velocities, that is, the muscles response to how quickly you move that muscle. The Tardieu and Modified Tardieu measure muscle tone at three velocities (V1, V2 and V3), as shown in the table below. The validity and reliability of the Tardieu scale remains unclear, however a recent critical review of available measures of spasticity for children suggested that the Tardieu scale is the most suitable instrument to measure spasticity in children.^{33, 34}

Administration

This test is performed with patient in the supine position, with head in midline.

Measurements take place at three velocities (V1, V2, and V3). Responses are recorded at each velocity as X/Y, with X indicating the 0 to 5 rating, and Y indicating the degree of angle at which the muscle reaction occurs. By moving the limb at different velocities, the response to stretch can be more easily gauged since the stretch reflex responds differently to velocity.

Velocities

- V1 As slow as possible, slower than the natural drop of the limb segment under gravity
- V2 Speed of limb segment falling under gravity
- V3 As fast as possible, faster than the rate of the natural drop of the limb segment under gravity

Scoring

- 0 No resistance throughout the course of the passive movement
- 1 Slight resistance throughout the course of passive movement, no clear catch at a precise angle
- 2 Clear catch at a precise angle, interrupting the passive movement, followed by release
- 3 Fatigable clonus with less than 10 seconds when maintaining the pressure and appearing at the precise angle
- 4 Unfatigable clonus with more than 10 seconds when maintaining the pressure and appearing at a precise angle
- 5 Joint is immovable

Assessor: Clinician assesses bilateral upper and lower limb muscles as per physical assessment protocol.

Time Allocated: N/A – part of total clinical assessment.

Availability: The scale can be found in Gracies, Marosszeky, Renton, Sandanam, Gandevia & Burke (2000).

Key References

Alhusaini, A.A., Dean, C.M., Crosbie, J., Shepherd, R.B. & Lewis, J. (2010). Evaluation of spasticity in children with cerebral palsy using Ashworth and Tardieu Scales compared with laboratory measures. *Journal of Child Neurology*, 25(10): 1242-1247.

Haugh, A.B., Pandyan, A.D. & Johnson, G.R. (2006). A systematic review of the Tardieu Scale for the measurement of spasticity. *Disability Rehabilitation*, 28(15): 899–907.

Scholtes, V.A., Becher, J.G., Beelen, A. & Lankhorst, G.J. (2006). Clinical assessment of spasticity in children with cerebral palsy: a critical review of available instruments. *Developmental Medicine & Child Neurology*, 48(1): 64-73.

Mackey, A.H., Walt, S.E., Lobb, G. & Stott, N. S. (2004). Intraobserver reliability of the modified Tardieu scale in the upper limb of children with hemiplegia. *Developmental Medicine & Child Neurology*, 46(4): 267-272.

Morris, S. (2002). Ashworth and Tardieu Scales: Their clinical relevance for measuring spasticity in adult and paediatric neurological populations. *Physical Therapy Reviews*, 7(1): 53-62.

Gracies, J-M., Marosszeky, J., Renton, R., Sandanam, J., Gandevia, S. & Burke, D. (2000). Short term effects of dynamic lycra splints on upper limb in hemiplegic patients. *Archives of Physical & Medical Rehabilitation*, 81(12): 1547-1555.

7.1.2.2 The Ashworth Scale (AS) and Modified Ashworth Scale (MAS)

(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.^{33, 34}

Ashworth Scale

- 0 No increase in tone
- 1 Slight increase in tone giving catch when the limb is moved in flexion and extension
- 2 More marked increase in tone, but limb is easily flexed
- 3 Considerable increases in tone, passive movement difficult
- 4 Limb rigid in flexion or extension

Modified Ashworth Scale

- 0 No increase in muscle tone
- 1 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
- 1+ 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
- 2 More marked increase in muscle tone through most of the range of movement, but the affected part(s) is easily moved
- 3 Considerable increases in muscle tone, passive movement difficult
- 4 Affected part(s) is/are rigid in flexion or extension

Administration

Assessor: Clinician assesses bilateral upper and lower limb muscles as per physical assessment protocol.

Time Allocated: N/A – part of total clinical assessment.

Availability: A description of the Ashworth Scale can be found in Mutlu, Livanelioglu & Gunel (2008) and the Modified Ashworth Scale can be found in Bohannon & Smith (1987).

Key References

- Alhusaini, A.A., Dean, C.M., Crosbie, J., Shepherd, R.B. & Lewis, J. (2010). Evaluation of spasticity in children with cerebral palsy using Ashworth and Tardieu Scales compared with laboratory measures. *Journal of Child Neurology*, 25: 1242-1247.
- Mutlu, A., Livanelioglu, A. & Gunel, K. M. (2008). Reliability of Ashworth and Modified Ashworth Scales in Children with Spastic Cerebral Palsy. *BMC Musculoskeletal Disorders*, 9: 44.
- Scholtes, V.A., Becher, J.G., Beelen, A. & Lonkhorst, G.J. (2006). Clinical assessment of spasticity in children with cerebral palsy: a critical review of available instruments. *Developmental Medicine & Child Neurology*, 48(1): 64-73.
- Bohannon, R.W. & Smith, M. (1987). Interrater reliability of a Modified Ashworth Scale of muscle spasticity. *Physical Therapy*, 67(2): 206-207.
- Ashworth, B. (1964). Preliminary trial of carisoprodol in multiple sclerosis. *Practitioner*, 192: 540-542.

7.1.2.3 Australian Spasticity Assessment Scale (ASAS)

(Williams, Love, Gibson & Blair 2008)

The Australian Spasticity Assessment Scale (ASAS) is a relatively new clinical measure of spasticity for people with cerebral palsy. It was developed to provide unambiguous, tessellated criteria for scoring spasticity. The scoring criteria are outlined below. Interobserver reliability information for the ASAS has been published.³⁵

Australian Spasticity Assessment Scale (ASAS) Scoring Criteria

- 0 No catch on rapid passive movement (RPM), i.e. no spasticity
- 1 Catch occurs on RPM followed by release. There is no resistance to RPM throughout rest of range
- 2 Catch occurs in second half of available range (after halfway point) during RPM and is followed by resistance throughout remaining range
- 3 Catch occurs in first half of available range (up to and including halfway point) during RPM and is followed by resistance throughout remaining range
- 4 When attempting RPM, the body part appears fixed but moves on slow passive movement

Administration

Assessor: Clinician.

Equipment: Goniometer.

Time Allocated: N/A – part of total clinical assessment.

Key References

- Love, S., Gibson, N., Smith, N., Bear, N., Blair, E. & Australian Cerebral Palsy Register Group (2016). Interobserver reliability of the Australian Spasticity Assessment Scale (ASAS). *Developmental Medicine & Child Neurology*, 58 Supplement 2: 18-24.
- Williams, N., Love, S., Gibson, N. & Blair, E. (2008). Reliability of the Australian Spasticity Assessment Scale. In: P. Baxter, AusACPDM Conference 2008. *The Australasian Academy of Cerebral Palsy and Developmental Medicine Broadening the Scope*, Brisbane, Qld, Australia. 10-13 April, 2008.

7.1.3 Measurement of Tone

Muscle tone refers to the tension in a muscle at rest. It is important to determine the types of muscle tone present in children with cerebral palsy as this can help guide assessment and intervention. Hypertonia is defined as “abnormally increased resistance to externally imposed movement about a joint”.^{36 p. e91} The three subtypes of neurologically mediated hypertonia are spasticity, dystonia and rigidity. Many children with cerebral palsy have mixed tone, a combination of spasticity and dystonia. Rigidity in children with cerebral palsy is rare. Hypotonia, also found in children with cerebral palsy, is characterised by low muscle tone. There are currently no assessment tools for hypotonia.

7.1.3.1 Hypertonia Assessment Tool (HAT)

(Jethwa, Mink, Macarthur, Knights, Fehlings & Fehlings 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 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.³⁷ The presence of at least one HAT item per hypertonia subgroup (i.e. 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.^{38, 39} 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: Clinician completes ALL six items on one extremity before moving to the next hypertonic extremity. Items are listed in the suggested order of administration.

Time Allocated: Approximately five minutes to conduct per limb assessed.

Availability: Download of forms available from:

http://research.hollandbloorview.ca/Assets/research/Documents/Research%20Centres%20and%20Labs/CP%20Discovery%20Lab/HATScoringChart_Nov20102.pdf.

Contact: For further information please contact Dr Darcy Fehlings, developer of the HAT, at dfehlings@bloorview.ca.

Key References

Knights, S., Datto, N., Kawamura, A., Switzer, L. & Fehlings, D. (2014). Further evaluation of the scoring, reliability and validity of the Hypertonia Assessment Tool (HAT). *Journal of Child Neurology*, 29(4): 500-504.

Jethwa, A., Mink, J., Macarthur, C., Knights, S., Fehlings, T. & Fehlings, D. (2010). Development of the Hypertonia Assessment Tool (HAT): a discriminative tool for hypertonia in children. *Developmental Medicine & Child Neurology*, 52(5): e83-e87.

7.1.4 Measurement of Dystonia

Dystonia is defined as “involuntary sustained muscle contractions resulting in twisting and repetitive movements, abnormal postures or both”.³⁶ 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. Contractures are less likely in children with dystonia, unless spasticity is also present (use HAT to determine hypertonia types).

Dystonia is becoming an increasingly recognised hypertonia subtype in children with cerebral palsy. An understanding of dystonia is essential as therapy outcomes are not necessarily as predictable in the dystonic child as the child with spasticity. There are a number of scales that measure dystonia. The Barry-Albright Dystonia Scale (BAD) has been included as it is one of the few specifically developed to assess secondary dystonia and for use in paediatrics.

7.1.4.1 Barry-Albright Dystonia Scale (BAD)

(Barry, Van Swearingen & Albright 1999)

The Barry-Albright Dystonia Scale (BAD) is a reliable and responsive five point criterion based ordinal rating scale for quantifying secondary dystonia.⁴⁰ It rates the severity of dystonia in eight body regions, including eyes, neck, mouth, trunk, upper limbs and lower limbs.

Administration

Assessor: Clinician or Physician experienced in secondary dystonia and cerebral palsy.

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

Availability: The scale can be found in Barry et al. (1999).

Key References

Monbaliu, E., Orbitus, E., Roelens, F., Desloovere, K., Deklerck, J., Prinzie, P., De Cock, P. & Feys, H. (2010). Rating scales for dystonia in cerebral palsy: reliability and validity. *Developmental Medicine & Child Neurology*, 52(6): 570-575.

Barry, M.J., Van Swearingen, J.M. & Albright, A.L., (1999). Reliability and responsiveness of the Barry-Albright Dystonia Scale. *Developmental Medicine & Child Neurology*, 41(6): 404-411.

7.1.5 Strength

Muscle strength can be assessed informally via observation of functional activity and formally via manual muscle testing. Manual muscle testing measures muscle strength using a grading system where the grades are based on three factors:

- The amount of resistance that can be given manually to a contracted muscle or muscle group
- The ability of the muscle or muscle group to move a part through a complete range of motion
- Evidence of the presence or absence of a contraction of the muscle or muscle group.

The grades are:

Muscle Strength Grades

- | | |
|---|--|
| 0 | No contraction |
| 1 | A flicker of contraction but no movement |
| 2 | Movement with gravity eliminated |
| 3 | Movement against gravity only |
| 4 | Movement against gravity with moderate resistance |
| 5 | Movement against gravity with maximum resistance at end of range |

Grasp and pinch strength in the upper limb can also be assessed informally through the observation of functional activities requiring strength (e.g. strength to hold onto pants as they are pulled up in dressing), and formally via instruments such as the Jamar dynamometer for grip strength and the pinch gauge. Whilst the Jamar dynamometer is generally recommended for measuring grip strength, its use is limited in children with very small hands, or in measuring very small changes. Hand-held dynamometers with digital displays may be good because of the small incremental steps that can be measured, however further research is required in the development of procedures to ensure the examiner and positioning does not contribute to inaccurate readings.⁴¹

Administration

Assessor: Physiotherapist or occupational therapist.

Equipment: A hand-held dynamometer to measure isometric strength is generally more reliable than manual muscle testing. A mean of three trials should be taken.

Time Allocated: Dependent on number of muscles assessed.

Availability: Hand-held dynamometers can be purchased through many medical equipment suppliers.

Key References

- Hébert, I., Maltais, D., Lepage, C., Saulnier, J., Crete, M. & Perron, M. (2011). Isometric Muscle Strength in Youth Assessed by Hand-held Dynamometry: A Feasibility, Reliability and Validity Study. *Pediatric Physical Therapy*, 23(3): 289-299.
- Klingels, K., De Cock, P., Molenaers, G., Desloovere, K., Huenaerts, C., Jaspers, E. & Feys, H. (2010). Upper limb motor and sensory impairments in children with hemiplegic cerebral palsy. Can they be measured reliably? *Disability and Rehabilitation*, 32(5): 409-416.
- Mahony, A., Hunt, K., Daley, D., Sims, S. & Adams, R. (2009). Inter-tester reliability and precision of manual muscle testing and hand-held dynamometry in lower limb muscles of children with spina bifida. *Physical and Occupational Therapy in Pediatrics*, 29(1): 44-59.
- Verschuren, O., Ketelaar, M., Takken, T., Van Brussel, M., Helden, P. & Gorter, J.G. (2008). Reliability of hand-held dynamometry and functional strength tests for the lower extremity in children with Cerebral Palsy. *Disability and Rehabilitation*, 30(18): 1358-1366.
- Crompton, J., Galea, M. & Phillips, B. (2007). Hand-held dynamometry for muscle strength measurement in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 49(2): 106-111.
- Taylor, N., Dodd, K. & Graham, G. (2004). Test-Retest Reliability of Hand-Held Dynamometric Strength Testing in Young People with Cerebral Palsy. *Archives of Physical & Medical Rehabilitation*, 85(1): 77-80.

7.1.6 Selective Motor Control

Selective motor control has been defined as “the ability to isolate the activation of muscles in a selected pattern in response to demands of a voluntary movement or posture”.⁴²

^{p.2162} Selective voluntary motor control (SVMC) is an important determinant of functional ability and evidence of SVMC impairment is evident in children with cerebral palsy.

7.1.6.1 Selective Control Assessment of the Lower Extremity (SCALE)

(Fowler, Staudt, Greenberg & Oppenheim 2009)

The Selective Control Assessment of the Lower Extremity (SCALE) is a clinical tool developed to quantify selective voluntary motor control (SVMC) in persons with cerebral palsy, in other words, isolation of joint movement upon request. It assesses SMVC at the hip, knee, ankle, foot and toes. SVMC is scored for each joint as:

Selective Voluntary Motor Control Scoring System

- 2 Normal (movement sequence completed without movement of untested ipsilateral or contralateral lower extremity joints)
- 1 Impaired (able to isolate movement but errors that include: movement in only one direction, movement less than 50% available passive range, movement occurs at non tested joint or time taken for execution greater than 3 seconds)
- 0 Unable (requested movement sequence not initiated or is performed using synergistic mass flexion or extension pattern)

Administration

Assessor: Clinician or Physician.

Time Allocated: Approximately 15 minutes.

Availability: Fowler, Staudt, Greenberg & Oppenheim (2009) reference contains score sheet and instructions.

Contact: Further information may be obtained by emailing Dr Eileen Fowler at efowler@mednet.ucla.edu.

Key References

Fowler, E.G., Staudt, L.A., Greenberg, M.A. & Oppenheim, W.L. (2009). Selective Motor Control of the Lower Extremity (SCALE): development, validation and interrater reliability of a clinical tool for patients with cerebral palsy. *Developmental Medicine & Child Neurology*, 51(8): 607-614.

7.1.6.2 Boyd and Graham Selective Motor Control Scale (SMC)

(Boyd & Graham 1999)

The Boyd and Graham Selective Motor Control Scale (SMC) is a five point observational scale that assesses selective motor control of the dorsiflexors of the ankle.

Boyd and Graham Selective Motor Control Scale (SMC)

- 0 No movement
- 1 Limited dorsiflexion using extensor hallucis longus/extensor digitorum longus
- 2 Dorsiflexion using extensor hallucis longus, extensor digitorum longus and some tibialis anterior activity
- 3 Dorsiflexion achieved mainly using tibialis anterior but accompanied by hip and/or knee flexion
- 4 Isolated dorsiflexion through available range, balance of tibialis anterior activity without hip and knee flexion

Administration

Assessor: Clinician or Physician.

Time Allocated: 10 minutes.

Availability: Guidelines found in Boyd & Graham (1999).

Key References

Smits, D.W., van Groenestijn, A.C., Ketebare, M., Scholtes, V.A., Becher, J.G. & Gorter, J.W. (2010). Selective motor control in the lower extremity in children with cerebral palsy: inter-rater reliability of two tests. *Developmental Neurorehabilitation*, 13(4): 258-265.

Löwing, K. & Brogren Carlberg, E. (2009). Reliability of the Selective Motor Control Scale in children with cerebral palsy. *Advances in Physiotherapy*, 11(2): 58-63.

Boyd, R. & Graham, H.K. (1999). Objective measurement of clinical findings in the use of botulinum toxin type A for the management of children with cerebral palsy. *European Journal of Neurology*, 6 Supplement 4: S23-S35.

7.2 FUNCTIONAL EATING AND DRINKING ASSESSMENT

Dysphagia (disordered oral-motor and swallowing function) is common in children with cerebral palsy due to neurological impairment, and it can affect the ability to eat, drink, take medications and control saliva. Dysphagia can be present across all GMFCS levels but increases in incidence and severity with higher GMFCS levels.⁴³ Incidence of dysphagia in children with cerebral palsy is also linked to brain stem lesion and intellectual disability. Dysphagia in children with cerebral palsy can also lead to increased risk of respiratory related illnesses⁴⁴, poor growth, low body fat stores and poor nutritional status.⁴⁵

Dysphagia can have an impact on the individual's health and growth status and quality of life, including education, sleep and relationships with family and others.

When a child is referred for a mealtime assessment, a multidisciplinary approach is best practice. This is because feeding issues and dysphagia are usually the symptom of an underlying disorder or illness and commonly involve many body and sensory systems. Additionally, mealtime issues are complex and multifactorial, and rely on the skills the client and carers bring to the mealtime situation. The multidisciplinary team can vary according to the resources available in the healthcare setting and the needs of the individual child, and should include members of the medical, nursing and allied health professions.

A clinical assessment of eating and drinking skills, within the mealtime context, should be conducted by a speech pathologist in the first instance. Whilst there are no standardised mealtime assessments specifically for children with cerebral palsy, there are many formal and informal assessments that can be used as a guide of oral-motor and swallowing function.

Assessment of paediatric dysphagia should establish if the child can eat and/or drink safely orally and whether the child gets adequate nutrition and hydration.⁴⁶ This assessment should include the following information:

- Background history (including medical diagnosis and current medical status, nutritional status, anthropometric measures, previous speech pathology involvement)

- Observation of:
 - Eating and drinking skills
 - Length and efficiency of the meal
 - Use of feeding equipment
 - Positioning of child and carer
 - Child's behaviour and level of alertness
 - General mood of the mealtime
 - Communication and cognition
 - Clinical oropharyngeal assessment
 - Oral trial assessment.

Common signs and symptoms suggestive of dysphagia are listed below:

Pulmonary:

- Apnoea/bradycardia
- Asthma and reactive airway disease
- Bronchiolitis/frequent upper respiratory tract infection (URTI)
- Congestion or changes in breathing patterns with possible association with oral intake
- Coughing/choking with oral intake
- Cyanosis, desaturation with oral intake
- Persistent oxygen needs
- Pneumonia (particularly right sided)
- Wet, gurgly, dysphonic voice quality with oral intake
- Wheezing, stridor
- Liquid or food from tracheostomy tube.

Gastrointestinal Tract:

- Arching
- Poor growth, weight loss, or failure to thrive (FTT).

Oral motor dysfunction/inappropriate feeding patterns:

- Drooling
- Gagging
- Feeding refusal
- Poor oral-motor skills
- Prolonged mealtimes.

Other:

- Fevers of unknown origin
- Irritability
- Lethargy with oral intake
- Nasopharyngeal reflux.

7.2.1 Dysphagia Disorder Survey (DDS)

(Sheppard 2002a)

This is standardised for adults with developmental disability but can be used with children older than 2 years of age, with developmental disability. It consists of two main parts: related factors (including Body Mass Index (BMI), restrictions in food textures, dependence in eating, need for special utensils, need for positioning strategies) and swallowing competency (observation of the oral preparatory, oral, pharyngeal and oesophageal phases of swallowing, while the child eats non-chewable and chewable foods, and drinks fluid).

Administration

Assessor: Clinicians need to be certified to use the tool.

Time Allocated: 10 to 15 minutes.

Availability: In Australia, the tool is distributed by the Centre for Disability Studies. For further information please email cds@med.usyd.edu.au.

Contact: For further information please contact Justine Joan Sheppard, developer of the DDS, at jjsheppard@nutritionalmanagement.org.

Key References

Sheppard, J.J., Hochman, R. & Baer, C. (2014). The dysphagia disorder survey: validation of an assessment for swallowing and feeding function in developmental disability. *Research in Developmental Disabilities*, 35(5): 929-942.

Sheppard, J.J. (2002a). *Dysphagia Disorder Survey (Adult and Pediatric Applications)*. Lake Hopatcong, NJ: Nutritional Management Associates, L.L.C.

7.2.2 Dysphagia Management Staging Scale (DMSS)

(Sheppard 2002b)

The Dysphagia Management Staging Scale (DMSS) is a five level staging scale that describes the level of severity of eating disorder. The severity levels are determined by the extent of the special mealtime strategies used and the medical and nutritional consequences of the disorder. The five levels within the DMSS are:

Dysphagia Management Staging Scale (DMSS) Levels

- I No swallowing or feeding disorder
- II Mild swallowing or feeding disorder
- III Moderate swallowing or feeding disorder
- IV Severe swallowing or feeding disorder
- V Profound swallowing or feeding disorder

Administration

Assessor: Clinicians need to be certified to use the tool.

Time Allocated: 10 to 15 minutes.

Availability: In Australia, the tool is distributed by the Centre for Disability Studies. For further information please email cds@med.usyd.edu.au.

Contact: For further information please contact Justine Joan Sheppard, developer of the DDS, at jjsheppard@nutritionalmanagement.org.

Key References

Sheppard, J.J. (2002b). *Dysphagia Disorder Survey and Dysphagia Management Staging Scale (Adult and Pediatric Applications) User's Manual*. Lake Hopatcong, NJ: Nutritional Management Associates.

7.2.3 Schedule for Oral-Motor Assessment (SOMA)

(Reilly, Skuse & Wolke 2000)

The Schedule for Oral-Motor Assessment (SOMA) objectively rates the oral-motor skills of pre-verbal children across a range of food textures and fluids. The tool has been validated with normally developing children and children with oral-motor dysfunction. Ten percent of the sample size was children with cerebral palsy. It enables the speech pathologist to distinguish those infants with normal oral-motor function from those with oral-motor dysfunction. The assessment can be administered by a trained observer and does not require any special equipment.

Administration

Assessor: Clinician.

Time Allocated: 15 to 20 minutes.

Availability: The SOMA is no longer available for purchase but remains a useful resource.

Key References

Reilly, S., Skuse, D. & Wolke, D. (2000). *The Schedule for Oral-Motor Assessment (SOMA)*. Eastgardens, NSW: Whurr.

7.2.4 Nutrition and Swallowing Risk Checklist

(Ageing, Disability and Home Care 2003)

This is a screening checklist developed by the Department of Family and Community Services Ageing, Disability and Home Care Division and intended to be used by people who care for people with a disability. It is not specifically designed for children with cerebral palsy, but the checklist questions apply to this population. By asking questions about the child's health, weight and eating and drinking skills, the checklist can help decide whether further referral/assessment and action is required in the areas of nutrition and swallowing. The person filling out the checklist should know the child well.

Administration

Assessor: Can be completed by the parents/carers, health professionals, case managers, residential care workers, and/or clinicians. The child should be included in answering the questions as much as possible.

Time Allocated: 30 minutes.

Availability: The Nutrition and Swallowing Risk Checklist can be downloaded from: <http://www.adhc.nsw.gov.au/>

Contact: Further information can be obtained by emailing the Ageing, Disability & Home Care Head Office at servicembx@fac.nsw.gov.au.

Key References

Ageing, Disability and Home Care (ADHC) (2003). Nutrition and Swallowing Risk Checklist. *Nutrition in Practice Manual (Second Edition)*.

7.2.5 Videofluoroscopic Swallow Study (VFSS)

A Videofluoroscopic Swallow Study (VFSS) (previously known as Modified Barium Swallow or MBS) is an objective radiological procedure of the structural and dynamic aspects of oropharyngeal and laryngeal function for drinking and eating. It is ONLY recommended after clinical signs of oropharyngeal dysphagia are observed in an initial swallowing evaluation. Speech Pathology Australia published the Videofluoroscopic Swallow Study Clinical Guideline in 2013. This document was developed to ensure that all speech pathology services and practising clinicians were provided with evidence-based guidelines for assessment and management of dysphagia. The guideline was developed to ensure a comprehensive evidence-based resource on VFSS is available for all speech pathology services and practising clinicians and is available from <http://www.speechpathologyaustralia.org.au>.⁴⁷

Many children with cerebral palsy require the use of wheelchairs and/or specialised seating systems for adequate support during meal times. It is important to accommodate supported seating when possible for the VFSS. Any compromises in seating need to be reflected on when analysing the VFSS results.

Indicators for VFSS:

Arvedson and Lefton-Greif⁴⁸ state that indicators for recommending VFSS include:

- The need to further investigate the anatomy and physiology of the oral cavity or pharynx during swallowing
- Identify disorders in motility through the oral cavity or pharynx that control the bolus and cause aspiration or inefficient swallowing
- Define treatment strategies that will eliminate aspiration and increase swallowing efficiency.

Most children are referred for VFSS because they demonstrate clinical presentations suggestive of dysphagia or have diagnostic conditions associated with an increased risk of aspiration.

NB: It should be noted that the VFSS is not the procedure of choice for the evaluation of oral preparatory or oesophageal function. If assessment of these is requested, alternative assessments such as a bedside swallowing assessment or a Barium Swallow should be considered.

Prior to referring for VFSS, the child should have had a clinical assessment of their oral feeding. The findings and impressions should be discussed with the child's managing doctor for a VFSS referral to be agreed upon and made.

Specialist clinics are available at a number of tertiary and non-tertiary facilities across NSW. It is recommended that clinicians make contact initially with local services and then proceed to specialist clinics and tertiary children's hospitals. For further information please refer to Appendix Three.

7.2.6 Drooling Impact Scale (DIS)

(Reid, Johnson & Reddihough 2010)

The Drooling Impact Scale (DIS) evaluates the impact of drooling in children with developmental disabilities. The tool was designed at the Melbourne Royal Children's Hospital and has been validated as a subjective measure of the impact of drooling on caregivers and families, that is sensitive to changes in drooling in response to saliva control interventions.

Administration

The questionnaire consists of ten questions that are rated between 1 and 10 on a semantic differential scale.

Assessor: Parent or caregiver who regularly cares for the child.

Time allocated: Questionnaire takes two minutes to complete.

Scoring: The scores are totalled to give an overall numerical rating of the degree and impact of drooling for that child over the previous week. The maximum possible total for the scale is 100.

Contact: For further information please contact Sue Reid, one of the developers of the DIS, at sue.reid@mcri.edu.au.

Key References

Reid, S. M., Johnson, H.M. & Reddihough, D.S. (2010). The Drooling Impact Scale: a measure of the impact of drooling in children with developmental disabilities. *Developmental Medicine & Child Neurology*, 52(2): e23-e28.

7.3 SENSATION

The purpose of assessing sensation in children with cerebral palsy is to assess the extent of sensory loss or altered sensation and determine the functional limitations decreased sensation may incur. Sensory impairment is often a limiting factor in the functional motor outcomes expected from therapy, casting or splinting. Generally the degree of spontaneous upper limb use parallels the degree of sensory awareness. If the limb is ignored, sensation is usually poor.

A sizeable proportion of children with cerebral palsy will demonstrate abnormal sensation. Therefore it is critical to assess sensibility so to appreciate how particular sensory deficits may undermine and may limit function. There is a link between sensation and motor performance because we need intact sensory feedback for modulating grip forces, in-hand manipulation and tool use. Poor sensation can cause delays in learning new skills, clumsiness and result in an unused extremity. It is important to note however that there are currently no interventions which can change sensation.

Sensory testing lacks good reliability and validity, particularly in the area of paediatric cerebral palsy although recent research not only highlights the importance of sensory assessment but the development of a reproducible assessment battery.^{49, 50}

Protective sensations include: touch, deep pressure, superficial pain and temperature.

Discriminative sensations include: vibration, position sense, two point discrimination, stereognosis and graphesthesia.

7.4 PAIN

A systematic review on cerebral palsy found that three in every four children with cerebral palsy experience pain, regardless of the level of their disability.⁵¹ The systematic review also found pain increases with age and is linked to lower participation levels and higher rates of behavioural problems. Three approaches to measurement of pain in children have been established and include: self-report; observational/behavioural; and physiologic. The literature recommends that in addition to observational and physiologic measures, seeking a child's self-report of pain wherever possible based on their age, communication and cognitive ability is important as pain is primarily an internal experience.^{52, 53} A number of Faces Pain Scales are available as self-report measures of pain intensity in children. Many demonstrate reasonable reliability and validity for use in children over the age of 5 years. A systematic review of Faces Pain Scales concluded that no particular scale demonstrated increased reliability or validity and selection of a scale should meet clinical needs.⁵²

7.4.1 Faces Pain Scale (FPS) and Faces Pain Scale – Revised (FPS-R)

(Bieri, Reeve, Champion, Addicoat & Ziegler, 1990; Hicks, von Baeyer, Spafford, von Korlaar & Goodenough 2001)

The Faces Pain Scale (FPS) is a series of seven horizontal gender neutral faces (scored 0-6) that depict 'no pain' on the left to 'most pain possible' on the right. The revised version, the Faces Pain Scale – Revised (FPS-R), shows six faces and is scored 0-5 or 0-10.

Administration

Assessor: Clinician, parent or caregiver.

Time Allocated: A few minutes to explain the scale and allow child to select pain level. In some cases pain at different body sites may be required.

Availability: The FPS can be found in the journal article – Bieri, Reeve, Champion, Addicoat & Ziegler (1990).

The FPS-R can be found by visiting:

<http://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1519>.

Contact: Further information can be obtained by emailing the International Association for the Study of Pain at IASPdesk@iasp-pain.org.

Key References

Hicks, C.L., von Baeyer, C.L., Spafford, P.A., von Korlaar, I. & Goodenough, J.B. (2001). The Faces Pain Scale-Revised: Toward a common metric in pediatric pain measurement. *Pain*, 93(2): 173-183.

Bieri, D., Reeve, R.A., Champion, G.D., Addicoat, L. & Ziegler, J.B. (1990). The Faces Pain Scale for the self-assessment of the severity of pain experienced by children: Development, initial validation and preliminary investigation for ratio scale properties. *Pain*, 41(2): 139-150.

7.4.2 The Wong-Baker FACES® Pain Rating Scale

(Wong & Baker 1988)

The Wong-Baker FACES® Pain Rating Scale is a horizontal scale with six faces, scored from 0-5 or 0-10, which ranges from smiling or 'no hurt' to crying or 'hurts worst'.

Administration

Assessor: Clinician, parent or caregiver.

Time Allocated: A few minutes to explain the scale and allow child to select pain level. In some cases pain at different body sites may be required.

Availability: The Wong-Baker FACES® Pain Rating Scale can be obtained by visiting <http://www.wongbakerfaces.org/>.

Contact: To contact the Wong-Baker FACES Foundation please visit <http://www.wongbakerfaces.org/contact/>.

Key References

Wong, D.L. & Baker, C.M. (1988). Pain in children: comparison of assessment scales. *Pediatric Nursing*, 14(1): 9-17.

7.5 NUTRITIONAL ASSESSMENT

Children with cerebral palsy frequently exhibit growth failure. Many researchers agree that the cause is multifactorial and is a combination of both nutritional and neurological, or non-nutritional factors. Nutritional factors are primarily protein-energy malnutrition due to inadequate intake, excess losses from vomiting and spillage, and possibly altered energy requirements.^{53, 54, 55, 56, 57, 58}

Neurological or non-nutritional factors that have been postulated to affect growth include:

- Central nervous system (CNS) injury inhibits growth
- A trophic influence from the brain is disrupted causing poor growth
- The abnormal muscle tone and activity created by damage to the CNS, and the consequent disuse and decreased blood flow to the affected limbs, causes dwarfing of the limbs
- Parietal lobe defects associated with sensory deficits inhibit growth.^{54, 56, 57}

In general, dietetic involvement is required for:

- GMFCS V – spastic quadriplegic cerebral palsy
- Poor growth, low fat stores
- Oromotor dysfunction
- Fractures, pressure ulcers
- Major orthopaedic surgery
- Children with cerebral palsy with a gastrostomy button
- Gastrointestinal complications e.g. constipation, reflux.

A comprehensive nutrition assessment should include:

- Anthropometry
- Biochemistry
- Clinical history
- Dietary assessment
- Estimated requirements.

An example of a nutrition assessment form can be found in Appendix Four of this document.

7.5.1 Anthropometry

The study of anthropometry includes measurements and proportions of the human body. When assessing children with cerebral palsy, it is important to consider these factors as they apply specifically to this population.

7.5.1.1 Growth

Growth assessment requires reliable serial measurements (weight, height and body composition) and comparison reference data taken over a period of time. Reliable alternative measures of linear growth are now being adopted; however, there are limited reference curves and reference data available for alternative measures.

7.5.1.2 Weight

Use a weighing chair, wheelchair scales, weighing hoist or bed if patient is unable to stand. Another option to obtain a smaller child's weight would involve the parent or caregiver holding the child on their lap then subtracting the carer's weight. It is always essential to consider Work, Health and Safety parameters during all manual handling tasks. Plot weight on the normal *Centers for Disease Control and Prevention (CDC) reference growth charts* and monitor changes over time, weighing the child every two to four months depending on age. These growth charts are available from their website at <http://www.cdc.gov/>.⁵⁹

An ideal or healthy weight is determined in conjunction with a triceps skinfold measure.

7.5.1.3 Stature

Measure standing height if able and plot on the normal CDC growth charts using standing height for 2-18 year olds. Recumbent length can be used if the child is less than 90cm in length and can fit on an infantometer and does not have joint contractures.

Accurate length measures are often impossible with joint contractures, muscle spasms and inability to stand. Under these circumstances a segmental measure can be used: knee height, tibial length (also known as lower leg length) or upper arm length. The landmarks for segmental lengths may be difficult to identify. Training and practice is required to develop skill and competence in their measurement. All measurements should be taken twice and on the left hand side of the body.⁶⁰ The average of the two measurements should be used.

Upper arm length and knee height should be measured using specialised equipment. Knee height should be measured from the heel to the anterior surface of the thigh over the femoral condyles using a sliding caliper or anthropometer.⁶¹ Upper arm length should be measured from the acromium process to the head of the radius with an anthropometer or Vernier calipers, depending on the size of the child.⁶¹

Figure 2: Measuring upper arm length ⁶⁰

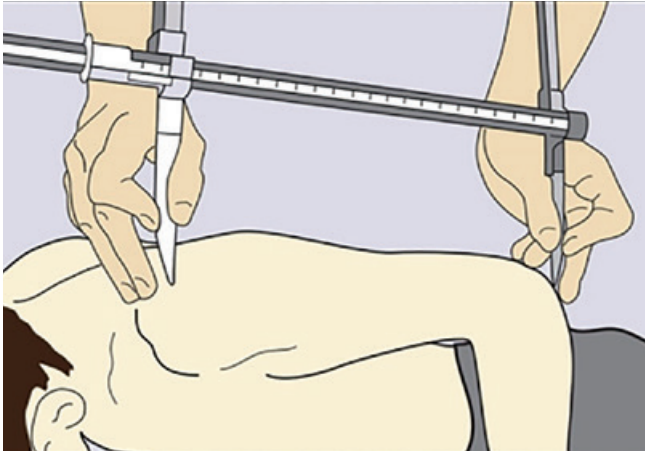


Figure 4: Pre-marking landmarks for accurate measurement of tibial length ⁶⁰

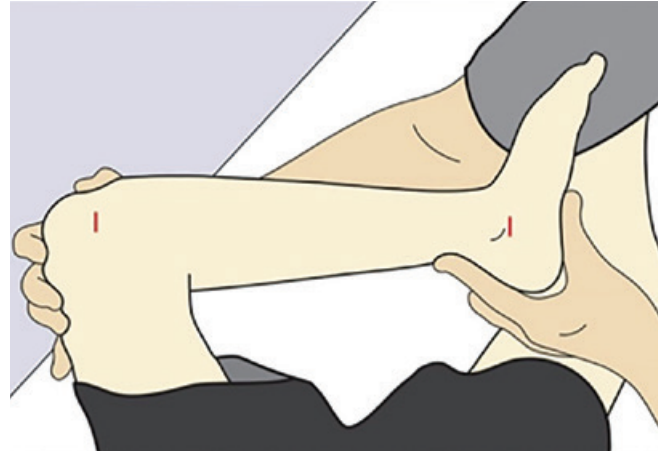


Figure 3: Measuring knee height ⁶⁰

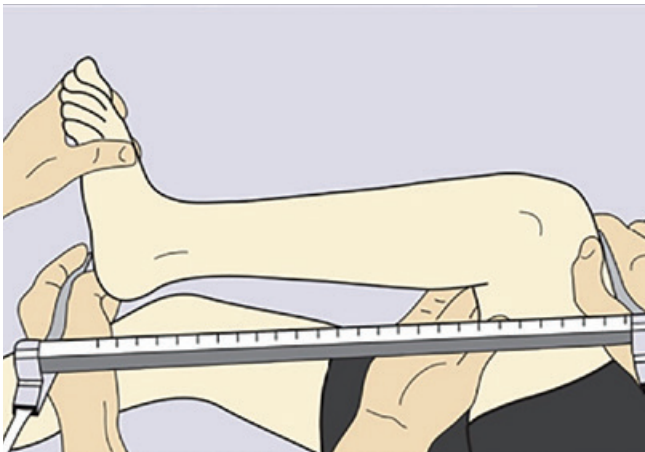
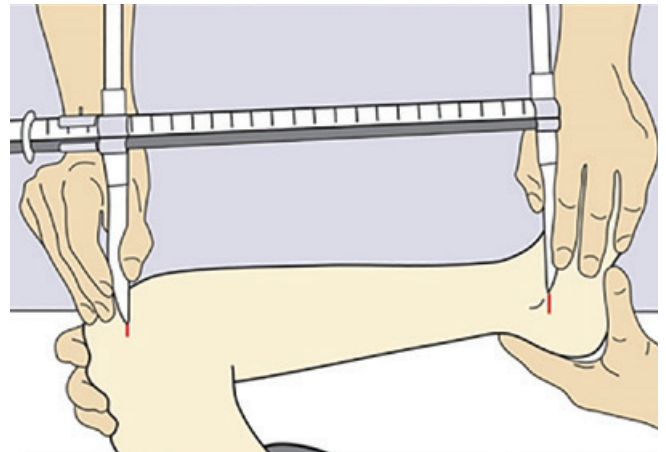


Figure 5: Measuring tibial length ⁶⁰



Tibial length can be measured accurately from the superomedial edge of tibia to the inferior edge of the medial malleolus using steel or plastic measuring tapes.⁶²

Equations are available to convert the segmental measures to standing height. The equations by Stevenson were developed from measurements on a group of children with varying degrees of cerebral palsy, whereas those of Chumlea, Guo & Steinbaugh were developed from a group of typically developing children without cerebral palsy.^{62, 63}

Table 3: Equations to estimate height from knee length in typically developing children and adolescents (6-18 years) ⁶³

Males	Height = 40.54 + (2.22 x KH*)
Females	Height = 43.21 + (2.15 x KH*)

*KH (represented in centimetres) = knee height

Table 4: Equations to predict height from segmental lengths in children with cerebral palsy (under 12 years of age) ⁶³

Segmental Measure	Prediction Equation
Upper arm length (UAL)	Height = (4.35 x UAL*) + 21.8
Tibial length (TL)	Height = (3.26 x TL*) + 30.8
Knee height (KH)	Height = (2.69 x KH*) + 24.2

*Measurements for UAL, TL and KH represented in centimetres

Of the three segmental measures, the landmarks for knee height are the easiest to identify and knee height has been found to be the most reproducible.⁶² Use the Stevenson⁶² equation for children 12 years of age or under and the Chumlea et al.⁶³ equation for children greater than 13 years of age. It may be difficult or impossible to obtain an accurate measurement of knee height in some children with severe contractures of the lower limb, as the distance to be measured crosses two joints. Since the measurement of tibial length does not require specialised equipment, it is not impacted on by knee and ankle contractures and the landmarks are relatively easy to palpate in lean individuals, it may be the most suitable alternative measure for height in children with cerebral palsy. However, training is required to ensure reliable and accurate results.

It is important to note that none of the segmental measures when converted to standing height have been validated in a population of children with severe cerebral palsy because in order to validate the measure the children have to be able to stand up straight to compare with standing height which is impossible in this group. So any alternate measure of height when converted to standing height is an estimate and to be interpreted with caution. For children with severe cerebral palsy, it would be more appropriate to use growth charts for knee height, upper arm length or tibial length to assess linear growth, thereby avoiding any of the potential error associated with prediction equations. Reference charts for lower leg length, upper arm length and knee height have been developed for healthy typically developing children and can be used to assess the linear growth of children with cerebral palsy.^{64, 65, 66}

7.5.1.4 Body Mass Index (BMI) and Weight-for-height

It is not recommended to convert weight and height measurements to body mass index (BMI) or to compare percent ideal body weight to height age because of:

1. Altered body composition (reduced muscle mass and bone mass), and
2. Height measurements in children with severe cerebral palsy are often estimated using alternate measures and may not be entirely accurate.⁶⁷

7.5.1.5 Growth Charts for Cerebral Palsy

Specialised growth charts have been developed for children with cerebral palsy.^{68, 69, 70} These charts however are not necessarily reflective of the optimal growth of well-nourished children as they were derived from populations with potentially high degrees of undernutrition.⁶⁰ Therefore, these charts describe how a group of children with cerebral palsy grew rather than a prescription of how they should grow, and should be viewed with caution.⁷¹ It is essential that a child's growth is monitored over time and that they are growing along their own growth curve.

7.5.1.6 Body Composition

Weight and height measurements do not describe the composition of the body, i.e. fat, muscle mass, water, or bone; or which proportions of these components are significantly different from the average ranges. Precise and accurate measurement of body composition is important to understanding the disease process so that deficits or excesses can be defined and corrected. Children with cerebral palsy generally have lower body fat, protein and bone density compared to the normal population for age.

^{53, 58, 72-75} In addition, there is an increasing divergence of body protein and bone density between children with severe quadriplegic cerebral palsy compared to the healthy population with increasing age. ^{53, 72, 76} A reduced muscle mass and bone density can be due to a combination of malnutrition and lack of use from neurologic impairment. Therefore, using percent of ideal body weight-for-height age (CDC charts) as a measure of nutritional status may fail to identify severe quadriplegic cerebral palsy with depleted fat and protein stores. ^{72, 76, 77}

7.5.1.7 Skinfold Thickness

The measurement of triceps and subscapular skinfold thickness can be used as a tool to measure fat stores in the clinic setting. The skinfold thickness measurements can be compared to reference charts published by Addo and Himes⁷⁸ and monitored over time, approximately every six months. However, the interpretation of skinfold thickness is difficult in children with cerebral palsy because of their unique fat distribution. Studies of children with cerebral palsy have shown that they tend to store more fat centrally, such as the abdomen, rather than in their limbs.^{58, 64, 67, 77, 79, 80} Therefore a reduced skinfold thickness may not necessarily mean that the child has low fat stores. Equations to calculate percent body fat in children with cerebral palsy have been developed however their validity is being evaluated in ongoing studies.⁸⁰

The current suggestion is to aim for a skinfold thickness >10th centile as a cut-off value to screen for sub-optimal fat stores.⁸¹ A study by Samson-Fang, Fung, Stallings, Conaway, Worley, Rosenbaum, Calvert, O'Donnell, Henderson, Chumlea, Liptak & Stevenson⁸² identified an association between children with cerebral palsy and low fat stores (triceps skinfold thickness <10th centile) and increased healthcare use, hospitalisation, doctor visits, missed school days, and days spent in bed.

A variety of different calipers are commercially available. The quality of these calipers differs greatly and will determine the accuracy of the readings. Specific training or supervision in the correct usage of this equipment is suggested.

7.5.2 Biochemistry

Ideally bloods to check nutritional status should be measured every 12 months, particularly for those children on long-term enteral feeds. Blood tests should specifically include:

- Full blood count
- Electrolytes (Sodium/Potassium/Chloride)/Urea/Creatinine
- Total protein
- Albumin
- Trace elements
 - Copper
 - Selenium
 - Zinc
- Vitamins
 - Vitamins A, C, D and E
 - B12, Folate
- Minerals
 - Calcium
 - Magnesium
 - Phosphate
 - Iron studies/ferritin.

7.5.2.1 Notes on Biochemical Markers

- Albumin and prealbumin – poor weight gain in children with cerebral palsy is primarily due to a lack of total calories rather than protein and therefore albumin and prealbumin are generally normal. This however, should not be interpreted as evidence of adequate nutritional status.⁸¹ A study by Lark, Williams, Stadler, Simpson, Henderson, Samson-Fang & Worley⁸³ investigated albumin and prealbumin in a large group of children with moderate to severe cerebral palsy and found that these tests showed little to no correlation with anthropometric measures, growth, severity of cerebral palsy, or general health and appear to be of little value in assessing malnutrition in this group. Samson-Fang & Bell⁸¹ identified that low values may be nutritional (chronic low protein intake) or non-nutritional (fluid shifts of an acutely ill patient, protein losses in urine or stool, or liver disease).

- Serum electrolytes do not necessarily reflect intake. For example, chronic deficient intake of calcium will not have an impact on serum calcium as calcium will be mobilised from the bones to maintain serum levels.⁸¹
- Zinc and carnitine levels are often obtained and carnitine levels are particularly important in the child taking valproic acid. If these levels are found to be low, supplements should be given but the extent to which serum levels reflect body stores is debated.⁸¹
- Vitamin D (measured with a 25 hydroxy vitamin D Level) and iron stores (measured with a serum ferritin along with C reactive protein to exclude artificial elevation by concurrent inflammation) may yield low values in a significant percentage of patients. Normalising vitamin D values is important given the multiple risks to bone health in children with cerebral palsy. If ferritin is low, iron stores should be repleted but consideration should be given to the possibility that deficiency may reflect chronic unrecognised oesophagitis/gastritis.⁸¹

7.5.3 Clinical History

During the assessment, it is important to collect information on relevant medical and social history, medications and supplements, bowels, chest infections, reflux and vomiting, bone health, dental health and recent or upcoming surgeries.

7.5.3.1 Medications

Children with cerebral palsy may be prescribed a variety of different medications. It is essential for clinicians to be aware of any possible side effects that these medications may have as well as the impact of any underlying conditions that these medications may be treating. Typical medications that may be prescribed include:

- Local injections – Neuromuscular blockers (Botulinum Toxin)
- Muscle relaxants – Baclofen, Diazepam, L-dopa
- Anticonvulsants – Lamotrigine, Carbamazepine, Phenytoin, Sodium valproate (Epilim®)
- Reflux Antacids – Omeprazole (Losec®), Ranitidine (Zantac®)
- Proton-pump inhibitors – Omeprazole (Losec®)
- Prokinetics – Erythromycin, Cisapride, Baclofen
- Bisphosphonates (Osteoporosis) – Pamidronate® injections
- Laxatives

◦ Stimulant laxatives

Action: Enhances colonic contractions.

Includes: sennosides (Senna®), bisacodyl (Dulcolax®, Bisalax®) and castor oil.

◦ Lubricant laxatives

Action: Lubricates passage of stool and decreases water re-absorption from stool.

Includes: Mineral oil or liquid paraffin (Agarol®, Parachoc®). Aspiration can cause severe lipoid pneumonia thus is contraindicated in children with cerebral palsy. Anal leakage can cause staining of underwear; it indicates the presence of a stool mass or an excessive dose.

◦ Osmotic laxatives

Action: Absorbs water and makes stools softer and bulkier, making it easier and less painful to pass.

Includes: Salts = magnesium hydroxide* (Milk of magnesia®) and magnesium citrate.

Sugars = lactulose (Actilax®)*, sorbitol*, barley malt extract, polyethylene glycol (Movicol®).

◦ Bulk laxatives

Action: Increases colonic residue and stimulates peristalsis.

Includes: Psyllium (Metamucil®), wheat dextrin (Benefiber®), multiple actives (Stimulance®) etc.

Begin an oral laxative (+ fibre & fluid) immediately after disimpaction and continue for months or longer (cerebral palsy) to prevent reaccumulation of retained stool. The correct dose is that which produces a daily soft stool without side effects. As a rough guide start with the child's age + 5 grams. Ensure adequate fluid intake.

Further information about medications and nutrition can be found in *Medications & Nutrition a Quick Reference for Busy Clinicians*⁸⁴ or *Medications & Nutrition Favourite Fifty General*⁸⁵.

7.5.3.2 Gastroesophageal Reflux Disease (GORD)

Gastroesophageal reflux disease (GORD) in neurologically impaired children is thought to be primarily related to abnormal CNS control mechanisms. In addition, contributing factors of GORD in children with cerebral palsy include prolonged supine positioning, liquid feeds, gastrostomy tube placement, delayed gastric emptying, impaired oesophageal motility, and increased abdominal pressure due to spasticity or seizures.^{86, 87, 88} Reflux in this group of patients can cause vomiting, oesophagitis leading to bleeding and iron deficiency, haematemesis, protein-losing enteropathy, irritability, pain, poor growth and failure to thrive.^{86, 87} Failure to thrive can result from GORD as a result of loss of ingested calories. Extra gastrointestinal symptoms of GORD are most commonly respiratory in nature and include pulmonary aspiration, cough, cyanosis, apnoea, reactive airway disease, pneumonitis, and bronchiectasis. Respiratory tract infections (RTI) have been shown to be a major cause of death in children with cerebral palsy. RTI in children with severe neurodisability are usually caused by aspiration of stomach contents from GORD or direct aspiration of solids or liquids from the mouth and pharynx due to oral and pharyngeal motor problems.⁸⁸

Treatment for GORD can begin with conservative measures such as formula changes (see Formula Selection in section 12.5.2.2), thickening of feeds, giving smaller more frequent feeds, avoidance of overfeeding, refeeding after emesis, and burping techniques.^{86, 87} If the conservative measures fail, the next step is pharmacologic therapy which consists of acid suppressing agents and prokinetic agents. Surgical treatment is available for children who fail pharmacological management, or who have serious complications such as oesophagitis or an oesophageal stricture, that warrant surgical correction of the reflux. Nissen fundoplication, which involves a complete wrap of the gastric fundus around the intra-abdominal oesophagus, is a commonly used procedure for the surgical treatment of GORD.

7.5.3.3 Other Gastrointestinal Complications

Other gastrointestinal complications of cerebral palsy include gastritis and constipation.⁸⁸ Gastritis can be caused by *Helicobacter pylori* infection. Up to 80% of institutionalised people with a disability are reported to be infected with *Helicobacter pylori*.⁸⁷ Gastritis can lead to abdominal pain and vomiting which in turn can lead to decreased food intake. Constipation may be caused by diminished colonic motility, but contributing factors include immobility, low fibre intake, low fluid intake, and the effects of medications. Constipation may cause early satiety, poor feeding, gassiness, abdominal pain, and vomiting, again leading to a decreased oral intake and possibly malnutrition.⁸⁷ In a survey of 271 children with cerebral palsy and neurological impairment, Sullivan, Juszczak, Lambert, Rose, Ford-Adams & Johnson⁸⁹ and Sullivan, Lambert, Rose, Ford-Adams, Johnson & Griffiths⁹⁰ found that gastrointestinal complications were prevalent with 59% suffering from constipation, and 22% with significant vomiting.

7.5.3.4 Bone Health

Many studies have found that children with cerebral palsy have poor bone density.^{74, 75, 91-93} Hypotheses for the poor bone mineralisation found in children with cerebral palsy can again be divided into nutritional and non-nutritional factors.^{94, 95} Non-nutritional contributing factors are lack of weight bearing activity; periods of immobilisation after multiple operative procedures; anticonvulsant medication interfering with vitamin D metabolism (sodium valproate); lack of exposure to sunlight; and metabolic bone disease associated with prematurity. Nutritional factors include oral motor dysfunction resulting in poor nutrition and low calcium intake.

The development of healthy bones is impacted by the following factors:

- Vitamin D
- Calcium intake
- Weight bearing or resistance physical activity
- Pubertal delay.⁹⁶

Vitamin D

Vitamin D deficiency can lead to osteopenia, which in turn can lead to chronic bone pain and fractures. The most common site of fracture in children with immobility is the distal femur.⁹⁶

Children with cerebral palsy that are high risk for vitamin D deficiency include those:

- With low exposure to sunlight
- Living in residential care
- With dark skin
- Taking anticonvulsant medications as they can cause increased degradation of 25 hydroxy vitamin D in the liver
- Suffering from abnormal gut function or malabsorption – small bowel disorders i.e. coeliac disease.

How much vitamin D?

Sunlight exposure is the most important determinant of vitamin D levels.⁹⁷ Skin synthesis of vitamin D occurs through the action of ultraviolet B (UVB) radiation in sunlight, and varies with skin colour, ultraviolet radiation protection (e.g. clothing, shade, sunscreen), time spent outside, latitude, season, time of day, amount of cloud cover, air pollution levels and atmospheric ozone levels.⁹⁸ Therefore, it is not possible to make a single recommendation on the sunlight exposure needed to achieve adequate vitamin D levels to suit all Australian children and adolescents. Recent recommendations are outlined in table 5 below.

Diet is a poor source of vitamin D for most Australians as few foods naturally contain vitamin D (e.g. some fatty fish, including salmon, herring and mackerel) and a small amount is added to table margarines.⁹⁷ Tube feeding formulas have added vitamin D and should be checked for adequacy.

The serum vitamin D status of children with cerebral palsy should be evaluated annually and if necessary vitamin D supplementation commenced at 400 IU/day.⁹⁶

Table 6: Definition of vitamin D status ⁹⁷

	Serum 25 Hydroxy Vitamin D level
Severe deficiency	<12.5 nmol/L
Moderate deficiency	12.5 – 29 nmol/L
Mild deficiency	30 – 49 nmol/L
Sufficient	>50 nmol/L
Elevated	>250 nmol/L

Table 5: Sunlight protection and exposure guidelines for people in Australia by skin type ⁹⁷

Infants, children, adolescents	Light to olive skin	Naturally dark skin
Summer or UV index >3	Avoid sunburn; full sun protection with sunscreen, hat, clothing, shade and sunglasses.	Avoid sunburn; intermittent sun exposure without sunscreen can be tolerated, but hat and sunglasses still recommended.
	Encourage active play and physical activity outside during and after school/preschool.	
Winter	Sun protection recommendations vary with latitude and UV index; if UV index <3, sun protection not required unless in alpine regions, outside for extended periods or near highly reflective surfaces such as snow or water.	Sunscreen not needed in southern states of Australia unless near highly reflective surfaces such as snow or water; it may not be possible to maintain recommended serum 25 hydroxy vitamin D levels through sun exposure alone in southern states of Australia.
	Encourage active play and physical activity outside during and after school/preschool.	

Table 7: Management of mild and moderate or severe vitamin D deficiency in infants, children and adolescents ⁹⁷

		Oral doses of vitamin D ₃	
		Treatment	Maintenance and prevention in those with ongoing risk factors
3 – 12 months old	Mild deficiency	400 IU/day for 3 months	400 IU/day
	Moderate or severe deficiency	1000 IU/day for 3 months or 50,000 IU stat	400 IU/day
1 – 18 years	Mild deficiency	1000-2000 IU/day for 3 months or 150,000 IU stat	400 IU/day or 150,000 IU at start of Autumn
	Moderate or severe deficiency	1000 – 2000 IU/day for 6 months, or 3000 – 4000 IU/day for 3 months or 150,000 IU stat, repeat in 6 weeks	400 IU/day or 150,000 IU at start of Autumn

Calcium intake

Recommended dietary calcium intakes for healthy children are shown below. A study by Henderson et al.⁷⁵ found that bone mineral density (BMD) in the femur of children with spastic cerebral palsy was lower than recommendations with calcium intakes of <500 milligrams per day. However, it is unclear whether higher intakes (above the recommended dietary intake) of calcium through supplementation improve bone strength in the longer term. Therefore, the current recommendations are to aim for the recommended dietary intake (RDI).⁹⁶

Table 8: Recommended Dietary Intake (RDI) of calcium⁹⁶ in milligrams (mg)

Calcium intake	
< 6 months	210 mg/day
6 – 12 months	270 mg/day
1 – 3 years	500 mg/day
4 - 8 years	800 mg/day
9 - 18 years	1300 mg/day

Dietary sources of calcium are better than supplements at improving markers of bone health.

Weight bearing or resistance physical activity

Reduced mobility is the major etiological factor for bone fragility in children with cerebral palsy.⁹⁶ In non-ambulant children with cerebral palsy, a standing frame to facilitate upright position has been shown to improve BMD, with the gains in BMD being proportional to the duration of standing.⁹⁹

Pubertal delay

Pubertal hormones, oestradiol in females and testosterone in males, influence longitudinal bone growth and bone mineral accrual, with their appropriate timing being important for normal skeletal development and the attainment of peak bone mass.⁹⁶

7.5.4 Dietary Assessment

There have been many studies investigating the energy and nutrient intakes of oral-fed children with cerebral palsy. In general, the studies agree that the energy and micronutrient intakes of most children with cerebral palsy are below that recommended for age; and that energy intakes tended to decrease with increasing severity of cerebral palsy.^{89, 100-104} Accurately estimating energy and nutrient intakes in oral-fed children with cerebral palsy is difficult due to losses from spillage, vomiting and regurgitation. Studies by Stallings, Zemel, Davies, Cronk & Charney¹⁰⁵ and Arrowsmith, Allen, Gaskin, Somerville, Birdsall, Barzi & O'Loughlin¹⁰⁶ have shown that food records from oral-fed children with severe cerebral palsy are greatly overestimated and are therefore of limited value in this population. However a further study by Walker, Bell, Boyd & Davies¹⁰⁷ found that three-day weighed food records did not accurately reflect energy intake in a group of children with varying degrees of cerebral palsy. Three-day food records are time-consuming and of questionable value in this group of patients. A qualitative, rather than quantitative, diet history could be more useful in oral-fed children to assess micronutrient intakes and to check if all food groups are represented. Gastrostomy tube feeding allows a more accurate estimate of dietary intake because there are no, or minimal, losses from spillage, and the exact energy and nutrient composition of the formula are known.

Questions that can be asked of the parents or caregivers about their child's feeding which may influence nutritional interventions include:

- Are you happy with your child's ability to feed?
- Are meal times stressful to you or your child?
- How long do meals take?
- Is your child able to feed themselves or do they require assistance?
- Does your child experience any coughing, gagging or choking during eating? How much food/drink is lost from vomiting or spillage?
- How is your child positioned during mealtimes?
- Has your child's ability to feed changed over time?
- What is the consistency of food and drink consumed? Do you use fluid thickeners?
- Has your child had a number of chest infections which have required the prescription of antibiotics or hospitalisation in the past 12 months?
- What is your child's meal time routine at home, school and respite?
- How does illness impact on your child's intake?
- Ask about the child's usual daily intake of food, fluids and supplements to check for adequate micronutrient, fibre and fluid intake.

Some indications that a child with cerebral palsy has feeding/swallowing problems are:

- Taking longer than 30 minutes to eat a meal
- If mealtimes are stressful to either the parent or child, or both
- Weight loss or lack of weight gain over two to three months in a young child
- Increased congestion at meal times, "gurgly" voice, frequent respiratory illness.¹⁰⁸

Ideally, all assessments should be completed with a Speech Pathologist. If a child displays any difficulty swallowing then further referral for detailed assessment should occur.

7.5.5 Estimating Energy Requirements

Studies have shown that the recommended age-specific equations to estimate energy requirements based on neurologically intact active children greatly overestimate the energy requirements of children with cerebral palsy.^{105, 106, 109} This overestimation is partly because of decreased basal metabolic rates (related to reduced lean body mass and adaptation to chronic poor nutrition) but largely because of reductions in physical activity levels.^{73, 105} However, despite the many years of research in this area, there are still no available equations to accurately estimate the energy requirements of children with cerebral palsy. Thus the recommendations are to roughly estimate requirements using the currently available equation based on healthy children and adjust according to weight change.^{106, 108}

To estimate energy requirements for children with cerebral palsy, it is recommended to use the Schofield equation for age and calculate a range from basal metabolic rate (BMR) to basal metabolic rate (BMR) x 1.2, and then monitor closely and adjust according to weight change.^{73, 105, 106} It is always best to underestimate rather than overestimate energy requirements as overfeeding can result in an increase of complications such as reflux and consequently aspiration and chest infections.

Table 9: Schofield equations for Basal Metabolic Rate (BMR)¹¹⁰

<3 years	BMR (m) = 0.249 wt – 0.127
<3 years	BMR (f) = 0.244 wt – 0.130
3-10 years	BMR (m) = 0.095 wt + 2.110
3-10 years	BMR (f) = 0.085 wt + 2.033
10-18 years	BMR (m) = 0.074 wt + 2.754
10-18 years	BMR (f) = 0.056 wt + 2.898

7.5.5.1 Protein Requirements

There is currently no evidence to suggest that protein requirements of children and adolescents with cerebral palsy differ to those of typically developing peers, and therefore recommendations for typically developing children and adolescents can be applied.^{108, 111}

For severely undernourished children (e.g. triceps skinfold thickness <3rd centile) additional protein and energy may be required to promote catch up growth. Overall, an intake of 2 g/kg/day of protein (or minimum of 9% of energy intake as protein) and an additional 10-20% increase in energy intake should be sufficient in these instances.^{106, 111, 112}

7.5.5.2 Fluid Requirements

Some children with cerebral palsy have fluid losses through excess salivation (sialorrhea) or sweating and are unable to consume adequate quantities of fluid and/or to communicate thirst. Actual body weight, rather than age, is used to calculate fluid requirements using the Holliday-Segar equation.¹¹³

Table 10: Calculating fluid needs ¹¹³

Weight	Calculation
1 - 10 kg	100 ml/kg
10 - 20 kg	1000 ml + 50 ml/kg for every kg over 10 kg
>20 kg	1500 ml + 20 ml/kg for every kg over 20 kg

However the calculated fluid needs may not be realistic, particularly for those children with reflux, therefore in clinical practice a goal of 90% of ideal fluid intake is feasible.¹¹³

Increasing the fluid intake in children with cerebral palsy who suffer from constipation may not be effective unless their fluid intake is particularly low.¹¹⁴

Signs of dehydration include:

- Strong smelling urine
- Reduced number of wet nappies
 - infants should have about six to eight wet nappies every day
 - older children should have about four to five wet nappies/trips to the toilet every day
- Increased irritability or drowsiness
- Dry skin, mouth and tongue
- Constipation
- Sunken eyes.¹¹⁵

7.5.5.3 Micronutrients

Children with cerebral palsy are at risk of inadequate micronutrient intakes because of their reduced energy requirements and subsequent intake.¹¹⁶ Micronutrient deficiency can impair immune function, lower cognitive function, reduce bone density, and stunt growth.¹¹⁶ There has been little research on micronutrient adequacy in children with cerebral palsy, either in those receiving supplemental nutrition or otherwise, making it difficult for any recommendations for micronutrient intakes.¹¹⁶ Therefore, for individuals with cerebral palsy aim for the Estimated Average Requirement (EAR) or approximately 70% of the Recommended Dietary Intake (RDI) or Adequate Intake (AI), with specific note to:

- Iron
- Zinc and vitamin C for pressure ulcers
- Calcium.¹¹⁷

7.5.6 Overall Summary of Nutritional Assessment

Given the complexity and challenges of nutritional assessment among patients there are no strict criteria to define malnutrition in children with cerebral palsy.⁸¹ It can therefore be difficult to determine when nutritional intervention is required. The keys to success are collaboration with families and carers, use of multiple methodologies (e.g. feeding history, anthropometry, skinfold thickness, and serum biochemistry) and longitudinal repeated assessments.⁸¹ Overall the child and family should enjoy a safe eating experience, diet should be varied enough to provide adequate macronutrients, micronutrients, fibre and fluid.⁸¹ Children should gain weight and grow. Fat stores should be in the broad range of normal.⁸¹ Plateaus in growth or “deviation from established pattern”, low fat stores, or periods of dehydration and poor dietary intake is a concern and indicate that nutritional intervention is required.⁸¹

MANAGEMENT OF CEREBRAL PALSY IN CHILDREN



ACTIVITY AND PARTICIPATION ASSESSMENT

8. ACTIVITY AND PARTICIPATION ASSESSMENT

Assessment Tool		Section
Gross Motor and Mobility Assessment		8.1
	Gross Motor Function Measure (GMFM)	8.1.1
	3 Dimensional Gait Analysis (3DGA)	8.1.2
	Observational (2D) Gait Analysis	8.1.3
	Gillette Mobility Scale	8.1.4
	Walk Tests	8.1.5
	Timed Up and Go	8.1.6
	Timed Up and Down Stairs	8.1.7
Fine Motor and Upper Limb Assessment		8.2
	Quality of Upper Extremity Skills Test (QUEST)	8.2.1
	Assisting Hand Assessment (AHA) & Mini Assisting Hand Assessment (Mini-AHA)	8.2.2
	Melbourne Assessment 2: A Test of Unilateral Upper Limb Function (MA2)	8.2.3
	Shriners Hospital Upper Extremity Evaluation (SHUEE)	8.2.4
	Children's Hand-Use Experience Questionnaire (CHEQ)	8.2.5
	ABILHAND-Kids	8.2.6
	Box and Blocks Test	8.2.7
	Jebsen-Taylor Hand Function Test (JTHFT)	8.2.8
Speech and Language Assessment		8.3
Quality of Life Assessment		8.4
	Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD™)	8.4.1
	Cerebral Palsy Quality of Life Questionnaire (CP QOL©)	8.4.2
	Paediatric Evaluation of Disability Inventory (PEDI)	8.4.3
	Care and Comfort Hypertonicity Questionnaire (CCHQ)	8.4.4

8.1 GROSS MOTOR AND MOBILITY ASSESSMENT

The assessment of gross motor abilities and mobility provide the clinician with information about each child's methods of mobility as well as information about their endurance and speed. A variety of assessments exist, some developed specifically for children with cerebral palsy and others for children with a variety of mobility difficulties.

8.1.1 Gross Motor Function Measure (GMFM)

(Russell, Rosenbaum, Avery & Lane 2002)

The Gross Motor Function Measure (GMFM) is a criterion referenced clinical measure designed to evaluate change in gross motor function in children with cerebral palsy. Existing research indicates that it is reliable, valid and responsive to change.¹¹⁸⁻¹²² It assesses gross motor function in five dimensions:

Gross Motor Function Measure (GMFM) Dimensions

- A Lying and rolling
- B Sitting
- C Crawling and kneeling
- D Standing
- E Walking, running and jumping

There are two versions of the GMFM. The GMFM-88 consists of 88 items and item scores can be summed to calculate raw and percent scores for each of the five dimensions to give a total percentage (%) score. The GMFM-66 consists of 66 items and the item scores are converted to an interval level total score using the Gross Motor Ability Estimator software.

The GMFM (either version) would be appropriate for children whose motor skills were at or below those of a 5 year old child without any motor disability.

Administration

Assessor: The GMFM was designed for use by paediatric physiotherapists who are familiar with assessing motor skills in children. Users should familiarise themselves with the GMFM guidelines and score sheet prior to assessing children. It may be helpful to practice on several children with and without motor disabilities prior to using it for clinical assessments. It is recommended that users assess their reliability with the GMFM prior to using it.

Time Allocated: GMFM-88 takes approximately 45 to 60 minutes to administer. GMFM-66 takes approximately 30 to 40 minutes to administer.

Availability: The GMFM-66 and GMFM-88 User's Manual can be purchased from Wiley Blackwell Publishing. Score sheets can be downloaded free of charge from the CanChild website at <https://www.canchild.ca/en/resources/44-gross-motor-function-measure-gmfm>.

Contact: For further information please contact the CanChild Centre for Childhood Disability Research at canchild@mcmaster.ca.

Key References

- Russell, D.J., Rosenbaum, P.L., Wright, M. & Avery, L.M. (2013). Gross Motor Function Measure (GMFM-66 and GMFM-88) user's manual. London: MacKeith Press.
- Harvey, A., Robin, J., Morris, M.E., Graham, H.K. & Baker, R. (2008). A systematic review of measures of activity limitation for children with cerebral palsy. *Developmental Medicine & Child Neurology*, 50(3): 190-198.
- Wei, S., Su-Juan, W., Yuan-Gui, L., Hong, Y., Xiu-Juan, X. & Xiao-Mei, S. (2006). Reliability and validity of the GMFM-66 in 0- to 3- year-old children with cerebral palsy. *American Journal of Physical Medicine & Rehabilitation*, 85(2): 141-147.
- Russell, D.J., Rosenbaum, P.L., Avery, L.M. & Lane, M. (2002). Gross Motor Function Measure (GMFM-66 and GMFM-88) user's manual. London: MacKeith Press.
- Russell, D.J., Avery, L.M., Rosenbaum, P.L., Raina, P.S., Walter, S.D. & Palisano, R.J. (2000). Improved scaling of the Gross Motor Function Measure for children with cerebral palsy: evidence of reliability and validity. *Physical Therapy*, 80(9): 873-885.

8.1.2 3 Dimensional Gait Analysis (3DGA)

The use of instrumented 3 Dimensional Gait Analysis (3DGA) to define gait deviations and facilitate appropriate treatment options is the 'gold standard'. The clinicians perform a physical assessment and use visual analysis to assess the child. Instrumented gait analysis adds biplanar video recording of the child's gait pattern to describe 3D motion of the body in terms of joint angles and angular displacements at the pelvis, hip, knee and ankle; and velocities and accelerations, otherwise referred to as kinematic analysis. 3DGA also provides kinetic analysis to measure the forces applied to the body and the mechanisms that produce motion otherwise known as moments and powers. The timing of muscle activity is recorded using dynamic electromyography (EMG). All of these data are collected, processed and analysed and then presented to a team of doctors, clinicians and biomechanists with experience in gait abnormalities and treatment. Final recommendations for interventions are determined from this team assessment.

Administration

Assessor: Clinicians employed by the gait laboratory - physiotherapists and biomechanists.

Time Allocated: Four hours to record the data, four hours to gather the data and analyse it, and 30 minutes to report on it at a gait reporting meeting.

Availability: Referrals are received from the rehabilitation specialists and orthopaedic surgeons only at the three tertiary hospitals (John Hunter Children's Hospital, Sydney Children's Hospital and Children's Hospital at Westmead). All 3DGA is done by the Paediatric Gait Analysis Service of NSW at the Humpty Dumpty Paediatric Gait Analysis Lab, Children's Hospital at Westmead.

Key References

Harvey, A. & Gorter, J.W. (2011). Video gait analysis for ambulatory children with cerebral palsy: Why, when, where and how! *Gait and Posture*, 33(3): 501-503.

McGinley, J.L., Baker, R., Wolfe, R. & Morris, M.E. (2009). The reliability of three-dimensional kinematic gait measurements: A systematic review. *Gait and Posture*, 29(3): 360-369.

8.1.3 Observational (2D) Gait Analysis

2D video analysis can be used when instrumented gait analysis is not possible. It is low cost, readily available and easy to use in the clinical setting. There are various observational gait scales that can be used to assist in analysis of the video recording of gait. These include the Ranchos Los Amigos Observational Gait Assessment, Edinburgh Visual Gait Scale, Salford Gait Tool and the Physician Rating Scale.

Administration

Assessor: Clinician.

Location: To be performed indoors, along a long, flat, straight enclosed corridor, with a hard surface, and that allows enough room to capture video from the front/back and lateral aspects.

Time Allocated: 10 minutes plus additional time to score.

Key References

Toro, B., Nester, C.J. & Farren, P.C. (2007). The development and validity of the Salford Gait Tool: an observation-based clinical gait assessment tool. *Archives of Physical Medicine & Rehabilitation*, 88(3): 321-327.

Maathuis, K.G.B., PhD, van der Schans, C.P., van Iperen, A., Rietman, H.S. & Geertzen, J.H.B. (2005). Gait in Children with Cerebral Palsy: Observer Reliability of Physician Rating Scale and Edinburgh Visual Gait Analysis Interval Testing Scale. *Journal of Pediatric Orthopaedics*, 25(3): 268-272.

Kerr, A.M., Hazlewood, M.E., van der Linden, M.I., Hillman, S.J. & Robb J.E. (2002). The Edinburgh Visual Gait Score as an outcome measure after surgical intervention cerebral palsy. *Gait and Posture*, 16: S116.

Read, H.S., Hillman, S.J., Hazlewood, M.E. & Robb, J.E. (1999). The Edinburgh Visual Gait Analysis Interval Testing (G.A.I.T.) Scale. *Gait and Posture*, 10(1): 63-64.

Koman, L.A., Mooney, J.F., Smith, B., Goodman, A. & Mulvaney, T. (1993). Management of cerebral palsy with botulinum-A toxin: preliminary investigation. *Journal of Pediatric Orthopaedics*. 13(4): 489-495.

Gronley, J. & Perry, J. (1984). Gait Analysis Techniques: Rancho Los Amigos Hospital Gait Laboratory. *Physical Therapy*, 64(12): 1831-1838.

8.1.4 Gillette Mobility Scale

(Novacheck, Stout & Tervo 2000)

The Gillette Mobility Scale is a 10 level, parent-report walking scale encompassing a range of walking abilities from non-ambulatory to ambulatory in all community settings and terrains. It was developed at Gillette Children's Specialty Healthcare (GCSH) as part of the Gillette Functional Assessment Questionnaire (FAQ). Good test-retest reliability among parents and good inter-rater reliability between parents and community caregivers was demonstrated. Content and concurrent validity were also high, as assessed by correlation to standardised functional outcome measures, energy expenditure, and gait-analysis information. A reliable and valid scale specific to the task of walking such as the FAQ can assist clinicians in documenting functional change in children with chronic neuromuscular conditions.

Administration

Assessor: Parents and/or carers are asked to select the level that best describes their child's usual/typical walking ability.

Time Allocated: 10 minutes.

Availability: The Gillette Mobility Scale can be found in Novacheck, Stout & Tervo (2000).

Key References

Novacheck, T.F., Stout, J.L. & Tervo, R. (2000). Reliability and validity of the Gillette Functional Assessment Questionnaire as an outcome measure in children with walking disabilities. *Journal of Pediatric Orthopaedics*, 20(1): 75-81.

8.1.5 Walk Tests

Walk tests measure the walking capacity of the child. They are an easy, repeatable and objective measure. The 10 minute walk measures speed, stride length and cadence and the six minute walk measures endurance. There are other walk tests measuring the distance walked over varying time periods e.g. one minute and two minute walk tests. The type of walk test used in assessment needs to be considered in relation to the functional mobility of the child and the clinical setting. Increasing evidence in the reliability and validity of these tests is emerging in the literature. For example, the six minute walk has been shown to have good reliability and sensitivity to change in adults with cerebral palsy.¹²³

Administration (six minute walk)

Based on the official statement of the American Thoracic Society.¹²⁴

Assessor: Clinician.

Location: To be performed indoors, along a long, flat, straight enclosed corridor, with a hard surface, of 30 metres in length.

Test Instructions: Children should start in the standing position at the starting line. Standardised phrases for encouragement are used at each minute during the test (as outlined in the guidelines, American Thoracic Society Statement).¹²⁴

Distance is calculated to the nearest metre using a metre marker or trundle wheel.

Retesting: This should be performed in the same environment using the same splinting, walking aides and measurement technique.

Key References

Chrysagis, N., Skordilis, E. & Koutsouki, D. (2014). Validity and clinical utility of functional assessments in children with cerebral palsy. *Archives of Physical Medicine & Rehabilitation*, 95(2): 369-374.

Slaman, J., Dallmeijer, A., Stam, H., Russchen, H., Roebroek, M. & van den Berg-Emons, R. Learn2Move Research Group (2013). The six-minute walk test cannot predict peak cardiopulmonary fitness in ambulatory adolescents and young adults with cerebral palsy. *Archives of Physical Medicine & Rehabilitation*, 94(11): 2227-2233.

Leunkeu, N.A., Shephard, R.J. & Ahmaidi S. (2012). Six-minute walk test in children with cerebral palsy Gross Motor Function Classification System levels I and II: reproducibility, validity, and training effects. *Archives of Physical Medicine & Rehabilitation*, 93(12): 2333-2339.

McDowell, B.C., Humphreys, L., Kerr, C. & Stevenson, M. (2009). Test-retest reliability of a 1-min walk test in children with bilateral cerebral palsy (BSCP). *Gait Posture*, 29(2): 267-269.

Thompson, P., Beath, T., Bell, J., Jacobson, G., Phair, T., Salbach, N.M. & Wright, F.V. (2008). Test-retest reliability of the 10-metre fast walk test and 6-minute walk test in ambulatory school-aged children with cerebral palsy. *Developmental Medicine & Child Neurology*, 50(5): 370-376.

McDowell, B.C., Kerr, C., Parkes, J. & Cosgrove, A. (2005). Validity of a 1 minute walk test for children with cerebral palsy. *Developmental Medicine & Child Neurology*, 47(11): 744-748.

8.1.6 Timed Up and Go

(Williams, Carroll, Reddihough, Phillips & Galea 2005)

The Timed Up and Go was first developed as a bedside balance and mobility test for the frail elderly population with good reliability and validity. Average scores for typically developing children have been studied (4, 6, 8 years) and good reliability with children with cerebral palsy established.

Administration

Child is seated on a stable stool or chair without arm rests (knee angle 90°, feet flat on floor) and asked to stand up, walk three metres, touch a mark on a wall then return and sit down. Usual footwear and orthoses are worn and walking aides permitted. No physical assistance is provided. Timing begins as child leaves seat and stops as child's bottom touches the seat. Three timed trials are conducted and the best trial is recorded.

Assessor: Clinician.

Location: To be performed indoors on a level surface.

Time Allocated: 15 minutes.

Availability: The Timed Up and Go test can be found in Dhote, Khatri & Ganvir (2012).

Key References

Dhote, S.N., Khatri, P.A. & Ganvir, S.S. (2012). Reliability of "Modified timed up and go" test in children with cerebral palsy. *Journal of Pediatric Neurosciences*, 7(2): 96-100.

Williams, E.N., Carroll, S.G., Reddihough, D.S., Phillips, B.A. & Galea, M.P. (2005). Investigation of the timed 'Up & Go' test in children. *Developmental Medicine & Child Neurology*, 47(8): 518-524.

8.1.7 Timed Up and Down Stairs

(Zaino, Marchese & Westcott 2004)

The Timed Up and Down Stairs was developed as a functional mobility outcome measure. It requires a certain amount of strength of the lower limbs and trunk, range of motion of the lower limbs, co-ordination of fast reciprocal movements and anticipatory and reactive postural control. It has been tested for reliability and validity in children with and without cerebral palsy aged 8-14 years.

Administration

Child stands 30 centimetres from the bottom of a 14 step flight of stairs and is instructed to "quickly but safely go up the stairs, turn around on the top step (landing) and come all the way down until both feet land on the bottom step (landing)".^{125 p.91} The child can choose any method of traversing the stairs but must be facing forwards, not sideways. The score is the time in seconds from the "go"^{125 p.91} cue to the second foot returned to the bottom landing.

Assessor: Clinician.

Location: Any location but needs to be documented and reproducible.

Time Allocated: Five minutes.

Availability: The Timed Up and Down Stairs is described in Zaino et al. (2004).

Key References

Zaino, C.A., Marchese, V.G. & Westcott, S.L. (2004). Timed Up and Down Stairs Test: Preliminary Reliability and Validity of a New Measure of Functional Mobility. *Pediatric Physical Therapy*, 16(2): 90-98.

8.2 FINE MOTOR AND UPPER LIMB ASSESSMENT

Specific upper limb assessments are frequently used to determine a baseline and guide and measure the effectiveness of upper limb interventions. A variety of assessments and questionnaires have been developed specifically for children with cerebral palsy whilst others mentioned in this section have been normed on the typically developing population but used with children with cerebral palsy.

8.2.1 Quality of Upper Extremity Skills Test (QUEST)

(DeMatteo, Law, Russell, Pollock, Rosenbaum & Walter 1992)

The Quality of Upper Extremity Skills Test (QUEST) is a standardised, criterion referenced paediatric assessment that evaluates the quality of upper extremity function in the domains of dissociated movement, grasp, protective extension and weight bearing. It is validated for children with spasticity aged 18 months to 8 years. The assessment focuses on patterns of movement that form the basis of developmental upper limb performance. The QUEST is a reliable and valid measure for evaluating quality of movement in children with cerebral palsy.

Administration

The QUEST is administered within a play context.

Assessor: Occupational therapist, no specific training or accreditation required.

Time Allocated: 30 to 45 minutes.

Availability: The QUEST can be purchased:

<https://canchild.ca/en/resources/49-quality-of-upper-extremity-skills-test-quest>.

Contact: For further information contact canchild@mcmaster.ca.

Key References

Klingels, K., De Cock, P., Desloovere, K., Huenaeerts, C., Van Nuland, I., Huysmans, A. & Feys, H. (2008). Comparison of the Melbourne Assessment of Unilateral Upper Limb Function and the Quality of Upper Extremity Skills Test in hemiplegic CP. *Developmental Medicine & Child Neurology*, 50(12): 904-909.

Sorsdahl, A.B., Moe-Nilssen, R. & Strand, L.I. (2008). Observer reliability of the Gross Motor Performance Measure and the Quality of Upper Extremity Skills Test, based on video recordings. *Developmental Medicine & Child Neurology*, 50(2): 146-151.

Haga, N., van der Heijden-Maessen, H.C., van Hoorn, J.F., Boonstra, A.M. & Hadders-Algra, M. (2007). Test-retest and inter- and intrareliability of the quality of the Upper-Extremity Skills Test in preschool-age children with cerebral palsy. *Archives of Physical Medicine & Rehabilitation*, 88(12): 1686-1689.

Sakzewski, L., Ziviani, J. & Van-Eldik, N. (2001). Test/retest reliability and inter-rater agreement of the Quality of Upper Extremities Skills Test (QUEST) for older children with acquired brain injuries. *Physical and Occupational Therapy in Pediatrics*, 21(2-3): 59-67.

DeMatteo, C., Law, M., Russell, D., Pollock, N., Rosenbaum, P. & Walter, S. (1992). *Quality of Upper Extremity Skills Test*. Hamilton, ON: McMaster University, Neurodevelopmental Clinical Research Unit.

DeMatteo, C., Law, M., Russell, D., Pollock, N., Rosenbaum, P. & Walter, S. (1993). The reliability and validity of Quality of Upper Extremity Skills Test. *Physical and Occupational Therapy in Pediatrics*, 13(2): 1-18.

8.2.2 Assisting Hand Assessment (AHA) and Mini Assisting Hand Assessment (Mini-AHA)

(Krumlinde-Sundholm, Holmefur & Eliasson 2007; Greaves, Imms, Dodd & Krumlinde-Sundholm 2013)

The Assisting Hand Assessment (AHA) and the Mini Assisting Hand Assessment (Mini-AHA) are criterion referenced outcome measures designed for use with hemiplegic children with cerebral palsy. The AHA is used for children aged 18 months to 12 years and the Mini-AHA for children aged 8 to 18 months. They aim to measure and describe how effectively the child uses their hemiplegic or affected hand in collaboration with their non-affected hand during bimanual play. The assessments consist of a 15 minute semi structured play session using a test kit (either the Mini-AHA: for children 8 to 18 months; Small Kids AHA: for children 18 months to 5 years of age; or School Kids AHA: for children aged 6 to 12 years). The AHA has been found to have excellent inter and intra-rater reliability, good validity and sensitivity to change.¹²⁶

Administration

Assessor: Occupational therapist accredited via three day training course and completion of additional calibration cases.

Time Allocated: 15 to 20 minutes for assessment, additional time for scoring from video.

Availability: Order through Handfast
AHA-project@kbh.ki.se.

Contact: Further information on the AHA can be obtained at <http://www.ahanetwork.se/>.

Key References

Greaves, S., Imms, C., Dodd, K. & Krumlinde-Sundholm, L. (2013). Development of the Mini-Assisting Hand Assessment: Evidence for content and internal scale validity. *Developmental Medicine & Child Neurology*, 55(11): 1030-1037.

Braendvik, S.M., Elvrum, A.K., Vereijken, B. & Roeleveld, K. (2010). Relationship between neuromuscular body functions and upper extremity activity in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 52(2): e29-34.

Holmefur, M., Aarts, P., Hoare, B. & Krumlinde-Sundholm, L. (2009). Test-retest and alternate forms reliability of the Assisting Hand Assessment. *Journal of Rehabilitation Medicine*, 41(11): 886-891.

Holmefur, M., Krumlinde-Sundholm, L. & Eliasson, A.C. (2007). Interrater and intrarater reliability of the Assisting Hand Assessment. *The American Journal of Occupational Therapy*, 61(1): 79-84.

Krumlinde-Sundholm, L., Holmefur, M., Kottorp, A. & Eliasson, A.C. (2007). The Assisting Hand Assessment: current evidence of validity, reliability and responsiveness to change. *Developmental Medicine & Child Neurology*, 49: 259-264.

Krumlinde-Sundholm, L. & Eliasson, A.C. (2003). Development of the Assisting Hand Assessment: A Rasch-built measure intended for children with unilateral upper limb impairments. *Scandinavian Journal of Occupational Therapy*, 10(1): 16-26.

8.2.3 Melbourne Assessment 2: A Test of Unilateral Upper Limb Function (MA2)

(Randall, Johnson & Reddihough 1999, 2003)

The Melbourne Assessment 2: A Test of Unilateral Upper Limb Function (MA2) evaluates the quality of upper limb movement in children aged 2 ½ to 15 years with a neurological condition. The MA2 is a validated and reliable, criterion referenced test that extends and refines the scale properties of the original Melbourne Assessment. It measures four elements of upper limb movement quality: movement range, accuracy, dexterity and fluency. It comprises 14 test items of reaching to, grasping, releasing and manipulating simple objects. It is recommended that the MA2 be used in place of the original tool in both clinical and research applications due to its enhanced scale and measurement properties.

Administration

Assessor: Occupational therapist.

Time Allocated: 30 minutes to administer and 30 minutes to score from video.

Availability: <http://www.rch.org.au/melbourneassessment/>.

Contact: For further information please contact the Occupational Therapy Department at the Royal Children's Hospital at ot.dept@rch.org.au.

Key References

- Randall, M., Imms, C., Carey, L.M. & Pallant, J.F. (2014). Rasch analysis of the Melbourne Assessment of Unilateral Upper Limb Function. *Developmental Medicine & Child Neurology*, 56(7): 665-672.
- Spirtos, M., O'Mahony, P. & Malone, J. (2011). Interrater reliability of the Melbourne Assessment of Unilateral Upper Limb Function for children with hemiplegic cerebral palsy. *American Journal of Occupational Therapy*, 65(4): 378-383.
- Braendvik, S.M., Elvrum, A.K., Vereijken, B. & Roeleveld, K. (2010). Relationship between neuromuscular body functions and upper extremity activity in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 52(2): e29-34.
- Jayaraman, P. & Puckree, T. (2009). A pilot study on the test re-test and the inter-rater reliability of the Melbourne Assessment of Unilateral Upper Limb Function. *South African Journal of Physiotherapy*, 65(2): 17-20.
- Klingels, K., De Cock, P., Desloovere, K., Huenaerts, C., Van Nuland, I., Huysmans, A. & Feys, H. (2008). Comparison of the Melbourne Assessment of Unilateral Upper Limb Function and the Quality of Upper Extremity Skills Test in hemiplegic CP. *Developmental Medicine & Child Neurology*, 50(12): 904-909.
- Randall, M., Imms, C. & Carey, L. (2008). Establishing validity of a modified Melbourne Assessment for children ages 2 to 4 years. *American Journal of Occupational Therapy*, 62(4): 373-383.
- Cusick, A., Vasquez, M., Knowles, L. & Wallen, M. (2005). Effect of rater training on reliability of Melbourne Assessment of Unilateral Upper Limb Function scores. *Developmental Medicine & Child Neurology*, 47(1): 39-45.
- The Royal Children's Hospital Melbourne. (2003). The Melbourne Assessment 2. Available from: http://www.rch.org.au/melbourneassessment/about_ma2/Overview_of_the_MA2/.
- Bourke-Taylor, H. (2003). Melbourne Assessment of Unilateral Upper Limb Function: Construct validity and correlation with the Pediatric Evaluation of Disability Inventory. *Developmental Medicine & Child Neurology*, 45(2): 92-96.

Randall, M., Carlin, J.B., Chronos, P. & Reddihough, D. (2001). Reliability of the Melbourne Assessment of Unilateral Upper Limb Function. *Developmental Medicine & Child Neurology*, 43(11): 761-767.

Randall, M., Johnson, L. & Reddihough, D. (1999). *The Melbourne Assessment of Unilateral Upper Limb Function: test administration manual*. Melbourne: Royal Children's Hospital, Melbourne.

Johnson, L.M., Randall, M.J., Reddihough, D.S., Oke, L.E., Byrt, T.A. & Bach, T.M. (1994). Development of a clinical assessment of quality of movement for unilateral upper-limb function. *Developmental Medicine & Child Neurology*, 36(11): 965-973.

8.2.4 Shriners Hospital Upper Extremity Evaluation (SHUEE)

(Davids, Peace, Wagner, Gidewall, Blackhurst & Roberson 2006)

The Shriners Hospital Upper Extremity Evaluation (SHUEE) assesses the segmental, dynamic alignment of the affected upper limb in children with hemiplegic cerebral palsy when involved in functional and spontaneous tasks. It focuses on alignment of the elbow, forearm, wrist, thumb and fingers. It is designed to be a video based assessment and to assist in determining clinical and functional change in upper limb function. The Modified House Scale is an additional part of the assessment that assesses actual function of the affected upper limb during activity.

Modified House Scale

- 0 Does not use - Extremity not utilised in any capacity for completion of task
- 1 Poor passive assist - Uses as stabilising weight only
- 2 Passive assist - Can hold onto object placed in hand & may stabilise it for use by other hand
- 3 Poor active assist - Can actively grasp object and hold it weakly
- 4 Active assist - Can actively grasp object, stabilise it well & may manipulate it against other hand
- 5 Spontaneous use, partial to complete - Performs bimanual activities easily, may use hand spontaneously or without reference to the other hand

Administration

Assessor: Occupational therapist.

Time Allocated: 30 minutes for assessment and scoring.

Availability: Contact Shriners Hospital, Greenville, South Carolina via email at PublicRelations-GRN@shrinet.org.

Contact: For further information please visit the Shriners Hospital website at <https://www.shrinershospitalsforchildren.org/en/Locations/greenville/About/Contact-Information>.

Key References

Davids, J.R., Peace, L., Wagner, L.V., Gidewall, M.A., Blackhurst, D. & Roberson, M.W. (2006). Validation of the Shriners Hospital for Children Upper Extremity Evaluation (SHUEE) for children with hemiplegic cerebral palsy. *Journal of Bone & Joint Surgery, America*, 88(2): 326-333.

8.2.5 Children's Hand-Use Experience Questionnaire (CHEQ)

(Sköld, Hermansson, Krumlinde-Sundholm & Eliasson 2011)

The Children's Hand-Use Experience Questionnaire (CHEQ) is a questionnaire developed for children aged between 6 and 17 years with unilateral functional limitations, for example hemiplegic cerebral palsy. The questionnaire evaluates and describes the experience of children in using their affected hand in bilateral activities. The questionnaire comprises 29 activities and investigates how independently the activities are performed, whether one or two hands are used as well as sub-questions regarding grip effectiveness, time required in comparison to peers and experience of feeling bothered while doing the activity (rated on four level scales).

Administration

Assessor: Child or parent/caregiver.

Time Allocated: 15 minutes to complete the online questionnaire.

Availability: The questionnaire and information about the CHEQ can be accessed online at <http://www.cheq.se/>.

Contact: For further information please visit the CHEQ website at <http://www.cheq.se/home/about>.

Key References

Sköld, A., Hermansson, L., Krumlinde-Sundholm, L. & Eliasson, A.C. (2011). Development and evidence of validity for the Children's Hand-use Experience Questionnaire (CHEQ). *Developmental Medicine & Child Neurology*, 53(5): 436-442.

8.2.6 ABILHAND-Kids

(Arnould, Penta, Renders & Thonard 2004)

The ABILHAND-Kids is a 21 item parent questionnaire that measures the bimanual ability of children with cerebral palsy with upper limb impairment and their ability to manage daily activities. It has been validated on children aged 6 to 15 years with cerebral palsy.

Administration

Assessor: Parent/caregiver.

Time Allocated: 10 minutes.

Availability: Available for download after a free registration process at <http://www.rehab-scales.org/abilhand-kids.html>.

Contact: For further information please contact Carlyne Arnould via email at abilhand-kids@rehab-scales.org.

Key References

Arnould, C., Penta, M., Renders, A. & Thonnard, J-L. (2004). ABILHAND-Kids: A measure of manual ability in children with cerebral palsy. *Neurology*, 63(6): 1045-1052.

8.2.7 Box and Blocks Test

(Mathiowetz, Federman & Weimer 1985)

The Box and Blocks Test is a psychometrically robust test that assesses unilateral manual ability. There is limited published research data in cerebral palsy. It has been designed for any client aged 6 years and over. It is a timed test that assesses the number of blocks a client can move from one side of the box to the other, with their dominant then non dominant hand, in one minute. Normative data is available for impaired and non-impaired upper limb function.

Administration

Assessor: Clinician.

Time Allocated: Less than 10 minutes to administer and score.

Availability: A test kit, including instructions, is available for purchase from <https://www.pattersonmedical.com.au>.

Contact: For further information please contact sales@pattersonmedical.com.au.

Key References

Mathiowetz, V., Federman, S. & Weimer, D. (1985). Box and Block test of manual dexterity: norms for 6-19 year olds. *Canadian Journal of Occupational Therapy*, 52(5): 241-245.

8.2.8 Jebsen-Taylor Hand Function Test (JTHFT)

(Jebsen, Taylor, Trieschmann, Trotter & Howard 1969)

The Jebsen-Taylor Hand Function Test (JTHFT) is a norm referenced, timed test of hand use in everyday activity. It was designed for children from 5 years of age to adults, with or without upper limb impairment. It has documented use with people with cerebral palsy. The test comprises seven sub-tests, timed and completed by the dominant and non-dominant hands.

Administration

Assessor: Clinician.

Time Allocated: 15 to 30 minutes.

Availability: A standardised kit can be purchased from the website <https://www.pattersonmedical.co.uk>, although the original article describes the fabrication of a test kit and instructions.

Key References

Sears, E.D., Chung, K.C. (2010). Validity and responsiveness of the Jebsen-Taylor Hand Function Test. *Journal of Hand Surgery*, 35(1): 30-37.

Jebsen, R.H., Taylor, N., Trieschmann, R.B., Trotter, M.J. & Howard, L.A. (1969). An objective and standardised test of hand function. *Archives of Physical Medicine & Rehabilitation*, 50(6): 311-319.

8.3 SPEECH AND LANGUAGE ASSESSMENT

About one in four people with cerebral palsy have communication difficulties.⁵¹ Communication difficulties include motor speech difficulties, voice and phonation difficulties and expressive and receptive language impairments. For people with cerebral palsy, communication difficulties are linked to intellectual disability, presence of seizures, severity of gross motor impairments and hearing and vision impairments. Communication difficulties may occur with all GMFCS levels but increase in frequency and severity with higher GMFCS levels.¹²⁷ People with dyskinetic cerebral palsy have a higher risk of experiencing communication difficulties than people with spastic type of cerebral palsy.¹²⁸

When assessing the speech and language skills of children with cerebral palsy, it is important to note the following:

- Mainstream communication assessments can be used to assess the speech, language and literacy skills of children with cerebral palsy. The assessment results need to be interpreted extremely carefully and used only to add to the clinical understanding of the child's communication skills rather than using standardised scores. It is also important to conduct observational assessments of the child's functional communication skills across environments
- Note the individual's GMFCS and MACS levels as this will reveal the need for possible alternate access method
- Communication skills may not follow developmental sequence
- Establish a mode of response prior to commencing the assessment. Language assessments typically require the child to point to pictures, manipulate objects or give verbal responses. Children with cerebral palsy may have reduced upper limb function and severe dysarthria that will limit the child's ability to respond to the assessment stimuli and therefore alternate response methods will need to be explored. These include eye gaze, using another body part to point, use of gestures or sign, partner assisted scanning for the test assessment stimuli items and/or the use of the child's AAC system. The child needs to be a proficient AAC user and have a system that enables the child to respond adequately to the test items
- Fatigue – If the child demonstrates signs of fatigue, discontinue assessing and have a break
- Possible sensory impairments; vision (1 in 10 people with cerebral palsy) and hearing (1 in 25).

8.4 QUALITY OF LIFE ASSESSMENT

The assessment of quality of life for a child with cerebral palsy is important as it can provide insight into their activity and participation, in addition to measures at the body structure and function level of the ICF. A variety of quality of life questionnaires are available, some of which have been designed specifically for children with cerebral palsy. It is important to be familiar with the questionnaires as some are more sensitive to changes in severely affected children with cerebral palsy (e.g. GMFCS IV and V) and others to children more mildly affected (e.g. GMFCS I, II & III).

8.4.1 Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD™)

(Narayanan, Fehlings, Weir, Knights, Kiran & Campbell 2006)

The Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD™) evaluates the function and health status, caregiver burden and health related quality of life in children with severe cerebral palsy. It has been validated for use with caregivers of children with severe developmental disabilities such as those with non-ambulatory cerebral palsy and traumatic brain injury, who would be categorised as level IV or V of the Gross Motor Function Classification System (GMFCS). It is not intended for use with children with ambulatory cerebral palsy. The five domains of the CPOCHILD™ include:

- Personal Care
- Positioning, Transferring and Mobility
- Comfort and Emotions
- Communication
- Social Interactions and Health.

The CPOCHILD™ also comments on the importance of quality of life items to the child.

Administration

Assessor: Parent or caregiver who regularly cares for the child. If the child is also able to respond it is desirable that both the child and parent/caregiver complete the report.

Time Allocated: Approximately 20 minutes.

Availability: The CPOCHILD™ questionnaire and manual can be obtained by visiting the SickKids website at www.sickkids.ca/cpchild/.

Contact: For further information please email Unni Narayanan, Paediatric Orthopaedic Surgeon and Associate Professor, University of Toronto at unni.narayanan@sickkids.ca.

Key References

Narayanan, U.G., Weir, S. & Fehlings, D. (2007). Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) *Questionnaire: Manual and Interpretation Guide*. The Hospital for Sick Children, Toronto, Ontario, Canada.

Narayanan, U.G., Fehlings, D., Weir, S., Knights, S., Kiran, S. & Campbell, K. (2006). Initial development and validation of the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD). *Developmental Medicine & Child Neurology*, 48(10): 804-812.

8.4.2 Cerebral Palsy Quality of Life Questionnaire (CP QOL®)

Waters, Davis, Mackinnon, Boyd, Graham, Lo, Wolfe, Stevenson, Bjornson, Blair, Hoare, Ravens-Sieberer & Reddihough 2007)

The Cerebral Palsy Quality of Life Questionnaire (CP QOL®) is a questionnaire developed for children with cerebral palsy to measure quality of life. There are two versions of the Questionnaire: CP QOL-Child for children aged 4 to 12 years and CP QOL-Teen for adolescents aged 13 to 18 years. Both questionnaires have parent proxy and child self-report versions.

The CP QOL-Child domains include:

- Social wellbeing and acceptance
- Participation and physical health
- Emotional wellbeing
- Pain and impact of disability
- Access to services and family health.

Access to services and family health are only included in the parent proxy version.

The CP QOL-Teen domains include:

- General wellbeing and participation
- Communication and physical health
- School wellbeing
- Social wellbeing
- Access to services
- Family health and feelings about functioning.

Access to services and family health are only included in the parent proxy version.

Administration

The CP QOL[®] can be administered either by face to face interview or mail out.

Assessor: Parent proxy version – parent/caregiver who regularly cares for the child. If the child is also able to respond it is desirable that both the child's and parent proxy version are completed.

Time Allocated: Approximately 10 minutes to complete questionnaire. Child report version may take longer.

Availability: The questionnaire and manual can be obtained by visiting the website at www.cpqol.org.au.

Contact: Further information can be obtained by emailing Dr Elise Davies, Associate Director, Wellbeing Research at eda@unimelb.edu.au.

Key References

Waters, E., Davis, E., Mackinnon, A., Boyd, R., Graham, H.K., Lo, S.K., Wolfe, R., Stevenson, R., Bjornson, K., Blair, E., Hoare, P., Ravens-Sieberer, U. & Reddihough, D. (2007). Psychometric properties of the Quality of Life Questionnaire for Children with CP. *Developmental Medicine & Child Neurology*, 49(1): 49-55.

8.4.3 Pediatric Evaluation of Disability Inventory (PEDI)

(Haley, Coster, Ludlow, Haltiwanger & Andrellos 1992)

The Paediatric Evaluation of Disability Inventory (PEDI) is a standardised assessment of how a child with a physical or combined physical and cognitive impairment functions in their daily life. It has been standardised on a normal population aged 6 months to 7 years 6 months and has established reliability and validity to detect the presence, extent and area of a functional delay in children with physical impairment or combined physical and cognitive impairment. The PEDI can be used in older children whose functional abilities fall below those expected of a 7 years 6 months old child without a disability. It is designed to measure a child's capability and performance across three domains:

- Self-care
- Mobility
- Social function.

Capability is measured by the child's mastery of functional skills and performance by the extent of caregiver assistance required. A measure of environmental modifications and equipment requirements is also noted.

Administration

Assessor: Occupational therapist or physiotherapist, training not required. Ensure same respondent completes the form at re-assessment.

Time Allocated: 30 minutes to one hour.

Availability: The PEDI can be obtained from Pearson by visiting the website at <https://www.pearsonclinical.com.au/products/view/165#tabs=1>.

Key References

McCarthy, M.L., Silberstein, C.E., Atkins, E.A., Harryman, S.E., Sponseller, P.D. & Hadley-Miller, N.A. (2002). Comparing reliability and validity of pediatric instruments for measuring health and well-being of children with spastic cerebral palsy. *Developmental Medicine & Child Neurology*, 44(7): 468-476.

Ziviani, J., Ottenbacher, K.J., Shepard, K., Foreman, S., Astbury, W. & Ireland, P. (2001). Concurrent validity of the Functional Independence Measure for Children (WeeFIM) and the Pediatric Evaluation of Disability Inventory in children with developmental disabilities and acquired brain injury. *Physical and Occupational Therapy in Pediatrics*, 21(2-3): 91-101.

Nichols, D.S. & Case-Smith, J. (1996). Reliability and validity of the Pediatric Evaluation of Disability Inventory. *Pediatric Physical Therapy*, 8(1): 15-24.

Haley, S.M., Coster, W.J., Ludlow, L.H., Haltiwanger, J.T. & Andrellos, P.J. (1994). Pediatric Evaluation of Disability Inventory. *Pediatric Physical Therapy*, 6: 42.

Haley, S., Coster, W., Ludlow, L., Haltiwanger, J. & Andrellos, P. (1992). Pediatric Evaluation of Disability Inventory (PEDI): Development, Standardization and Administration Manual. New England Medical Center Hospitals, Inc. and PEDI Research Group; Boston, MA.

Haley, S., Coster, W. & Faas, R. (1991). A content validity study of the Pediatric Evaluation of Disability Inventory. *Pediatric Physical Therapy*, 3(4): 177-184.

8.4.4 Care and Comfort Hypertonicity Questionnaire (CCHQ)

(Nemer McCoy, Blasco, Russman & O'Malley 2006)

The Care and Comfort Hypertonicity Questionnaire (CCHQ) is a short questionnaire that evaluates the functional care needs and quality of life of children with hypertonia, for example cerebral palsy.

Administration

Assessor: Parent/caregiver.

Time Allocated: 10 minutes to complete, five minutes to score.

Availability: The questionnaire can be found in McCoy, Blasco, Russman & O'Malley (2006).

Key References

Nemer McCoy, R., Blasco, P., Russman, B. & O'Malley, J. (2006). Validation of a Care and Comfort Hypertonicity Questionnaire. *Developmental Medicine & Child Neurology*, 48(3): 181-187.

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ENVIRONMENTAL ASSESSMENT

9. ENVIRONMENTAL ASSESSMENT

Assessment Tool		Section
Preschool		9.1
School Readiness		9.2
	School Function Assessment (SFA)	9.2.1
	Assistance to Participate Scale (APS) for Children with Disabilities	9.2.2
	Functional Independence Measure for Children (WeeFIM)	9.2.3

Children with cerebral palsy should be assessed in their home as well as in their usual or potential preschool/ school environments. It is essential that educational based and cognitive assessments are considered as part of the decision making process. Additional considerations for assessment in these environments are listed below.

9.1 PRESCHOOL

Access to mainstream or special preschools is often sought for young children with cerebral palsy. Issues that may require investigation include:

- Physical access to classrooms, bathrooms and play areas
- Fine motor skills to participate in desk top activities
- Gross motor skills to participate in outdoor activity and access different areas of the classrooms
- Additional equipment for seating and toileting and bathroom safety
- Eating/drinking/swallowing skills for safe and enjoyable mealtimes
- Communication skills to participate in interactions and activities.

9.2 SCHOOL READINESS

School readiness is a widely used phrase that generally describes a child's readiness to commence formal schooling. It encompasses such aspects as chronological age, fine and gross motor skills, social and emotional characteristics, pre-academic performance, physical wellbeing, language skills and cognitive development. School readiness, either for entry to mainstream schooling or special schooling, for younger children with cerebral palsy may involve the following:

- Formal cognitive assessment through school counsellor or other service
- Assessment of fine motor skills and their impact on pencil use, scissor use and manipulation of desk top objects
- Keyboard and technology access
- Classroom and school environment access may require investigation depending on gross motor ability and independence on uneven surfaces, stairs and over distances
- Support may be required in the classroom for organisation, access to the curriculum, handwriting or one on one academic support
- Assessment of speech and language skills
- May require augmentative and alternative communication (AAC)
- Assessment of mealtime skills
- May require support and assistance at mealtimes.

9.2.1 School Function Assessment (SFA)

(Coster, Deeney, Haltiwanger & Haley 1998)

The School Function Assessment (SFA) provides a structured method to evaluate and monitor a student's performance of functional tasks and activities that support participation in school. It was designed to facilitate collaborative program planning for children with a variety of disabling conditions and is appropriate for use with students from 5 to 12 years. The SFA contains three parts:

School Function Assessment (SFA) Parts

- I Participation is used to rate the student's participation in six major school activity settings – regular or special education classroom, playground/recess, transportation, bathroom/toileting, transitions, and mealtime/snack time
- II Task Supports is used to rate the assistance and adaptations currently provided to the student for both physical and cognitive/behavioural tasks. Physical Tasks include travel, maintaining and changing positions, recreational movement, manipulation with movement, using materials, setup and cleanup, eating and drinking, hygiene, clothing management, up/down stairs, written work, and computer and equipment use. Cognitive/Behavioural Tasks include functional communication, memory and understanding, following social conventions, compliance with adult directives and school rules, task behaviour /completion, positive interaction, behaviour regulation, personal care awareness, and safety
- III Activity Performance is used to examine the student's performance of specific school-related functional activities in each of the task areas assessed globally in Part II. The items of each of these scales are written in measurable, behavioural terms that can be used directly in the student's individual educational plan. All ratings are assigned based on the student's typical or most consistent level of performance as compared to other students of the same grade. Criterion cut-off scores are provided to help establish eligibility for special services

Administration

Assessor: Judgement based questionnaire completed by one or more school professionals who know the student well.

Time Allocated: Can take up to two hours to complete full assessment if not familiar with SFA. Individual sections may only take five to 10 minutes. Usually completed over multiple days, should not take longer than two to three weeks.

Availability: The SFA can be obtained from Pearson by visiting the website at <https://www.pearsonclinical.com.au/products/view/184>.

Contact: For further information please contact Dr Wendy Coster, co-author for the SFA, at wjcoster@bu.edu.

Key References

- Hwang, J.L. & Davies P.L. (2009). Rasch Analysis of the School Function Assessment Provides Additional Evidence for the Internal Validity of the Activity Performance Scales. *American Journal of Occupational Therapy*, 63(3): 369-373.
- Sakzewski, L., Boyd, R. & Ziviani, J. (2007). Clinimetric Properties of Participation Measures for 5-to-13-year old Children with Cerebral Palsy: A Systematic Review. *Developmental Medicine & Child Neurology*, 49(3): 232-240.
- Davies, P.L., Soon, P.L., Young, M. & Clausen-Yamaki, A. (2004). Validity and Reliability of the School Function Assessment in Elementary Students with Disabilities. *Physical and Occupational Therapy in Paediatrics*, 24(3): 23-42.
- Hwang J.L., Davies, P.L., Taylor, M.P. & Gavin, W.J. (2002). Validation of the School Function Assessment with Elementary School Children. *OTJR: Occupation, Participation and Health*, 22(2): 48-58.
- Coster, W., Deeney, T., Haltiwanger, J. & Haley, S. (1998). SFA – School Functional Assessment. San Antonio, Texas: Psychological Corp.

9.2.2 Assistance to Participate Scale (APS) for Children with Disabilities

(Bourke-Taylor, Law, Howie & Pallant 2009, 2013)

The Assistance to Participate Scale (APS) for Children with Disabilities measures the amount of caregiver assistance a child with a disability requires to participate in leisure and play activities both at home and in their community. It is designed for school aged children aged 5 to 18 years. The questionnaire includes eight questions and asks caregivers to rate, on a five point Likert scale, the amount of assistance they provide for their child to participate in the activities:

Assistance to Participate Scale (APS) Rating Scale

- 1 Unable to participate
- 2 Participates with my assistance at all stages of the activity
- 3 Participates after I have set him/her up and help at times during the activity
- 4 Participates with my supervision only
- 5 Participates independently

The questionnaire has two sub scales:

- Home Alone
- Community.

A higher score indicates less assistance is required for participation.

Administration

Assessor: Caregiver.

Time Allocated: Five minutes to complete questionnaire.

Availability: Free to download at

<https://www.canchild.ca/en/resources/231-assistance-to-participate-scale-aps>.

Contact: For further information please contact the CanChild Centre for Childhood Disability Research at canchild@mcmaster.ca.

Key References

Bourke-Taylor, H.M., Law, M., Howie, L. & Pallant, J.F. (2013). *Assistance to Participate Scale (APS) for children with disabilities participation in play and leisure information booklet*. CanChild.

<https://www.canchild.ca/en/resources/231-assistance-to-participate-scale-aps>.

Bourke-Taylor, H.M., Law, M., Howie, L. & Pallant, J.F. (2009). Development of the Assistance to Participate Scale (APS) for children's play and leisure activities. *Child Care, Health and Development*, 35(5): 738-745.

9.2.3 Functional Independence Measure for Children (WeeFIM)

(McCabe & Granger 1990)

The Functional Independence Measure for Children (WeeFIM) was developed for children aged 6 months to 7 years with an acquired or congenital disease. The WeeFIM comprises an 18 item checklist that rate the amount of assistance required for performance of activities in the areas of self-care, mobility and cognition. A seven point scale is utilised (7=independent to 1=totally dependent). It is a valid and reliable assessment tool.¹²⁹⁻¹³¹

Administration

Assessor: Clinician or caregiver.

Training: Formal training is required and a credentialing process completed for use of the WeeFIM.

Time Allocated: Five minutes to complete questionnaire.

Availability: A contract for use of both assessments can be purchased at www.udsmr.org.

Contact: For further information please contact Uniform Data System for Medical Rehabilitation via email at info@udsmr.org.

Key References

Msall, M.E., Ottenbacher, K., Duffy, L., Lyon, N., Heyer, N., Phillips, L., Hard, B.J., Braun, S. & Granger, C. (1996). Reliability and validity of the WeeFIM in children with neurodevelopmental disabilities. *Pediatric Research*, 39(4): 378.

Ottenbacher, K.J., Taylor, E.T., Msall, M.E., Braun, S., Lane, S.J., Granger, C.V., Lyons, N. & Duffy, L.C. (1996). The stability and equivalence reliability of the Functional Independence Measure for Children (WeeFIM)®. *Developmental Medicine & Child Neurology*, 38(10): 907-916.

Msall, M.E., DiGaudio, K., Duffy, L.C., LaForest, S., Braun, S. & Granger, C.V. (1994). WeeFIM. Normative sample of an instrument for tracking functional independence in children. *Clinical Pediatrics*, 33(7): 431-438.

McCabe, M.A. & Granger, C.V. (1990). Content validity of a paediatric functional independence measure. *Applied Nursing Research*, 3(3): 120-122.

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10

**ADDITIONAL ASSESSMENTS
- NON CEREBRAL PALSY SPECIFIC**

10. ADDITIONAL ASSESSMENTS – NON CEREBRAL PALSY SPECIFIC

Assessment Tool	Section
Physiotherapy Specific Assessments	10.1
High-Level Mobility Assessment Tool (HiMAT)	10.1.1
Community Balance and Mobility Scale (CB&M)	10.1.2
Pediatric Balance Scale (PBS)	10.1.3
Occupational Therapy Specific Assessments	10.2
Handwriting Assessments	10.2.1
Evaluation Tool of Children's Handwriting (ETCH)	10.2.1.1
Handwriting Speed Test (HST)	10.2.1.2
Play Assessments	10.3
Child Initiated Pretend Play Assessment (ChIPPA)	10.3.1
Speech Pathology Specific Assessments	10.4
The Viking Speech Scale	10.4.1
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10.1 PHYSIOTHERAPY SPECIFIC ASSESSMENTS

10.1.1 High-Level Mobility Assessment Tool (HiMAT)

(Williams, Robertson, Greenwood, Goldie & Morris 2005a)

The High-Level Mobility Assessment Tool (HiMAT) is a high level mobility and balance assessment used in adolescents and adults with acquired brain injury. It has been used with children with cerebral palsy however studies have not been published to date. It is a 13 item assessment that includes a wide range of activities including running, jumping, stairs, hopping and skipping. No data is currently available for children with cerebral palsy.

Administration

Assessor: Clinician.

Time Allocated: 15 minutes.

Equipment: Stop watch, tape measure, house brick or similar, 20 metre walkway, flight of 14 stairs.

Availability: see www.rehabmeasures.org to download assessment details.

Key References

Williams, G., Robertson, V., Greenwood, K., Goldie, P. & Morris, M.E. (2005a). The high-level mobility assessment tool (HiMAT) for traumatic brain injury. Part 1: Item generation. *Brain Injury*, 19(11): 925-932.

Williams, G., Robertson, V., Greenwood, K., Goldie, P. & Morris, M.E. (2005b). The high-level mobility assessment tool (HiMAT) for traumatic brain injury. Part 2: Content validity and discriminability. *Brain Injury*, 19(10): 833-843.

10.1.2 Community Balance and Mobility Scale (CB&M)

(Howe, Inness, Venturini, Williams & Verrier 2006)

The Community Balance and Mobility Scale (CB&M) was developed for adolescents with acquired brain injury to detect 'high level' balance and mobility deficits based on tasks that are commonly encountered in community environments. It comprises 13 tasks, six of which are performed on both sides. Each task is scored from zero (complete inability to perform task) to five (most successful completion of task possible). It has been used with children with cerebral palsy by Brien & Sveistrup.¹³²

Administration

Assessor: Clinician.

Time Allocated: 30 to 60 minutes.

Equipment: Stop watch, laundry basket, two x weights (2lb and 7lb), 20 centimetre diameter target, bean bag, eight metre walkway.

Availability: To download assessment details please visit the website at see www.rehabmeasures.org.

Contact: For further information please email Jo-anne Howe at howe.jo-anne@torontorehab.on.ca.

Key References

Howe, J.A., Inness, E.L., Venturini, A., Williams, J.I. & Verrier, M.C. (2006). The Community Balance and Mobility Scale – a balance measure for individuals with traumatic brain injury. *Clinical Rehabilitation*, 20(10): 885-895.

10.1.3 Pediatric Balance Scale (PBS)

(Franjoine, Gunther and Taylor 2003)

The Pediatric Balance Scale (PBS) is a modification of Berg's Balance Scale, and was developed as a balance measure for school-age children with mild to moderate motor impairments.¹³³ It provides clinicians with a standardised format for measurement of functional balance tasks which are seen to be routine components of a physical assessment. Balance in cerebral palsy is considered to be a primary impairment which reflects the body functions and structure component of the ICF model.¹³⁴ The scale contains 14 items. Each item contains a 0 to 4 grading scale to assess performance.

Administration

Assessor: Clinician.

Target Group: GMFCS I-III, aged 5 to 15 years.

Time Allocated: 15 minutes for administration and scoring.

Availability: The PBS and instructions for its use are contained within the Franjoine et al. (2003) article.

Key References

Bartlett, D.J., Chiarello, L.A., McCoy, S.W., Palisano, R.J., Rosenbaum, P.L., Jeffries, L., LaForme Fiss, A. & Stoskopf, B. (2010). The Move & PLAY Study: An Example of Comprehensive Rehabilitation Outcomes Research. *Physical Therapy*, 90(11): 1660-1672.

Franjoine, M.R., Gunther, J.S. & Taylor, M.J. (2003). Paediatric Balance Scale: A Modified Version of the Berg Balance Scale for the School-Age child with Mild to Moderate Motor Impairment. *Pediatric Physical Therapy*, 15(2): 114-128.

10.2 OCCUPATIONAL THERAPY SPECIFIC ASSESSMENTS

Occupational therapists access a wide range of assessments that encompass all areas of occupational performance, namely self-maintenance, productivity, rest and leisure.¹³⁵ Many of these assessments are normed on the typically developing population or developed for children experiencing difficulties in a specific area of occupational performance. The list of assessments included below is not all encompassing and should be used as a guide only.

10.2.1 Handwriting Assessments

Children with cerebral palsy frequently experience handwriting difficulties and may require assessment of their handwriting speed and legibility.

10.2.1.1 Evaluation Tool of Children's Handwriting (ETCH)

(Amundson 1995)

The Evaluation Tool of Children's Handwriting (ETCH) is a criterion referenced handwriting assessment that evaluates manuscript and cursive handwriting in students in grades 1 to 6. It assesses both speed and legibility in the areas of alphabet and number writing, near and far-point copying, dictation and sentence generation.

Administration

Assessor: Clinician.

Time Allocated: 15 to 25 minutes to administer and 15 minutes to score.

Availability: The ETCH Test manual can be purchased online by visiting the website:
<http://www.therapro.com/>.

Contact: For further information please contact the author Susan Amundson at P.O. Box 118, Homer, Alaska 99603.

Key References

Amundson, S. J. (1995). *Evaluation Tool of Children's Handwriting*. Homer, AK: O.T. Kids, Inc.

10.2.1.2 Handwriting Speed Test (HST)

(Wallen, Bonney & Lennox 2006)

The Handwriting Speed Test (HST) is an assessment with normative data on the speed of handwriting for children in years 3 to 12 in NSW schools. In the test children are required to write the sentence 'The quick brown fox jumps over the lazy dog' as neatly and as quickly as they can continuously for three minutes. A score of 10 is average and seven to 13 is within the normal range.

Administration

Assessor: Clinician.

Time Allocated: 15 minutes to administer and collect relevant information and 10 minutes to score.

Availability: The HST can be obtained from Dr Margaret Wallen.

Contact: For further information about the HST please contact Dr Margaret Wallen at mwallen@optusnet.com.au.

Key References

Wallen, M., Bonney, M.A. & Lennox, L. (2006). The Handwriting Speed Test. *Australian Occupational Therapy Journal*, 53(2): 141.

10.3 PLAY ASSESSMENTS

Occupational therapists have long regarded play as the primary occupation of childhood. Play can be informally observed or more formally assessed.

10.3.1 Child Initiated Pretend Play Assessment (ChIPPA)

(Stagnitti 2007)

The Child Initiated Pretend Play Assessment (ChIPPA) is a norm referenced, standardised assessment that investigates the quality of a child's ability to self-initiate pretend play. It has been developed to use with children aged 3 years to 7 years 11 months with male and female norms. It measures the elaborateness of a child's play (that is, how complex and organised the play is), the ability of a child to use symbols in play, and a child's reliance on others for play ideas. It distinguishes between the play of typically developing preschoolers and preschoolers with pre-academic problems.

Administration

Assessor: Clinician or Early Educators.

Time Allocated: The ChIPPA takes 18 minutes to administer to 3 year olds and 30 minutes to administer to children from 4 years to 7 years 11 months.

Availability: The ChIPPA kit, including manual and score guidelines, is available for purchase from
<http://www.therapystore.com.au/>.

Contact: For further details please email Karen Stagnitti via the website at <https://www.learntoplayevents.com/contact/>.

Key References

Stagnitti, K. (2007). *The child initiated pretend play assessment (ChIPPA) [kit]*. Co-ordinates Publications, West Brunswick, Victoria.

10.4 SPEECH PATHOLOGY SPECIFIC ASSESSMENTS

10.4.1 The Viking Speech Scale

(Pennington, Mj  en, Andrada & Murray 2010)

The Viking Speech Scale classifies the clarity of the child's speech production as understood by an unfamiliar listener. It is designed for children aged over 4 years. It is not intended to classify communication clarity of children who use alternative and augmentative communication.

It classifies usual speech using a four level ordinal scale:

The Viking Speech Scale

- I Speech is not affected by motor disorder
- II Speech is imprecise but usually understandable to unfamiliar listeners
- III Speech is unclear and not usually understandable to unfamiliar listeners out of context
- IV No understandable speech

Administration

Score each child to the level at which they are understandable to strangers and unfamiliar conversation partners.

Assessor: Parent, teacher or healthcare professional.

Time Allocated: The scale can be completed during a routine appointment.

Availability: The Viking Speech Scale can be obtained by visiting the website at <http://www.scpnetwork.eu/assets/SCPE-Tools/VSS/Viking-Speech-Scale-2011-Copyright.pdf>.

Contact: For further information please email Lindsay Pennington via lindsay.pennington@ncl.au.uk.

Key References

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

Pennington, L., Mj  en, T., Andrada, M. & Murray, J. (2010). *Viking Speech Scale*. Newcastle University, UK, Vestfold Hospital Trust Norway, Centro de Reabilita  o de Paralisia Cerebral Calouste Gulbenkian-Lisbon & Manchester Metropolitan University, UK.

10.4.2 Communication Matrix

(Rowland 1990, Revised 2004)

The Communication Matrix is an observational tool and behavioural inventory designed to evaluate the expressive communication skills of children with severe and multiple disabilities, including children with sensory, motor and cognitive impairments. It accommodates any type of communication behaviour observed in typically developing infants during the first two years of life. It provides a framework for determining logical communication goals.

The Matrix involves two major aspects of communication: the reasons that individuals communicate and the behaviours they use to communicate. An online version is available as a free web-based service in English and Spanish. Users register to log in and can track and review progress of their entries. Information including basic demographic information, health conditions and specific impairments as well as information about communication behaviours is logged without identifying information on the database for future research projects.

Administration

Can either be completed using an online questionnaire or a printed version that can be entered later. The interviewees are those that are familiar with the communication behaviours of the child e.g. parent, teacher.

Assessor: Speech pathologist or teacher.

Time Allocated: N/A – questions asked during appointments or answered during direct observation.

Availability: www.designtolearn.com, <http://www.communicationmatrix.org/>.

Contact: For further information please email Charity Rowland, Ph.D., via rowlandc@ohsu.edu.

Key References

Rowland, C. (2013). *Communication matrix for parents and professionals: Online Handbook*. Oregon Health and Science University, USA.

Rowland, C. & Fried-Oken, M. (2010). Communication matrix: A clinical and research assessment tool targeting children with severe communication disorders. *Journal of Paediatric Rehabilitation Medicine: An interdisciplinary Approach*, 3(4): 319-329.

Rowland, C. (2004). *Communication Matrix (Revised Edition)*. Portland, OR: Oregon Health and Science University.

Rowland, C. (1990). *The Communication Matrix*. Unpublished manuscript. Portland, OR: Oregon Health and Science University.

10.4.3 C.O.D.E.S. Framework

(KEYCOMM, Lothian Communication Technology Service 2011)

**C.O.D.E.S. = Competency – Opportunities
– Driving Communication Forward – Engagement
– Skill Acquisition**

C.O.D.E.S. Framework is designed to monitor the progress of an individual using an AAC system and to measure the effectiveness of the individual's communication.

C.O.D.E.S. is based on Janice Light's four communicative competencies – linguistic, operational, social and strategic competencies. C.O.D.E.S. also considers the role of the environment, and barriers to communication, as well as the individual's level of independence and motivation to communicate. These communication competencies are identified as key skills that an individual who uses AAC will need to develop in order to become a competent and effective communicator.

Administration

Scoring: Involves input by all team members involved with the child, including clinicians, teachers and parents.

Availability: <https://codesframework.wordpress.com/>.

Contact: For further information please visit the website at <https://codesframework.wordpress.com/contact-us/>.

Key References

Light, J. & McNaughton, D. (2014). Communicative competence for individuals who require augmentative and alternative communication: A new definition for a new era of communication? *Augmentative and Alternative Communication*, 30(1): 1-18.

KEYCOMM, Lothian Communication Technology Service. (2011). C.O.D.E.S. Framework. <https://codesframework.wordpress.com/>.

10.4.4 SETT Framework

(Zabala 2008)

SETT = Student – Environment – Tasks – Tools

SETT Framework is a framework that involves gathering and analysing information about the individual's communication skills and demands in different environments. It also outlines the communication tasks that the individual faces and what tools the individual has and would require in order to communicate effectively.

SETT framework involves collaborative teams to create client-centred, environmentally useful and task-focused solutions around functional AAC use.

Administration

Assessment: Collaborative team approach.

Availability: The framework can be obtained by visiting the website at <http://atto.buffalo.edu/registered/ATBasics/Foundation/Assessment/sett.php> or by visiting <http://www.joyzabala.com/>.

Contact: For further information please email Joy Zabala at joy@joyzabala.com.

Key References

Zabala, J. (2008). The SETT Framework: An assessment process. Retrieved June 19, 2010 from <http://atto.buffalo.edu/registered/ATBasics/Foundation/Assessment/sett.php>.

10.4.5 Test of Aided-Communication Symbol Performance (TASP)

(Bruno 2010)

The Test of Aided-Communication Symbol Performance (TASP) is a test of symbolic skills. It aims to define symbolic communication performance for symbols with single meaning. These include the symbols size, grammatical encoding, categorisation and syntactical skills.

TASP results can be used in selecting and designing appropriate AAC systems and layouts for communication boards.

It is designed for use with individuals with cognitive and communication impairments.

Administration

Requires the individual to be able to point to the stimulus items.

Assessor: Clinician.

Time: 20 minutes.

Availability: The TASP is available for purchase at the website <http://www.spectronics.com.au/product/tasp-test-of-aided-communication-symbol-performance>.

Contact: For further information please email Amanda Hartmann via amanda@spectronicsinoz.com.

Key References

Bruno, J. (2010). *Test of Aided-Communication Symbol Performance*, Pittsburgh, PA: Dynavox Mayer Johnson.

Bruno, J. (2006). *Test of Aided-Communication Symbol Performance*, Solana Beach, CA: Mayer-Johnson.

Bruno, J. (2005). *Test of Aided-Communication Symbol Performance (TASP)*. Pittsburgh, PA: Dynavox Mayer-Johnson.

MANAGEMENT OF CEREBRAL PALSY IN CHILDREN



MANAGEMENT OF CHILDREN WITH CEREBRAL PALSY

11. MANAGEMENT OF CHILDREN WITH CEREBRAL PALSY

Intervention	Section
Cerebral Palsy Surveillance	11.1
Hip Surveillance	11.2

11.1 CEREBRAL PALSY SURVEILLANCE

Over the past decade there has been an increase in the number of surveillance programs nationally and internationally. These include the various cerebral palsy registers as well as surveillance programs such as the hip surveillance guidelines as outlined in section 11.2 of The Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care.¹³⁶ Cerebral palsy registers collect information about people with cerebral palsy. In Australia there are registers in each state as well as the Australian Cerebral Palsy Register, launched in 2007. The aims of these registers are to gain a greater understanding of cerebral palsy, monitor trends and incidence, assist planning for people with cerebral palsy and increase the scope of cerebral palsy research in Australia (<http://www.cpreregister.com/>).

11.2 HIP SURVEILLANCE

The Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM) endorsed *The Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care*¹³⁶, which was launched at the 3rd International Cerebral Palsy Conference in Sydney Australia, February 2009. These guidelines were reviewed and endorsed in 2014 by the AusACPDM.

Three published booklets provide information on the importance of hip surveillance and timeframe guidelines for recommended hip surveillance x-rays for GMFCS I to GMFCS V children.



The following link provides information on the importance of hip surveillance and time frame guidelines for recommended hip surveillance x-ray for GMFCS I to GMFCS V children. <https://ausacpdm.org.au/professionals/hip-surveillance/australian-hip-surveillance-guidelines/>¹³⁷

**MANAGEMENT OF
CEREBRAL PALSY
IN CHILDREN**

12

**BODY STRUCTURE AND
FUNCTION INTERVENTIONS**

12. BODY STRUCTURE AND FUNCTION INTERVENTIONS

Intervention		Section
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	Splinting/Orthoses	12.1.2
	• Functional Orthoses • Positional Orthoses	12.1.2.1 12.1.2.2
Strengthening Interventions		12.2
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12.1 STRETCH INTERVENTIONS

Stretch interventions are widely utilised for the treatment of contractures in children with cerebral palsy with the aim of maintaining or increasing the range of motion of a specific joint. Stretch can be applied in three main forms: the application of orthoses or a specific positioning program; serial casting; or a manual stretch program. Stretch interventions aim to elongate soft tissue. Katalinic, Harvey, Herbert, Moseley, Lannin & Schurr¹³⁸ concluded in their published Cochrane Review that there was limited evidence to support the application of stretch interventions. Wallen & Stewart¹³⁹ argue that whilst it is a rigorous review of the available literature, the Katalinic et al.¹³⁸ review does not provide enough evidence to abandon stretch interventions, particularly in children with cerebral palsy.

12.1.1 Casting

Casting is a therapy intervention used to gain/restore muscle length and provide soft tissue elongation. Casting can be done as a one off or as a series of casts depending on the desired outcome and the child's tolerance for the cast. Casting is indicated when soft tissue contracture is interfering with function or causing potential biomechanical misalignment. Casting is not indicated when there are bony changes occurring at a joint. Casting only provides a short-term stretch and is usually required to be repeated at regular intervals and is particularly effective following Botulinum Toxin injections. There is currently no evidence to support upper limb casting being used in isolation, that is, it should be used in conjunction with other treatments that are focused on the activity level of the ICF.¹⁴⁰

Biomechanically, casting imposes a continuous stretch on a group of muscles, leading to an increase in muscle fibre length due to an increase in the number of sarcomeres. This increased muscle length reduces the overall soft tissue contracture. It is important to note here that casts should never be left on for more than five to seven days as there is evidence to support the loss of sarcomeres if a joint is left immobilised in a cast for too long and that longer casting periods do not necessarily translate to greater gains in range of motion.¹⁴¹

Serial casting for the upper limb and lower limb should only be applied by clinicians who have completed sufficient training and gained basic competencies in the techniques. An understanding of the neurophysiological and biomechanical reasons for casting, types of casts, timings, adverse events and complications is required prior to commencing any casting program. Casting is unlikely to be an effective intervention for long-term contractures where bony changes might be limiting range of movement.

12.1.2 Splinting/Orthoses

The prescription and manufacture of upper and lower limb orthoses is common practice with children with cerebral palsy. Evidence suggests splints may be of some benefit when provided in conjunction with other therapies, although further research regarding splinting and orthoses is needed.¹⁴⁰ The main purposes of orthoses or splints are to maintain range of motion and assist with function. An orthosis is usually applied at the tolerable end of joint range. Often a variety of orthoses may be required for different activities and to achieve different goals. Orthoses are generally manufactured from low temperature thermoplastics or materials such as lycra and neoprene (by occupational therapists and physiotherapists in the therapy setting) or from high temperature thermoplastics (by orthotists).

12.1.2.1 Functional Orthoses

Functional orthoses generally position joints in a biomechanically advantageous position to either enable or improve function. Examples may include:

- Ankle foot orthoses (AFOs) – a variety of AFOs are available with varying purposes
- Wrist extension orthoses
- Neoprene wrist and thumb orthoses.

12.1.2.2 Positional Orthoses

Positional orthoses aim to maintain corrected anatomical alignment of the joint and maintain range of motion around that joint. This may be important for ease of care, to reduce the requirement for future orthopaedic surgery and in some cases to maintain healthy skin integrity. Examples of positional orthoses may include:

- Spinal braces
- Leg or elbow wrap arounds
- Hip abduction orthoses.

12.2 STRENGTHENING INTERVENTIONS

Strengthening programs and resistance training is an accepted intervention for children with cerebral palsy, in particular lower limb strengthening.^{142, 143} Various systematic reviews of the literature into strengthening indicate that the effectiveness of strength training, particularly in the lower limbs, is still disputed but that clinical practice continues despite the lack of published evidence. The literature also indicates there are no adverse increases in spasticity arising from strength training programs. There is limited evidence regarding the effects of strengthening programs on activity and participation level outcomes. A critically appraised topic investigating strength training in the upper limbs of children with cerebral palsy found limited evidence to suggest that strengthening programs may increase upper limb strength in children with cerebral palsy.¹⁴⁴ Strength training/progressive resistance exercise is based on three principles:

- To perform a small number of repetitions until fatigue
- Allow sufficient rest between exercises for recovery
- To increase the resistance as the ability to generate force increases.

Strengthening programs applied to children with cerebral palsy can be based on the guidelines published by The American Academy of Pediatrics¹⁴⁵ and the National Strength and Conditioning Association (NSCA)¹⁴⁶. Due to its intensity and the need for the muscles to rest and recover, it is not meant to be performed frequently and for long durations. Strength training needs to be combined with other activity-based programs such as treadmill training or cycling where you can look at other aspects of function such as endurance or coordination.

12.3 ELECTRICAL STIMULATION

There are three main forms of Electrical Stimulation:

- Functional Electrical Stimulation (FES) uses surface electrodes to stimulate muscles/nerves that have impaired motor control with the aim of eliciting functional movement
- Neuromuscular Electrical Stimulation (NMES) is a high intensity, short duration stimulation using surface electrodes in which a muscle contraction is elicited
- Therapeutic Electrical Stimulation (TES) is a low intensity (sub-threshold) stimulation applied continuously for longer durations.

FES is the preferred form of electrical stimulation. FES works by sending an electronic pulse to the muscle causing the muscle to be stimulated in conjunction with an activity or a specific task, for example foot switches during the gait cycle. FES is based on the concept that stimulation may be used to activate weak or inaccurate muscle responses

and thus strengthen muscles and produce functional improvements through coordinated, sequenced muscle activation.

FES is widely used in adult stroke populations but can be used for children with cerebral palsy. There is emerging evidence to support the use of FES for children with cerebral palsy in the lower limb¹⁴⁷ and inconclusive evidence for its use in the upper limb¹⁴⁸.

12.4 MEDICAL INTERVENTIONS AND MEDICATIONS

12.4.1 Botulinum Toxin A Injections

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

Botulinum Toxin A injections are considered following careful functional and/or carer goal identification and goal attainment. Adverse events are closely monitored post injections. Current literature indicates there is strong evidence to support the use of Botulinum Toxin A injections for upper and lower limb spasticity management. There is insufficient evidence to support its use in improving motor function.^{149, 150}

12.4.2 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 crosses the blood brain barrier poorly 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 or minus bolus doses of Baclofen over a 24 hour period.^{151, 152}

There is currently weak evidence to support the administration of intrathecal Baclofen to help with the reduction of spasticity and dystonia. Weak evidence also exists to support its use in improving health related quality of life outcomes.¹⁵⁰

12.4.3 Selective Dorsal Rhizotomy (SDR)

Selective Dorsal Rhizotomy (SDR) is a neurosurgical spasticity-reducing intervention for children with spastic cerebral palsy. 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 electromyography (EMG). Sensory nerve rootlets with abnormal, excessive and contralateral responses are surgically sectioned. There is evidence that SDR is effective in reducing spasticity.¹⁵⁰ In combination with physiotherapy, SDR has been reported to improve functional outcome in spastic diplegia.¹⁵³

It is suitable for a small selection of children with bilateral involvement, fulfilling the following criteria: GMFCS II/III, spastic, strong, symmetrical, straight with no significant contractures, good selective motor control, supportive family environment and young i.e. around 4 to 6 years of age.

The surgery will not correct existing contractures or deformities and does not cure the primary effects of cerebral palsy, 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 rhizotomy to correct persistent contractures and deformities of the bone.

12.4.4 Deep Brain Stimulation (DBS)

Deep Brain Stimulation (DBS) is a neurosurgical technique involving the implantation of electrodes into specific areas of the brain (the globus pallidus and/or subthalamic nucleus). These electrodes are attached to a neuro-stimulator, usually implanted below the patient's clavicle(s). Treatment aims to decrease dyskinetic movements and improve health related quality of life. DBS has been effectively used in the treatment of pain since the 1960s and in the control of primary dystonias common in Parkinson's disease.¹⁵⁴ DBS has been used, with varying results, in patients with cerebral palsy and secondary dystonias over the past decade.

Currently there is limited evidence and only a small number of studies available to support this intervention, although DBS has been shown to be an effective treatment option for dyskinetic cerebral palsy.¹⁵⁴

12.4.5 Medications

A variety of oral medications are routinely prescribed for children with cerebral palsy when a generalised reduction in spasticity and/or dystonia is the desired outcome. Commonly prescribed medications used for generalised spasticity include: Baclofen, Diazepam, Dantrolene and Tizanidine. Medications prescribed for the treatment of generalised dystonia include: Baclofen, Haloperidol, Levodopa, Tetrabenazine and 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. There is evidence to support the use of Diazepam for the short-term treatment of spasticity in children with cerebral palsy.^{149, 150} Limited evidence is available to support or refute use of other medications for the treatment of generalised spasticity and/or dystonia.

It is important to be aware that medicines may interact with other medicines or be influenced by food intake. This may impact the medicines effectiveness or cause adverse consequences. Please refer to the Product Information, Micromedex at <http://www.micromedexsolutions.com/micromedex2/librarian/>¹⁵⁵ or consult the pharmacist for any such interactions. The presence of food may affect the absorption of certain medicines and this can be avoided by taking the medicine one hour before or two hours after the food. Some medicines are recommended to be taken with food e.g. Baclofen. For children with swallowing difficulties or enteral feeding tubes, it is important to determine if solid oral dosage forms can be modified by crushing and or dispersing in liquids before administration. For guidance on administering medicines to patients with swallowing difficulties and enteral feeding tubes consult the Australian Don't Rush to Crush Handbook, Second Edition¹⁵⁶ or the relevant medicine monograph which can be accessed via MIMS Online at <http://www.mimsonline.com.au/Search/>¹⁵⁷ or the pharmacist.

12.4.6 Phenol Injections

Phenol, an anaesthetic drug, can be injected to help control local spasticity in children with cerebral palsy. It acts as a chemical neurolytic agent or nerve block, temporarily destroying a portion of the nerve to reduce overactivity and spasticity. The main side effects may include local pain, tender nodules, skin slough, oedema, loss of sensation and dysaesthesias (neuropathic pain). Currently there is insufficient evidence to support or refute the use of phenol injections to treat spasticity in children with cerebral palsy.^{149, 150}

12.4.7 Alcohol Injections

Intramuscular alcohol injections can be used in the treatment of children with cerebral palsy to reduce spasticity for varying periods of time, although it is reported these periods diminish with each subsequent injection. Following the injection spasticity is reduced and there is an opportunity for clinicians and orthopaedic surgeons to determine whether corrective surgery is indicated. No adverse effects have been documented. Currently there is no evidence to support or refute the use of alcohol injections in children with cerebral palsy.^{149, 150}

12.4.8 Gastrostomy

Gastrostomy is a surgical procedure whereby a tube is inserted through the abdomen wall into the stomach to provide nutrition to supplement or replace oral feeding. In children with cerebral palsy gastrostomy is considered when the child has significant difficulty with safe swallowing, is at risk of aspiration and/or is unable to have adequate nutritional intake through oral feeding. Some children receive all their dietary requirements via their gastrostomy tube, including any medications and for others the gastrostomy is used to supplement their inadequate oral intake. Currently there is weak evidence to support the use of gastrostomy in improving growth and weight gain in children with cerebral palsy.¹⁵⁰

12.4.9 Fundoplication

Fundoplication surgery is performed when children have severe gastroesophageal reflux disease (GORD). This is a digestive disorder that affects the lower oesophageal sphincter, whose function is to prevent food moving from the stomach back up the oesophagus. Children with GORD suffer from reflux which if left untreated can cause aspiration pneumonia and failure to thrive. Surgery, for example Nissan fundoplication, corrects gastroesophageal reflux by strengthening and improving the valve mechanism at the bottom of the oesophagus, preventing the flow of food and acid upwards. There is currently no cerebral palsy specific evidence to support the use of fundoplication and evidence for this surgery in the general population is weak.¹⁵⁸

12.4.10 Orthopaedic Surgery

The goals of orthopaedic surgery are to increase/maintain function, and to prevent further pain and deformity. Some children with cerebral palsy require orthopaedic surgery to correct and/or assist positioning of their upper and/or lower limbs, and to correct curvature of the spine.

The type of orthopaedic surgery recommended is considered in relation to the child's functional abilities (GMFCS level) and the goals of the child/family as a result of the surgery.

Orthopaedic procedures include muscle lengthening, correction of bony deformities, tendon transfers, joint stabilisation, and growth plate surgery. Emphasis is on minimal immobilisation and early mobilisation to prevent loss of strength. If contractures are severe, surgery to lengthen affected muscles can improve a child's ability to move, walk and to be positioned comfortably. This surgery may also help if tightly contracted muscles cause stress to joints and lead to deformities or dislocations.

An example of soft tissue surgery is hip adductor muscle releases to increase hip movement, allowing a child to sit and walk more easily. It may also be done to help prevent hip dislocation in children who are at risk.

Muscle transfers may be considered to assist with functional goals for the upper and lower limbs. For example, semi-tendinosis muscle transfer to allow for more upright stance and gait.

Combined bony and soft tissue surgery may be considered for:

- A bone or joint deformity causing pain or interfering with function, and worsening over time
- Dislocated joints
- Guided growth (growth plate surgery)
- Worsening spinal deformity. Spinal surgery usually takes the form of screws or rodding to straighten a scoliosis, lordosis or kyphosis curvature
- A deformity that makes some caregiving functions, such as bathing, extremely difficult or impossible e.g. wrist flexion contractures.

Post-operatively, children may need to wear a brace/orthosis to support an area to maintain corrected joint alignment.

Corrections made during orthopaedic surgery may be temporary. As a person grows, the same muscles or other muscles may become tight and cause contractures. Additional surgery may be needed. Careful timing to reduce the number of surgical procedures is required during growth.

There is some debate amongst doctors about the ideal age for children with cerebral palsy to have surgery. Surgery may be delayed to a suitable age so as to allow for multiple muscle releases and bony corrections over two to three joint levels (hips, knees and ankles) during the same surgery, rather than releasing only one muscle at a time. This is known as single event multi-level surgery (SEMLS). Avoiding repeated surgeries is advantageous.

Surgery of any kind carries the risk of bleeding, infection, or need for repeated surgery.

12.5 NUTRITIONAL INTERVENTIONS

The selection of a nutritional intervention relies primarily on a thorough assessment. This will enable purposefully selected strategies to address areas identified as in need of improvement. It should be carefully planned to take into account the child's individual needs and abilities, involving parents or caregivers in the process.

The first line of treatment for undernutrition and dysphagia in children with cerebral palsy is usually oral nutrition supplementation combined with assessment and advice from a speech pathologist. If that fails, or if the dysphagia is so severe that swallowing is not safe, the next step is enteral feeding via a nasogastric (NG) or gastrostomy tube.

12.5.1 Oral Nutrition Support

For children with cerebral palsy who are safe to consume an oral diet intervention typically involves oral nutrition support.

12.5.1.1 Dietary Modification

Feeding difficulties and oromotor dysfunction are common in infants and children with cerebral palsy⁴⁴ and safety in oral intake must first be established. It is essential to work in conjunction with medical officers and speech pathology services where feeding difficulties exist.

Modifications may include, but are not limited to:

- Weight control requiring lowering of energy intake, whilst maintaining nutrition
- High fibre +/- increased fluid to address constipation
- Texture modification +/- thickened fluids due to oromotor dysfunction
- High protein, high energy using food additives to address poor weight gain or reduced intake
- Increasing intake of individual nutrients at risk as identified in the dietary assessment or proven by patient blood biochemistry.

12.5.1.2 Food Fortification

Fat has a higher energy density per gram (37kJ or 9kcal/g) when it is compared with protein and carbohydrate (17kJ or 4kcal/g). The addition of extra fats to the diet, therefore, can significantly increase the energy intake of a child without increasing the volume of food consumed. This can be achieved through the use of products typically found in the home.¹¹¹ Fats and oils may be added during cooking or to the child's meal upon serving. High fat spreads can be used such as nut spreads, cheese spreads, or avocado. Milk drinks can be fortified using full cream milk powder, cream or ice cream, as well as flavourings to boost energy and protein density.¹¹¹

12.5.1.3 Supplementation

When oral feeding is still considered the optimal route but dietary modification alone is unable to address nutritional issues, then oral supplementation using commercially available products may be useful to boost energy, protein and micronutrient intakes.

- **Boosting energy intake:** When all other nutrients are adequate and additional energy is required calories can be added to food and beverages using commercially produced fat, protein, or carbohydrate supplements, available in powder and liquid forms
- **Boosting energy and micronutrient intake:** Milk and juice based commercial supplements can be used to improve nutrition either as a supplement to the child's usual diet or as a sole source of oral nutrition (check individual product suitability for use as sole source of nutrition and volume required for individual).

These supplements are available in powder, ready to drink and pudding styles, often in a neutral or variety of flavours to prevent taste fatigue.

12.5.2 Enteral Feeding

If no improvement in nutritional status is seen after a suitable time period of oral nutrition support (approximately six months), or if it has been deemed unsafe to feed orally then an alternate route of feeding may be necessary. This decision is usually made using a team approach. Refer to decision making tree in Appendix Five.

Routes may include nasogastric, nasojejunal, gastrostomy or jejunostomy. From a nutrition point of view use of the feeding tube may be for fluid only, supplementing oral intake or total nutrition.

Tube feeding may be used as the sole source of nutrition for children with an unsafe swallow, or to supplement oral intake in those children safe to consume some food and/or fluids orally. Tube feeding may also be used for a short period of time while a child is experiencing a health crisis or undergoing surgery.

12.5.2.1 Enteral Tube Feeding Regimens

Enteral tube feeding regimens must be tailored to the individual child's needs and will be influenced by the route of access (i.e. gastric versus trans-pyloric), tolerance of feed, contribution of oral intake, and family routine¹¹¹. Refer to Paediatric Home Enteral Nutrition (HEN): Tube Feeding - A Multidisciplinary Resource for Health Professionals¹⁵⁹ for the advantages and disadvantages of the different feeding methods. Provide the parents or caregivers with a written HEN feeding regimen and recipe if made from powdered formula.

Method of delivering the feed should take into consideration patient tolerance and fit the family routine wherever possible. This may consist of gravity bolus feeds; pump assisted bolus feeds, continuous pump feeds or a combination of any of these.

For further information on enteral nutrition please refer to the NSW Agency for Clinical Innovation ACI Nutrition Network Guidelines for Home Enteral Nutrition (HEN) Services 2nd Edition¹⁶⁰ at: <https://www.aci.health.nsw.gov.au/resources/nutrition/hen/hen-clinicians>

12.5.2.2 Formula Selection

The initial feed of choice is usually a standard energy density (1cal/ml) polymeric feed suitable for the age of the child, such as NutriniDrink™ (Nutricia®) (made to 1cal/ml), Sustagen Kid Essentials™ (Nestle®) or PediaSure™ (Abbott®). A fibre-containing feed should be considered if it is the sole source of nutrition. For those children with an increased energy requirement or poor tolerance of large volumes of feed, a high energy density formula, or concentrating a standard powdered feed up to 1.5cal/ml, may be useful. Alternatively for those children with low energy requirements, dilution of a standard powdered or liquid feed may be required (in the absence of a specialised low energy density formula). However micronutrient intakes will need to be analysed to check the child is meeting their requirements. Feeds with dietary fibre have potential beneficial effects for the prevention of both diarrhea and constipation.¹¹¹ Whey-based or whey dominant (60:40 whey to casein) formulas may be beneficial in children with poor feed tolerance because of delayed gastric emptying.^{161, 162} The purported benefits of whey protein relate to the predominance of beta-lactoglobulin, which remains soluble in the stomach, therefore transitioning more rapidly to the upper jejunum. Casein protein, in contrast, clots and or precipitates in the acid environment of the stomach, resulting in slower gastric emptying.¹⁶²

12.5.2.3 Blenderised Tube Feeding

Blenderised tube feeding, or the provision of food that has been pureed using a blender through a patient's feeding tube, is a practice that has recently been gaining in popularity.¹⁶³ Pureed food given via gastrostomy has been suggested to reduce gagging and retching in children following fundoplication surgery¹⁶⁴, however there is insufficient evidence to support this claim.¹¹¹ In addition there are no studies that have verified the efficacy and safety of using blenderised tube feeds in a hospital setting. The potential for bacterial contamination is a key reason most hospitals use commercially prepared formulas. Other reasons against using blenderised tube feeds is that they provide unpredictable levels of micronutrients and macronutrients, the viscosity may be unsuitable for feeding tubes, and they are difficult and time consuming to customise to individual patient needs. The cost of blenderised feeds compared to commercially prepared formulas is also another factor that needs to be taken into consideration.

If the parents or caregivers express a strong interest in using blenderised tube feeding, it should be discussed with the child's managing medical physician.

12.5.3 Other Considerations

12.5.3.1 Constipation

Prevalence estimates of constipation in children with cerebral palsy range from 26% to 74% depending on the definition of constipation.^{90, 114} At present there is no generally accepted definition of functional constipation in children with cerebral palsy.¹¹⁴ A proposed definition of constipation in one recent study was the presence of two or more of the following symptoms for at least two months:

- two or fewer defaecations per week
- painful or hard bowel movements
- the presence of large faecal mass in the abdomen palpable on abdominal examination.¹¹⁴

Constipation may be caused by diminished colonic motility, but contributing factors include immobility, low fibre intake, low fluid intake, and the effects of medications. Medications commonly used in this population which cause constipation are Trihexyphenidyl (Artane®), Glycopyrrolate (Robinul®), Diazepam (Valium®) or narcotics.

Constipation may cause early satiety, poor feeding, gassiness, abdominal pain, and vomiting, again leading to a decreased oral intake and possibly malnutrition.⁸⁷

Clinical practice has found increasing fluid intake to 90% of fluid needs can help manage constipation in cerebral palsy.¹¹³ The RDI for fibre is typically used to determine fibre recommendations; however, this may not be realistic due to food choices in individuals with cerebral palsy, although fibre supplements may be helpful.¹¹³ Ensuring adequate fluid intake prior to increasing fibre intake can help prevent additional problems with constipation.¹¹³ Adjusting fluid and/or fibre intake does not always improve constipation, and increasing fibre can sometimes worsen constipation; therefore, medical management is frequently required.¹¹³

12.5.3.2 Chest Health and Minimising Aspiration

In some cases aspiration occurs with fatigue and therefore can be minimised with smaller more frequent meals. A speech pathologist and occupational therapist can also assist by advising on correct positioning and seating during mealtimes, the use of specialised feeding utensils, and the modification of the thickness of fluids and texture of food. Asking the child's parent/carer about the number of chest infections a child has per year can indicate if the child is possibly aspirating and if this requires further investigation.

12.5.3.3 Dental Hygiene and Dietary Management

Children with cerebral palsy who have eating, drinking and swallowing difficulties are generally more at risk of dental and oral hygiene problems.^{165, 166} Periodontal disease has a higher prevalence in children with cerebral palsy.¹⁶⁷ A higher load of pathogenic bacteria increases the risk of aspiration pneumonia.¹⁶⁸

Neglect of oral care can result in infection, pain, odour and poor dental appearance, which can contribute both to feeding difficulties and influence social interaction.^{165, 169, 170}

Factors that can increase the risk of oral hygiene and dental problems include:

- Involuntary physical movements, orofacial motor dysfunction and spasticity in masticatory muscles¹⁶⁶
- Inability to adapt a toothbrush to the teeth adequately or to floss effectively resulting in insufficient removal of plaque and residual food¹⁶⁶
- Hyperactive gag reflex resulting in gagging or vomiting if toothbrushing and flossing is poorly controlled¹⁷¹
- Dietary consistency has a significant effect on oral hygiene. Children receiving a liquid diet are most at risk¹⁷²
- Patients on small frequent meals and drinks
- Higher calorie diets needed by some children contain higher levels of sugary foods and carbohydrates which the bacteria in plaque feed upon causing acids that eat away the outer enamel layer on teeth causing decay^{173, 174}
- The mildly alkaline nature of saliva is the key protective element against erosion of teeth by acids. If dehydration occurs from inadequate intake or from particular medications, an adequate intake of water is essential for maximising the protective effect of saliva on oral health.¹⁷⁵ Dehydration also causes loss of salivary protection against attrition, erosion and abrasion.

Dietary management for oral health may include:

- Rinse or swab the mouth with fluoridated water ¹⁷⁶ following meals and snacks ¹⁷⁵
- Brush teeth twice a day. Even when children are exclusively tube fed, bacteria can still gather on the teeth. Brushing is still recommended at least twice a day (http://www.schn.health.nsw.gov.au/files/factsheets/tube_feeding_-_the_importance_of_a_clean_mouth-en.pdf) ¹⁷⁷
- Visit the dentist every six months ¹⁷⁸
- Reduce the number of sugary snacks
- Choose sugar free medications where possible
- For those needing extra calories try high fat rather than sugary foods
- Increase intake of raw fruits and vegetables (if possible) which require chewing to massage gums, exercise the jaw and help remove some of the plaque and bacteria from the teeth.

For further information, consult a paediatric speech pathologist and/or paediatric dentist. The following resource may also provide guidance:

A Clean Mouth is Crucial for Children with Special Needs – Factsheet available to be used by health professionals, families and parents. This addresses dental care and health for children with special needs. ¹⁷⁷

MANAGEMENT OF CEREBRAL PALSY IN CHILDREN

13

ACTIVITY AND PARTICIPATION INTERVENTIONS

13. ACTIVITY AND PARTICIPATION INTERVENTIONS

Intervention	Section
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13.1 UPPER LIMB SPECIFIC INTERVENTIONS

13.1.1 Modified Constraint Induced Movement Therapy (mCIMT)

Constraint Induced Movement Therapy (CIMT) involves the constraint of the unaffected arm in individuals with hemiplegia, providing them with no option but to use their affected upper limb. Constraint is teamed with intensive upper limb therapy of the affected side. Research indicates improvements in upper limb function in children with hemiplegic cerebral palsy following CIMT.

CIMT was developed as a result of neuroscientific research with monkeys, where it was found that constraint of an intact limb led to learned reuse of the affected limb. Its use in humans is based on the hypothesis that in hemiplegia, disuse of the affected side occurs as a result of learned non-use. It was first used in adults with hemiplegia following stroke.

CIMT with children with cerebral palsy has involved the use of slings, mitts, splints and casts applied for most of the waking day, for a set period of weeks. Concerns regarding the intensity of the intervention has led to a modified model where the constraint is applied for up to two hours a day but for a longer overall duration. Outcomes of modified Constraint Induced Movement Therapy (mCIMT) have been shown to be just as effective as CIMT.^{180, 181}

The evidence indicates that mCIMT is more effective than usual care¹⁸⁰ and the model of treatment appears to be age dependant. Under the age of 4 years shorter periods of daily practice at home and/or preschool over an eight to 10 week period is effective while in children over 4 years of age intensive two to three week camps or group based intervention appears more effective. Higher intensity does not always result in better outcomes and CIMT is not age dependant, although children with poorer hand function do tend to make greater improvements.¹⁸⁰

13.1.2 Bimanual Therapy

Bimanual training provides an increased opportunity to practice bilateral activities with the goal of leading to an improved use of both hands during activity. Bimanual training involves practicing the specific task or goal, or parts of the task, rather than focussing on the underlying body structure and function deficits. There is reliable evidence to support the use of bimanual therapy¹⁸², with outcomes of bimanual therapy being equal to that of CIMT when the same amount of therapy is provided.

Best candidates for bimanual training are typically older than 12 months, have spontaneous use of affected hand, selective motor control, have basic skills such as grasp and hold and have the cognitive skills to respond to cues.

13.2 LOWER LIMB SPECIFIC INTERVENTIONS

13.2.1 Gait Training

Gait training is the process of first learning or re-learning how to walk after an intervention such as orthopaedic surgery and can be used as a therapy intervention for persons with cerebral palsy.

It can be achieved in a number of ways, but repetition of the actual motions/gait pattern performed during walking is the most important factor. Depending on the severity of the person's impairment, one or more physiotherapists may be present to assist in maintaining the person's appropriate posture and moving their lower limbs to assist in facilitating the prerequisites of a normal gait pattern. Parallel bars may be used to help with gait training, especially in the early stages of rehabilitation as the bars provide support for the child, and the clinician facilitates the desired movement. Other equipment, such as high support and low support assistive mobility devices are also utilised.

13.2.1.1 Treadmill Training

Treadmill training is an active approach to gait training in which the child practices the movement of walking on a treadmill rather than within the real-world environment. Treadmill training may include partial body-weight support, in which the child is placed in a harness that supports their weight, whilst a clinician manually guides the legs in a walking motion.¹⁸³

Treadmill training, including those with partial body-weight support, are based on motor learning theories, in which the child carries out the activities of walking repetitively, with increasing speed and weight-bearing with the aim of this skill carrying over to walking within an everyday context.

Combined results from four systematic reviews suggest that there is low quality evidence to support treadmill training to improve weight-bearing. It also found low quality evidence that treadmill training will improve functional walking although the practice of overground walking, rather than treadmill training may be more effective.¹⁵⁰

13.3 SPEECH/LANGUAGE AND ORAL MOTOR INTERVENTIONS

13.3.1 Communication Training

Communication training involves training communication partners so that they can recognise and respond to children's communication attempts, and create communication opportunities. It is an indirect therapy focused on changing the interactional style of communication partners and training them to facilitate children's communication development. Communication training programs are delivered through group training (e.g. groups of parents, teachers, educational assistants) or during individual sessions. Communication partners may be trained to increase responsiveness, reduce directiveness, improve face to face contact and use of imitation and facilitate use of augmentative and alternative communication.

Available evidence indicates that communication training and conversational partner training may be effective intervention strategies for children with cerebral palsy.¹⁸⁴

13.3.2 Augmentative and Alternative Communication (AAC)

Augmentative and Alternative Communication (AAC) systems are used to supplement or replace verbal speech. These are divided into aided and unaided systems. Unaided AAC systems include signing, gestures and facial expressions, while aided AAC systems are divided into high and low technology. Low technology systems include communication boards, alphabet boards, timetables and communication diaries. High technology communication systems refer to devices that use a power source to operate, known as speech generating devices (SGD). These include single message switches, static display devices and dynamic display devices with additional functions, such as environmental control unit (ECU) and access to the internet and social media.¹⁸⁵

AAC aims to support expressive and receptive language skills to improve the individual's ability to take part in the community and have control of what happens to them and to reduce frustration.

Aided language stimulation (ALS) is a communication intervention strategy whereby the communication partner points to symbols on an AAC system while saying the corresponding word. The communication partner models communication by combining speech and AAC symbols. ALS aims to promote AAC and language comprehension in a motivating and naturalistic context.

The key considerations for AAC implementation are the individual needs and priorities of the person with complex communication needs. In addition, support and education directed to the family and other relevant people in the individual's environment are crucial in promoting success for AAC use. Successful AAC implementation includes competencies in linguistic, operational, social and strategic domains.

AAC requires a careful multidisciplinary assessment process before it can be implemented. Assessment of the individual's communication skills is followed by identifying the specific areas of difficulty that can be addressed with an AAC system. SETT Framework can be used for this. Once these have been established, the individual's communication skills and needs, physical, sensory and other requirements, such as environmental control unit (ECU) are matched to a suitable AAC system. This is referred to as 'feature matching'.

Once a suitable speech generating device has been identified, a trial period with the device is commenced. An individual may trial a number of speech generating devices in order to select the one that best meets the individual's needs. It is important to include specific functional goals for the duration of the trial. The outcomes of these goals will help decide the suitability of the device. Once the best system is identified, the speech pathologist can apply for government funding with EnableNSW. Please see page 93 for further information on EnableNSW.

Once the individual has a speech generating device, it is important that a carefully selected team provides training and support for the use of the system. It is also important to support the individual to use their device and other forms of AAC systems in the different environments. Intervention should cover all competency domains, including linguistic, operational, social and strategic competencies. Intervention typically progresses from learning to use the selected vocabulary to using the system in supported activity to ultimately using the system functionally.

There are a number of commercially available Smartphone apps that function as speech generating devices.

For more information, please refer to:

http://www.speechpathologyaustralia.org.au/library/Clinical_Guidelines/AAC.pdf (Speech Pathology Australia members only).¹⁸⁶

For assessment and support for assistive technology, please contact:

<https://www.cerebralpalsy.org.au/services/all-programs-and-services/assistive-technology/>¹⁸⁷

<https://www.northcott.com.au/support/service/equipment-and-technology/>⁽¹⁸⁸⁾

13.3.3 Social Stories

Social stories describe a situation, skill or a concept in style and format that is easily understood by the individual, such as a series of photos. Social stories are designed to assist the individual to better understand social situations, events and expectations.

For example, a social story or a picture schedule may assist the child in understanding what is going to take place in a hospital visit.

For more information please refer to:

<http://www.educateautism.com/social-stories.html>¹⁸⁹

<http://carolgraysocialstories.com/social-stories/>¹⁹⁰

13.4 GOAL DIRECTED THERAPY/ FUNCTIONAL THERAPY

There are four main stages involved in goal directed therapy. The first is the formation of an age and developmentally appropriate goal. Goals should always be child focused to increase motivation. Assessment to identify the goal limiting factor(s) is a crucial next step. The task should then be analysed, considering the child's skills as well as environmental limitations. Intervention should be structured and involve repetitive practice, appropriate adaptations to the task or the environment and outcomes evaluated using validated tools.

13.5 FITNESS TRAINING

The health benefits of regular exercise for the general population have been known for many years providing protective benefits against cardiovascular disease, type II diabetes, obesity and some cancers.¹⁹¹ Over recent years there has been increased focus on interventions to improve the general health of children with cerebral palsy.

Exercise can be defined as "planned structured activities involving repeated movement of skeletal muscles that result in energy expenditure to improve or maintain levels of physical fitness".^{150 p.891} Physical fitness is "a set of attributes that people have or achieve that relates to the ability to perform physical activity".^{192 p.129} The major components of health related fitness are cardiorespiratory fitness and muscle strength.¹⁴³ The primary and secondary impairments of cerebral palsy affect both cardiorespiratory fitness and muscle strength contributing to reduced physical fitness.¹⁴³

Current evidence suggests that fitness training to improve aerobic fitness provides short-term benefits for clients with sufficient motor skills to be able to undertake training and any increase in capacity following training is not maintained when training stops.¹⁵⁰ There is currently insufficient evidence to support the use of fitness training to improve function and participation however the research would suggest that aerobic fitness does not translate into either activity or participation gains.¹⁵⁰

Frequency and intensity of interventions vary across the literature and generally focus on structured moderate to vigorous exercise. Attention is shifting with a growing recognition of the importance of reducing sedentary behaviour and encouraging light intensity activities throughout the day.¹⁴³ It is recommended that fitness training to improve aerobic fitness, muscle strength and the general health of children with cerebral palsy should be integrated into the child's daily life on an ongoing basis.¹⁴³

[For information relating to strengthening, see Strengthening Interventions in Section 12.2.]

13.6 HOME PROGRAMS

Home programs are a "form of guidance and advice"^{193 p.175} that support the "therapeutic practice of goal-based tasks by the child, led by the parent and supported by the therapist, in the home environment".^{150 p.892}

There is strong evidence to support the effectiveness of home programs aimed at improving the performance of functional activities when based upon the following five step model.^{150, 193}

1. Establish collaborative relationships between parents and therapist
2. Set mutually agreed upon family and child goals
3. Select therapeutic activities that focus on achieving family and child goals that are supported by best available evidence
4. Support implementation of home program through parent education, home visits and program updates to sustain motivation
5. Evaluate outcomes.^{194 p. e608}

There is currently insufficient evidence to support the use of home programs aimed at improving participation. The use of appropriate outcome measures for evaluation is recommended.¹⁵⁰

13.7 CONTEXT FOCUSED THERAPY

Context focused therapy consists of changing the task or the environment (but not the underlying body structure and function of the child) to promote successful task performance. In context focused therapy activities are identified which a child likes or needs to do, but has difficulty doing. The focus is then on changing the activity to make it easier to do by reducing restricting factors in the environment or the task. A child will practice activities within context, and individualised strategies are determined for each child and family member.¹⁹⁵ A large multi-site trial has provided evidence for this intervention.¹⁹⁶ In this study, children were given treatment approximately once a week, and more research is needed to find out whether the frequency of treatment can affect the improvements seen with therapy. Novak et al.¹⁵⁰ indicate there is strong high quality evidence to support the use of context focused therapy to improve the function of children with cerebral palsy. Therapy that focuses on changing the activity and the environment is considered as effective in improving functioning as therapy focusing on changing the child.

14

ENVIRONMENTAL INTERVENTIONS

14. ENVIRONMENTAL INTERVENTIONS

Intervention	Section
Equipment	14.1
Home Modifications	14.2
Vehicle Modifications	14.3

14.1 EQUIPMENT

Equipment prescription is an ongoing aspect of any therapy program for children with cerebral palsy. A variety of aids and equipment are commonly used to facilitate function and participation in all aspects of life. Examples of equipment and equipment modifications, commonly prescribed for children with cerebral palsy include:

- Standing frames
- Walking frames
- Wheelchairs – manual and power chairs
- Pressure care
- Seating systems
- Sleep systems
- Bathing aides
- Car modifications
- Hoists.

It is essential that equipment prescription is part of an overall intervention plan and outcome measures are utilised when prescribing equipment. There is currently little evidence supporting specialised equipment and technology. Novak et al. concluded that may be because “the benefits are easily observable”.¹⁵⁰ Successful outcomes rely on client-centred goal setting, assessment and the monitoring of outcomes to ensure equipment is not abandoned.

There are a number of organisations that provide a specialist equipment service offering consultation, support and technical expertise in the assessment, prescription and procurement of functional and position equipment for children. These include:

Independent Living Centre: <http://ilcaustralia.org.au/>¹⁹⁷

Offers information about products and services to help people remain independent and improve their quality of life.

Northcott: <https://www.northcott.com.au/service-categories/equipment-and-technology>¹⁹⁸

Assistance with equipment and technology needs, including devices to improve communication or mobility and repairing or modifying wheelchairs or other equipment.

Each state and territory in Australia has a government-funded aids and equipment program to assist people with disabilities obtain equipment to enhance their safety and independence. These schemes are operated differently in each state, with some variation in eligibility criteria, items able to be funded and the extent of the subsidy provided.

EnableNSW: <http://www.enable.health.nsw.gov.au/>¹⁹⁹

This scheme is run by EnableNSW, a division of NSW Health. The Aids and Equipment Program helps people who have a life-long or long-term disability by providing appropriate equipment, aids and appliances. More information can be found on the EnableNSW website including Prescription and Prescriber Guidelines.

Technical Aids for the Disabled: <http://tadnsw.org.au/>²⁰⁰

Personalised and customised equipment solutions including the Freedom Wheels program which assists families and children to customise, adapt or modify equipment to better suit each individuals needs.

14.2 HOME MODIFICATIONS

Home modifications consist of removing or adapting environmental barriers that restrict a child with cerebral palsy entering, using space within the home or developing independence in daily routines. Home modifications can generally be broken down into two categories: structural and minor adaptations. These home improvements can also benefit parents, other family members or caregivers.

14.3 VEHICLE MODIFICATIONS

Clinicians are often required to assess and provide recommendations to assist with safe travel. There are many options available including recommendations regarding equipment and restraints. Vehicle modifications are considered when working with children with cerebral palsy as the clinician focuses on transporting a child with disabilities in relation to comfort, safety and positioning. TranSPOT identifies that a clinician's "core area of expertise in transport is identified as a person's mobility, seating and postural/positioning issues regarding safe transport".^{201 p.7} Examples of this include a child's difficulty maintaining postural control or transferring in/out of vehicles.

Any modifications to a motor vehicle are required by law to be carried out by an approved fitting station.²⁰¹ Vehicle modifications will require an engineering certificate and are outside the remit of a clinician. NSW Roads and Maritime Services (RMS) are able to provide information concerning authorised engineers in your area.

The hard shell or anchorage system of car seats, booster seats and postural supports must not be modified in any way as this can compromise their performance in the event of an accident. Only soft modifications to the restraint should be attempted by anyone other than the restraint manufacturer. TranSPOT identifies that the clinician working with children should have "access to AS/NZS 4370, as it lists options for child restraint in situations where it is not possible to use a child restraint complying with AS/NZS 1754. This standard lists specific disabilities and recommended restraint options".^{201 p.6}

TranSPOT: http://spotondd.org.au/?page_id=17²⁰²

TranSPOT is a useful resource for answering questions regarding vehicle modifications and safe transport options.

For more information on transport safety guidelines for people with a disability please refer to the TranSPOT (2010) Transport Safety Guidelines for People with a Disability at

http://spotondd.org.au/wp-content/uploads/2014/07/TranSPOT_SafetyGuide.pdf²⁰¹

**MANAGEMENT OF
CEREBRAL PALSY
IN CHILDREN**

15

**ADJUNCT THERAPIES/
INTERVENTIONS ACCESSED BY
CHILDREN WITH CEREBRAL PALSY**

15. ADJUNCT THERAPIES/ INTERVENTIONS ACCESSED BY CHILDREN WITH CEREBRAL PALSY

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15.1 BODY STRUCTURE AND FUNCTION ADJUNCT INTERVENTIONS

15.1.1 Acupuncture

Acupuncture, a component of Traditional Chinese Medicine (TCM), is classified as a complementary health approach. It involves the insertion of fine needles into the skin to stimulate certain parts of the body. According to traditional Chinese medicine the stimulation of specific acupuncture points, located along meridians in the body, can correct the flow of vital energy or qi. A systematic review by Zhang, Liu, Wang & He²⁰³ found that the use of acupuncture, with or without additional interventions such as conventional therapy may benefit children with cerebral palsy but lacks sufficient evidence. Novak et al.¹⁵⁰ indicated there is weak evidence to support the use of acupuncture to improve gross motor function in children with cerebral palsy.

15.1.2 Biofeedback

Biofeedback uses electronic or electromechanical instruments to provide individuals with feedback regarding their neuromuscular activity, for example their gait or upper limb use. The main purpose of biofeedback is for individuals to gain a greater awareness of their movement with the aim of increasing voluntary control, muscle re-training and reducing the effects of spasticity on functional tasks.

There is currently weak evidence to support the use of biofeedback for improving muscle activation, active range of motion, improving walking and improving hand function in children with cerebral palsy.^{150, 204, 205}

15.1.3 Facilitated Communication (FC)

Facilitated Communication (FC) is a strategy used to assist a person with a physical disability to communicate. A facilitator physically assists the person to choose objects, pictures, symbols, words or letters by touching his or her hand, elbow, shoulder or body. The purpose of FC is to teach the person to independently access a communication aid with his or her hand(s).

Most evidence to support FC is anecdotal and substantial research evidence exists that contraindicates its use. There is a body of evidence that facilitators influence, either consciously or unconsciously, the message output.

The Speech Pathology Australia Augmentative and Alternative Clinical Guideline¹⁸⁶ recommends that alternative and augmentative communication systems should always allow a person to communicate independently and therefore does not endorse the use of FC. It recommends that “speech pathologists have an ethical responsibility to inform clients and their families of the lack of supportive evidence and evidence of known harms associated with FC in the literature”.^{186 p.183}

Further information can be obtained by visiting <http://www.qldfctinc.com.au/>²⁰⁶ and <http://www.annemcdonaldcentre.org.au/facilitated-communication-training>.²⁰⁷

15.1.4 Hydrotherapy

Hydrotherapy provides stimulation to a body while being able to enhance or facilitate relaxation, strength, balance and coordination in a variety of positions. Flotation devices may or may not be used. A specific technique for cerebral palsy is the Halliwick Method. The Bad ra Gaz method employs flotation with the clinician using the water to provide resistance which may help improve range of motion, reduce tone, or facilitate specific movement patterns.

The warmth and buoyancy of the water provides support which can aid pain relief, but also a different movement experience to that on land. The heat of the water may assist relaxation, or help reduce spasms. Walking may not only be easier but possible without aides for some children and young adults with cerebral palsy. Fitness and endurance can be more easily challenged in a controlled way. Hydrotherapy is also an excellent recreational pursuit which can lead to improved swimming skills, and respiratory function. Blohm’s²⁰⁸ systematic review on effectiveness of aquatic treatments noted all studies reported benefits such as improved function for children with cerebral palsy, including better walking efficiency, improved strength,

range of motion or balance. However further more robust studies were needed.

For further information please refer to www.halliwicktherapy.org/en/²⁰⁹ and <http://www.badragazringmethod.org/en/>.²¹⁰

15.1.5 Hyperbaric Oxygen Therapy

Hyperbaric oxygen therapy is the inhalation of 100% oxygen inside a hyperbaric chamber pressurised to no greater than 1 atmosphere. Its use with children with cerebral palsy is based on the theory of improving oxygen availability to inactive damaged brain cells to stimulate them to function normally. There is currently no evidence to support the use of hyperbaric oxygen therapy with children with cerebral palsy.^{150, 211}

15.1.6 Massage

Massage is considered one of a variety of complementary and alternative medicines. There are a wide variety of massage techniques from gentle effleurage to deep tissue massage or myofascial release. Use of massage may help relieve muscle pain and tightness with a flow on effect to improve gait, range of motion and/or balance. Massage may be used to relax a child after a bath, before sleeping, or to prepare for a therapy session. Children and young adults with cerebral palsy may suffer from cramps and spasms, more than their non-cerebral palsy peers. There is little evidence on the benefits of massage in children with cerebral palsy even though it is often recommended for the psychological and/or relaxation benefits due to changes seen in cortisol levels.^{212, 213}

15.1.7 Neurodevelopmental Therapy (NDT)

Neurodevelopmental therapy (NDT) involves direct, passive handling and guidance to optimise function. The NDT approach aims to establish normal motor development and function, and prevent contractures and deformities. The focus is on the sensorimotor components of muscle tone, reflexes, abnormal movement patterns, postural control, sensation, perception, and memory. Handling techniques are used to facilitate normal muscle tone, equilibrium responses, and movement patterns. The child is a relatively passive recipient of the treatment and the approach is embedded into the context of normal developmental sequence. Novak et al.¹⁵⁰ report a lack of evidence to support the use of NDT in current practice and indicate that alternative evidence based therapy interventions and approaches be used to provide more effective results.

15.1.8 Sensory Integration (SI)

Sensory integration (SI) is a treatment approach involving the use of therapeutic activities to organise sensation from the body and environment to facilitate adaptive responses e.g. hammock swinging to stimulate the vestibular system, crucial for movement against gravity. Therapy is designed to help children interpret sensory input, understand its relevance, and respond – especially to external stimuli that are often beyond their control. A child's sensory processing may be considered problematic if they are over-responsive (avoidance, caution and fearful), under-responsive (withdrawn, passive or difficult to engage), or sensory seeking (impulsive and takes risks). The goals of sensory integration therapy might include:

- Determining how a child's specific sensory perceptions affect their overall physical, social and human development
- Identifying and eliminate barriers caused by disordered perception
- Implementing new sensory processing approaches that organise multiple sensations, filter out background stimuli, and compensate for deficits in perception
- Restoring a child's sense of body position and function (also known as vestibular and proprioception)
- Restoration of motor planning (praxis) capabilities, so a child can focus on his or her senses to plan movement, respond to other's movements, and understand the body's relationship to space
- Encouraging activities that allow children to explore their environment, learn and develop their senses; assisting children with perception issues in sorting out mixed messages
- Creating a physical environment that fosters participation in activities that depend on the senses.

The key characteristics of sensory integration treatment are:

- Active participation by the individual being treated
- Client-directed activity
- Treatment which is individualised
- Activities which are purposeful and require an adaptive response
- Activities which emphasize sensory stimulation
- Treatment based on improving underlying neurological processing and organisation
- Treatment which is provided by a clinician with advanced training in specific sensory integration treatment techniques.

Sensory integration aims to improve sensory organisation and improve motor skills, however only low quality evidence exists for its use with children with cerebral palsy¹⁵⁰ and other intervention options have been proven to be more effective.

15.1.9 Sensory Processing

Sensory processing is a treatment involving the use of therapeutic activities to organise more appropriate responsiveness (i.e. not hyper-responsive and not hypo-responsive) to task and environmental demands, including self-regulation. Common sensory processing approaches to intervention include listening programs, sensory-rich environments or gyms, and sensory diets. Sensory processing is a term that refers to the way the nervous system receives messages from the senses and turns them into appropriate motor and behavioural responses. The goal of therapy is to foster appropriate responses to sensation in an active, meaningful, and fun way so that children are able to behave in a more functional manner. Over time, the aim is for appropriate responses to generalise to the environment beyond the clinic including home, school, and the larger community. Novak et al.¹⁵⁰ are inconclusive in their recommendations for the use of sensory processing approaches with children with cerebral palsy in the absence of any evidence, and therefore recommend caution and the need to measure outcomes if proceeding. Their review comments on the fact that evidence for sensory processing interventions in the non-cerebral palsy population is not well established either.

15.1.10 Suit Therapy

Suit therapy involves the wearing of a biomechanical suit based on the design of a Russian space suit created for the Russian space program. The suit is a breathable soft dynamic orthotic full body suit that aims to increase feedback to the brain and enhance purposeful movement.

Suit therapy is based on the elimination of pathological reflexes and establishing new, correct, functional patterns of movement. This is thought to be done through increasing the feedback the body sends to the brain through doing activities while wearing the suit. It is designed to improve proprioception and aims to align the body as close to normal as possible, therefore re-establishing the correct postural alignment and is thought to play a crucial role in normalising muscle tone, sensory and vestibular function. Some examples of suits used are Therasuits, Neurosuits and Adeli Suits.

Currently there is conflicting and limited evidence on the benefits of suit therapy. Some studies have shown no improvement in motor function while other studies have shown some benefit, including improved gait parameters.²¹⁴ However, further investigation with larger sample sizes is recommended in the literature to determine the benefits of this intervention.

15.1.11 Vojta

The Vojta method or technique was developed by Dr Vojta in Czechoslovakia in the 1950s and 1960s. It is a specialised type of alternative physical therapy that is designed to primarily enhance the motor development of a child, improve strength and lessen the severity of cerebral palsy. Vojta therapy is based on automatic responses and reflex movements to specific stimuli. The treatment encourages those responses through specific positions and pressures applied.

The Vojta approach is based on the observation that children with cerebral palsy exhibit many of the reflexes seen in typically developing newborns. Patel states that:

According to Vojta, the persistence of these newborn reflex patterns in a child with CP interferes with postural development. It is postulated that with appropriate stimulation, the newborn reflex pattern can be provoked and activated in a child with CP, thereby facilitating the development of reflex locomotion.^{215 p.982}

Franki, Desloovere, De Cat, Feys, Molenaers, Calders, Vanderstraeten, Himpen & Van den Broeck stated that:

in the Vojta method normal patterns of movement sequences, for example, reaching, grasping, standing up and walking are not taught or trained as such. Vojta therapy rather stimulates the brain, activating innate, stored movement patterns, which are then exported as co-ordinated movements involving the musculature of the trunk and extremities.^{216 p.397}

In order to practice Vojta therapy, clinicians are trained specifically in the Vojta method. It is practiced widely in Japan and Europe. It is used less in Australia.

The clinician administers goal-directed pressure to defined areas on the body in a patient who is prone, supine or side lying. Stimulation applied using the Vojta technique is thought to lead to automatic and involuntarily complex movements such as reflex creeping in prone and reflex rolling from supine to side lying. Vojta is based on the theory that the therapeutic use of reflex locomotion or movement enables elementary patterns of movement in patients with impaired central nervous systems and locomotor systems to be restored once more, at least in part.

Families are taught the stimulation techniques by the clinician and needs to be carried out daily as a home program. This approach is applied to young at risk infants and is thought to be most beneficial in the first or second year of life.

There is conflicting evidence available regarding the outcomes of Vojta therapy and the quality of evidence has been classified as very low. Studies are generally small in numbers making it difficult to draw conclusions on the benefits of Vojta therapy.

15.1.12 Whole Body Vibration

Whole body vibration therapy (WBVT) has been preliminarily shown as a simple and effective technique to increase bone mass, muscle mass and strength in a variety of clinical settings. In a typical vibration session, the user stands on the device in a static position or performs dynamic movements.

It has been hypothesised that the vibrations stimulate the muscle spindles and alpha-motor neurons, eliciting a muscle contraction resulting in an increase in muscle mass. It has also been postulated that the direct effect of mechanical deformation of bones and increased fluid flow in the canalicular spaces and stimulation of the osteocytes, may contribute to an increase in bone mass with vibration therapy.

Studies have examined the long term use of vibration therapy with the aim to increase muscle strength, improve balance and increase bone mass. To date, there is low level evidence in the cerebral palsy population primarily due to small sample sizes.^{217, 218} Further studies of rigorous research design and homogeneous participants are required to show if WBVT is effective in improving individuals with cerebral palsy.

15.2 ACTIVITY AND PARTICIPATION ADJUNCT INTERVENTIONS

15.2.1 Animal-Assisted Therapy (AAT)

Animal-Assisted Therapy (AAT) is defined as:

a goal-directed intervention in which an animal meeting specific criteria is an integral part of the treatment process. Animal-assisted therapy is delivered and/or directed by health or human service providers working within the scope of his or her profession. Animal-assisted therapy is designed to promote improvement in human physical, social, emotional, or cognitive function.²¹⁹

The child's goals must be monitored and evaluated when used as an intervention. AAT is provided in a variety of settings and may be group or individual in nature. Dogs, horses and dolphins are some of the kinds of animals that have been used for animal-assisted therapy.

A systematic literature review by Matuszek²²⁰ found benefits from AAT including improvement in feelings of happiness, and decreased loneliness, anxiety and pain in paediatric, geriatric and psychiatric patient populations. However, most studies are of low quality and the only literature specific to AAT and the cerebral palsy population is hippotherapy, as described below. Further studies to gather scientific evidence is needed to explore the benefits of AAT.

15.2.2 Conductive Education (CE)

Conductive Education (CE) is an holistic educational approach designed to assist children with motor dysfunction overcome movement problems to increase functional independence. It was developed in Hungary in the 1940s by Professor Andreas Peto.²²¹

CE theory suggests that problems of movement are problems of learning. It is an educational approach rather than a form of therapy or treatment. CE conductors are trained for four years and supervise a group, school or centre-based program, incorporating teacher and clinician roles. CE requires intensive and repetitive practise of motor skills on a daily basis.

The aims of CE are to teach the child to function more independently and cope and adapt to new situations. Outcomes are reported to have a positive effect not only on motor development but also other functional skills.

Research studies on the effectiveness of CE have been inconclusive, and positive results “probably can be attributed to the very intensive training involved and the strict criteria used for selecting particular cerebral palsy children for this method”.^{222 p.75} Darrah, Watkins, Chen & Bonin suggests that:

In the absence of strong evidence of its effectiveness, parents must consider other important aspects of intervention such as cost, accessibility, time and the effect of the intervention on family dynamics. The focus of CE intervention on education, function and activities of daily living may fit with the needs of many families.^{223 p.202}

Novak et al.¹⁵⁰ suggested that CE should be accompanied by a sensitive outcome measure to monitor progress.

CE programs are available through the Cerebral Palsy Alliance at Allambie Heights in Sydney, NSW. More information can be found at <http://www.peto.hu/start/en/>²²⁴ and <https://www.cerebralpalsy.org.au/services/for-children/group-skills-classes-for-children/>.²²⁵

15.2.3 Hippotherapy – Horse Riding

Horseback riding for therapy uses the horse's movement which has an individual and variable gait, tempo, rhythm, repetition and cadence. It may influence neuromuscular development in humans. Improvements in trunk control and balance have been noted in children with cerebral palsy due to the physical adjustments to maintain proper alignment on the horse. From the current evidence it appears that hippotherapy and therapeutic horse riding have positive effects on balance and gross motor function in children with cerebral palsy although current literature and evidence is limited.^{226, 227}

15.2.4 Play Therapy

Play is seen as the primary occupation of young children, a major key to a child's cognitive and physical development and viewed as an essential medium through which child learning occurs.^{228, 229} Occupational therapists have long recognised the importance of play and its role in developing the crucial foundations of learning and skill acquisition across all domains in a child's life.²³⁰

My Child at cerebralpalsy.org²³¹ states that the benefits of play therapy include increased self-confidence, relaxation, learning; improved decision making, self-expression and feeling of control over their environment; enabled adaptive play; reduced feelings of anxiety, depression, separateness and anger; resolved emotional barriers; developed cognitive problem-solving and improved self-expression.

The Association of Child Life Therapists Australia reports that “Play Therapy is also a highly effective adjunctive treatment for the emotional difficulties which can arise when a child has been accurately diagnosed with a neurological, biological or organic disorder”.²³² Children with cerebral palsy frequently experience fine and gross motor limitations which impact their ability to engage in play and thus decrease their opportunities for play based skill development.²³³ The systematic review of interventions for children with cerebral palsy published by Novak et al.¹⁵⁰ identified that there is insufficient higher level evidence to support play therapy as an effective intervention approach with this population however anecdotally play continues to be the primary medium through which therapy is delivered for younger children with cerebral palsy.

Child life therapists are located in the three paediatric tertiary hospitals in NSW as well as in a number of paediatric wards in regional hospitals. These professionals use their knowledge and skills to promote the psychosocial care of children, young people and their families. Further information can be obtained by visiting <http://childlife.org.au>.²³⁴

Child life therapy aims to desensitise and normalise the hospital environment, reduce anxiety and increase coping skills, promote self-esteem and self-expression, and provide education and support to children for specific medical procedures.

16

**GLOSSARY OF TERMS
AND LIST OF ACRONYMS**

16. GLOSSARY OF TERMS AND LIST OF ACRONYMS

GLOSSARY OF TERMS

Dystonia – sustained or intermittent muscle contractions causing repetitive or twisting movements.

Hypertonia – “abnormally increased resistance to externally imposed movement about a joint”.^{36 p.e91}

Hypotonia – a state of low muscle tone.

Multidisciplinary team – represents a group of different disciplines working sequentially or in parallel within their own discipline boundary.¹⁰

Muscle tone – the tension in a muscle at rest.

Interdisciplinary team – members of different disciplines identify and achieve integrated goals by demonstrating both components of integrated and separated practices, i.e. working reciprocally within blurred disciplinary boundaries.¹⁰

Rigidity – abnormal stiffness of muscle.

Spasticity – velocity-dependent resistance to stretch by the muscles.

Transdisciplinary team – involves a group of professional disciplines working holistically and transcending disciplinary boundaries through role expansion and role release.¹⁰

LIST OF ACRONYMS

3DGA 3 Dimensional Gait Analysis	CPCHILD Caregiver Priorities and Child Health Index of Life with Disabilities	Mini-AHA Mini Assisting Hand Assessment
AAC Augmentative and Alternative Communication	DBS Deep Brain Stimulation	NDT Neurodevelopmental Therapy
AAT Animal-Assisted Therapy	DDS Dysphagia Disorder Survey	NG Nasogastric
ACPR Australian Cerebral Palsy Register Group	DIS Drooling Impact Scale	NHDC Neurological Hand Deformity Classification
ADHC Ageing, Disability and Home Care	DMSS Dysphagia Management Staging Scale	NMES Neuromuscular Electrical Stimulation
AFO Ankle Foot Orthoses	EAR Estimated Average Requirement	NSCA National Strength and Conditioning Association
AHA Assisting Hand Assessment	ECIA Early Childhood Intervention Australia	ONS Oral Nutrition Support
AI Adequate Intake	ECU Environmental Control Unit	PBS Pediatric Balance Scale
AIHW Australian Institute of Health and Welfare	EDACS Eating and Drinking Ability Classification System	PEDI Paediatric Evaluation of Disability Inventory
AMA American Management Association	EMG Electromyography	PN Parenteral Nutrition
APS Assistance to Participate Scale	EN Enteral Nutrition	QUEST Quality of Upper Extremity Skills Test
ASA Ashworth Scale	ETCH Evaluation Tool of Children's Handwriting	RDI Recommended Dietary Intake
ASAS Australian Spasticity Assessment Scale	FC Facilitated Communication	RMS NSW Roads and Maritime Services
AusACPDM Australasian Academy of Cerebral Palsy and Developmental Medicine	FCCS Functional Communication Classification System	ROM Range of Motion
BAD Barry-Albright Dystonia Scale	FES Functional Electrical Stimulation	RTI Respiratory Tract Infections
BMD Bone Mineral Density	FMS Functional Mobility Scale	SCALE Selective Control Assessment of the Lower Extremity
BMI Body Mass Index	FPS Faces Pain Scale	SDR Selective Dorsal Rhizotomy
BMR Basal Metabolic Rate	FPS-R Faces Pain Scale - Revised	SEMLS Single event multi-level surgery
CB&M Community Balance and Mobility Scale	GAS Goal Attainment Scaling	SETT Student – Environment – Tasks – Tools
CCHQ Care and Comfort Hypertonicity Questionnaire	GMFCS Gross Motor Function Classification System	SFA School Function Assessment
CDC Centers for Disease Control and Prevention	GMFM Gross Motor Function Measure	SGD Speech generating devices
CE Conductive Education	GORD Gastroesophageal Reflux Disease	SHUEE Shriners Hospital Upper Extremity Evaluation
CFCS Communication Function Classification System	HAT Hypertonia Assessment Tool	SI Sensory Integration
CHEQ Children's Hand-Use Experience Questionnaire	HEN Home Enteral Nutrition	SMC Boyd and Graham Selective Motor Control Scale
ChIPPA Child Initiated Pretend Play Assessment	HiMAT High-Level Mobility Assessment Tool	SOMA Schedule for Oral-Motor Assessment
CIMT Constraint Induced Movement Therapy	ICF International Classification of Functioning, Disability and Health	TASP Test of Aided-Communication Symbol Performance
CNS Central Nervous System	ITB Intrathecal Baclofen	TCM Traditional Chinese Medicine
CODES Competency – Opportunities – Driving Communication Forward – Engagement – Skill Acquisition	IU International Units	TES Therapeutic Electrical Stimulation
COPM Canadian Occupational Performance Measure	JTHFT Jebsen-Taylor Hand Function Test	TL Tibia Length
CP Cerebral Palsy	KH Knee Height	UAL Upper Arm Length
CP QOL Cerebral Palsy Quality of Life Questionnaire	MA2 Melbourne Assessment 2	UVB Ultraviolet B
	MACS Manual Ability Classification	VFSS Videofluoroscopic Swallow Study
	MAS Modified Ashworth Scale	WBVT Whole body vibration therapy
	MBS Modified Barium Swallow	WeeFIM Functional Independence Measure for Children
	mCIMT modified Constraint Induced Movement Therapy	

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REFERENCES AND APPENDICES

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1. World Health Organisation. International Classification of Functioning, Disability and Health (ICF) 2011 [Available from: <http://www.who.int/classifications/icf/en/>].
2. Rosenbaum P, Stewart D. The World Health Organization International Classification of Functioning, Disability, and Health: a model to guide clinical thinking, practice and research in the field of cerebral palsy. *Semin Pediatr Neurol*. 2004;11(1):5-10.
3. NSW Government. Keep them Safe [Available from: <http://www.keepthemsafe.nsw.gov.au/>].
4. NSW Health. Child Wellbeing and Child Protection Policies and Procedures for NSW Health. 2013.
5. NSW Government. The Child Wellbeing and Child Protection - NSW Interagency Guidelines 2011 [Available from: <http://www.community.nsw.gov.au/kts>].
6. Stewart D, Cameron D. Client centred practice in paediatrics. In: Sumsion T, editor. *Client-Centred Practice in Occupational Therapy: A Guide to Implementation*. Philadelphia: Churchill Livingstone; 2006. p. 147-60.
7. Rosenbaum P, King S, Law M, King G, Evans J. Family-Centred Service. *Physical & Occupational Therapy In Pediatrics*. 1998;18(1):1-20.
8. King S, Teplicky R, King G, Rosenbaum P. Family-centered service for children with cerebral palsy and their families: a review of the literature. *Semin Pediatr Neurol*. 2004;11(1):78-86.
9. Croker A, Coyle J, Hobbs C. Teams and collaboration in physiotherapy practice. In: J. Higgs MS, G. Webb, M. Skinner & A. Croker, editor. *Contexts of physiotherapy practice*. Chatswood, NSW: Churchill Livingstone, Elsevier; 2008. p. 206-73.
10. Choi BC, Pak AW. Multidisciplinarity, interdisciplinarity and transdisciplinarity in health research, services, education and policy: 1. Definitions, objectives, and evidence of effectiveness. *Clin Invest Med*. 2006;29(6):351-64.
11. Australian Institute of Health and Welfare (AIHW). Therapy and equipment needs of people with cerebral palsy and like disabilities in Australia. Disability Series. Canberra: Australian Institute of Health and Welfare; 2006.
12. Prigg A. Experiences and perceived roles of occupational therapists working with children with special learning needs during transition to school: A pilot study. 2002;49(2):100-11.
13. Early Childhood Intervention Australia (ECIA) NSW Chapter. Transition to School Resource 2016 [Available from: <http://www.transitiontoschoolresource.org.au/>].
14. Cerebral Palsy Alliance. Cerebral Palsy Alliance - Our Services [Available from: <https://www.cerebralpalsy.org.au/services/>].
15. My Child at Cerebralpalsy.org. Transition to Adulthood 2016 [Available from: <http://www.cerebralpalsy.org/the-journey/transition>].
16. Hanna S, Russell D, Bartlett D, Kertoy M, Rosenbaum P, Swinton M. Clinical Measurement Practical Guidelines for Service Providers: CanChild Centre for Childhood Disability Research; 2005. Available from: <https://www.canchild.ca/en/resources/29-clinical-measurement-practical-guidelines-for-service-providers>.
17. Mutch L, Alberman E, Hagberg B, Kodama K, Perat MV. Cerebral palsy epidemiology: where are we now and where are we going? *Dev Med Child Neurol*. 1992;34(6):547-51.
18. Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N, Dan B, et al. Proposed definition and classification of cerebral palsy, April 2005. *Dev Med Child Neurol*. 2005;47(8):571-6.
19. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl*. 2007;109:8-14.
20. Australian Cerebral Palsy Register Group (ACPR). Report of the Australian Cerebral Palsy Register, birth years 1993-2006. Sydney; 2013.

21. McIntyre S, Taitz D, Keogh J, Goldsmith S, Badawi N, Blair E. A systematic review of risk factors for cerebral palsy in children born at term in developed countries. *Dev Med Child Neurol.* 2013;55(6):499-508.
22. Australian Cerebral Palsy Register Group (ACPR). Report of the Australian Cerebral Palsy Register, birth years 1993-2003. Sydney; 2009.
23. Doran GT. There's a S.M.A.R.T. way to write management's goals and objectives. *Management Review (AMA Forum).* 1981;70(11):35-6.
24. Bower E. Goal setting and the measurement of change. In: D. Scutton DDMM, editor. *Management of the Motor Disorders of Children with Cerebral Palsy.* 2nd ed. London: Mac Keith Press; 2004.
25. Novak I, Smithers-Sheedy H, Morgan C. Predicting equipment needs of children with cerebral palsy using the Gross Motor Function Classification System: a cross-sectional study. *Disabil Rehabil Assist Technol.* 2012;7(1):30-6.
26. Rodda J, Graham HK. Classification of gait patterns in spastic hemiplegia and spastic diplegia: a basis for a management algorithm. *Eur J Neurol.* 2001;8 Suppl 5:98-108.
27. Rodda JM, Graham HK, Carson L, Galea MP, Wolfe R. Sagittal gait patterns in spastic diplegia. *J Bone Joint Surg Br.* 2004;86(2):251-8.
28. Eliasson AC, Krumlinde-Sundholm L, Rösblad B, Beckung E, Arner M, Ohrvall AM, et al. The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. *Dev Med Child Neurol.* 2006;48(7):549-54.
29. House JH, Gwathmey FW, Fidler MO. A dynamic approach to the thumb-in palm deformity in cerebral palsy. *J Bone Joint Surg Am.* 1981;63(2):216-25.
30. Zancolli EA, Zancolli ER. Surgical management of the hemiplegic spastic hand in cerebral palsy. *Surg Clin North Am.* 1981;61(2):395-406.
31. Georgiades M, Elliott C, Wilton J, Blair E, Blackmore M, Garbellini S. The Neurological Hand Deformity Classification for children with cerebral palsy. *Aust Occup Ther J.* 2014;61(6):394-402.
32. Lance JW. Symposium synopsis. In: Young RR, Feldman, R.G. & Koella, W.P., editor. *Spasticity: Disordered Motor Control.* Miami: Symposia Specialists; 1980. p. 485-94.
33. Scholtes VA, Becher JG, Beelen A, Lankhorst GJ. Clinical assessment of spasticity in children with cerebral palsy: a critical review of available instruments. *Dev Med Child Neurol.* 2006;48(1):64-73.
34. Alhusaini AA, Dean CM, Crosbie J, Shepherd RB, Lewis J. Evaluation of spasticity in children with cerebral palsy using Ashworth and Tardieu Scales compared with laboratory measures. *J Child Neurol.* 2010;25(10):1242-7.
35. Love S, Gibson N, Smith N, Bear N, Blair E, Group ACPR. Interobserver reliability of the Australian Spasticity Assessment Scale (ASAS). *Dev Med Child Neurol.* 2016;58 Suppl 2:18-24.
36. Sanger TD, Delgado MR, Gaebler-Spira D, Hallett M, Mink JW, Disorders TFoCM. Classification and definition of disorders causing hypertonia in childhood. *Pediatrics.* 2003;111(1):e89-97.
37. Knights S, Datto N, Kawamura A, Switzer L, Fehlings D. Further evaluation of the scoring, reliability, and validity of the Hypertonia Assessment Tool (HAT). *J Child Neurol.* 2014;29(4):500-4.
38. Fehlings D, Switzer L, Jethwa A, Mink J, Macarthur C, Knights S, et al. Hypertonia Assessment Tool (HAT): User manual. Toronto, ON, Canada: Bloorview Kids Rehab; 2010. Available from: <http://research.hollandbloorview.ca/outcomemeasures/hat/hatmanuals>.
39. Jethwa A, Mink J, Macarthur C, Knights S, Fehlings T, Fehlings D. Development of the Hypertonia Assessment Tool (HAT): a discriminative tool for hypertonia in children. *Dev Med Child Neurol.* 2010;52(5):e83-7.
40. Barry MJ, VanSwearingen JM, Albright AL. Reliability and responsiveness of the Barry-Albright Dystonia Scale. *Dev Med Child Neurol.* 1999;41(6):404-11.
41. Dekkers KJ, Rameckers EA, Smeets RJ, Janssen-Potten YJ. Upper extremity strength measurement for children with cerebral palsy: a systematic review of available instruments. *Phys Ther.* 2014;94(5):609-22.

42. Sanger TD, Chen D, Delgado MR, Gaebler-Spira D, Hallett M, Mink JW, et al. Definition and classification of negative motor signs in childhood. *Pediatrics*. 2006;118(5):2159-67.
43. Benfer KA, Weir KA, Bell KL, Ware RS, Davies PS, Boyd RN. Oropharyngeal dysphagia and gross motor skills in children with cerebral palsy. *Pediatrics*. 2013;131(5):e1553-62.
44. Andrew MJ, Parr JR, Sullivan PB. Feeding difficulties in children with cerebral palsy. *Arch Dis Child Educ Pract Ed*. 2012;97(6):222-9.
45. Bell KL, Fiori S, Davies PS, Boyd RN. Is growth and nutritional status in children with cerebral palsy related to the severity of the brain lesion? *Developmental Medicine & Child Neurology* March. 2014;2:3.
46. Arvedson JC. Assessment of pediatric dysphagia and feeding disorders: clinical and instrumental approaches. *Dev Disabil Res Rev*. 2008;14(2):118-27.
47. Speech Pathology Australia. Videofluoroscopic Swallow Study Clinical Guideline. Melbourne: The Speech Pathology Association of Australia Limited; 2013.
48. Arvedson JC, Lefton-Greif MA. Pediatric videofluoroscopic swallow studies: A professional manual with caregiver guidelines. San Antonio, TX: Communication Skill Builders; 1998.
49. Auld M, Ware R, Boyd R, Moseley LG, Johnston L. Reproducibility of tactile assessments for children with unilateral cerebral aply. *Physical and Occupational Therapy in Pediatrics*. 2011;32(2):151-66.
50. Auld ML, Boyd RN, Moseley GL, Ware RS, Johnston LM. Impact of tactile dysfunction on upper-limb motor performance in children with unilateral cerebral palsy. *Arch Phys Med Rehabil*. 2012;93(4):696-702.
51. Novak I, Hines M, Goldsmith S, Barclay R. Clinical prognostic messages from a systematic review on cerebral palsy. *Pediatrics*. 2012;130(5):e1285-312.
52. Tomlinson D, von Baeyer CL, Stinson JN, Sung L. A systematic review of faces scales for the self-report of pain intensity in children. *Pediatrics*. 2010;126(5):e1168-98.
53. Stevenson RD, Hayes RP, Cater LV, Blackman JA. Clinical correlates of linear growth in children with cerebral palsy. *Dev Med Child Neurol*. 1994;36(2):135-42.
54. Stevenson RD, Roberts CD, Vogtle L. The effects of non-nutritional factors on growth in cerebral palsy. *Dev Med Child Neurol*. 1995;37(2):124-30.
55. Stevenson RD. Feeding and nutrition in children with developmental disabilities. *Pediatric Annals*. 1995a;24(5):255-60.
56. Shapiro BK, Green P, Krick J, Allen D, Capute AJ. Growth of severely impaired children: neurological versus nutritional factors. *Dev Med Child Neurol*. 1986;28(6):729-33.
57. Rempel GR, Colwell SO, Nelson RP. Growth in children with cerebral palsy fed via gastrostomy. *Pediatrics*. 1988;82(6):857-62.
58. Stallings VA, Charney EB, Davies JC, Cronk CE. Nutrition-related growth failure of children with quadriplegic cerebral palsy. *Dev Med Child Neurol*. 1993;35(2):126-38.
59. Centers for Disease Control and Prevention. Centers for Disease Control and Prevention [Available from: <http://www.cdc.gov/>].
60. Bell KL, Davies PSW, Boyd RN, Stevenson RD. Use of segmental lengths for the assessment of growth in children with cerebral palsy. In: Preedy VR, editor. *Handbook of Anthropometry: Physical measures of human form in health and disease*. New York, USA: Springer; 2012. p. 1279-97.
61. Cameron N. The Methods of Auxological Anthropometry. In: Tanner FFaJ, editor. *Human Growth, A Comprehensive Treatise*. New York: Plenum Press; 1986. p. 3-46.
62. Stevenson RD. Use of segmental measures to estimate stature in children with cerebral palsy. *Archives of Pediatrics & Adolescent Medicine*. 1995b;149(6):658-62.
63. Chumlea WC, Guo SS, Steinbaugh ML. Prediction of stature from knee height for black and white adults and children with application to mobility-impaired or handicapped persons. 1994;94(12):1385-8.

64. Spender QW, Cronk CE, Charney EB, Stallings VA. Assessment of linear growth of children with cerebral palsy: use of alternative measures to height or length. *Dev Med Child Neurol*. 1989;31(2):206-14.
65. White TK, Ekvall SW. Appendix 8 - Skinfold Grids - Children: Other Anthropometry Standards. In: Ekvall SW, editor. *Pediatric Nutrition in Chronic Diseases and Developmental Disorders: Prevention, Assessment and Treatment*. New York: Oxford University Press; 1993. p. 489-91.
66. Gauld LM, Kappers J, Carlin JB, Robertson CF. Height prediction from ulna length. *Dev Med Child Neurol*. 2004;46(7):475-80.
67. Kuperminc MN, Gurka MJ, Bennis JA, Busby MG, Grossberg RI, Henderson RC, et al. Anthropometric measures: poor predictors of body fat in children with moderate to severe cerebral palsy. *Dev Med Child Neurol*. 2010;52(9):824-30.
68. Krick J, Murphy-Miller P, Zeger S, Wright E. Pattern of growth in children with cerebral palsy. *J Am Diet Assoc*. 1996;96(7):680-5.
69. Stevenson RD, Conaway M, Chumlea WC, Rosenbaum P, Fung EB, Henderson RC, et al. Growth and health in children with moderate-to-severe cerebral palsy. *Pediatrics*. 2006;118(3):1010-8.
70. Day SM, Strauss DJ, Vachon PJ, Rosenbloom L, Shavelle RM, Wu YW. Growth patterns in a population of children and adolescents with cerebral palsy. *Dev Med Child Neurol*. 2007;49(3):167-71.
71. Kuperminc MN, Stevenson RD. Growth and nutrition disorders in children with cerebral palsy. *Dev Disabil Res Rev*. 2008;14(2):137-46.
72. Arrowsmith FE, Allen JR, Gaskin KJ, Gruca MA, Clarke SL, Briody JN, et al. Reduced body protein in children with spastic quadriplegic cerebral palsy. *Am J Clin Nutr*. 2006;83(3):613-8.
73. Bandini LG, Schoeller DA, Fukagawa NK, Wykes LJ, Dietz WH. Body composition and energy expenditure in adolescents with cerebral palsy or myelodysplasia. *Pediatr Res*. 1991;29(1):70-7.
74. Henderson RC, Lark RK, Gurka MJ, Worley G, Fung EB, Conaway M, et al. Bone density and metabolism in children and adolescents with moderate to severe cerebral palsy. *Pediatrics*. 2002;110(1 Pt 1):e5.
75. Henderson RC, Lin PP, Greene WB. Bone-mineral density in children and adolescents who have spastic cerebral palsy. *J Bone Joint Surg Am*. 1995;77(11):1671-81.
76. Stallings VA, Cronk CE, Zemel BS, Charney EB. Body composition in children with spastic quadriplegic cerebral palsy. *J Pediatr*. 1995;126(5 Pt 1):833-9.
77. Samson-Fang LJ, Stevenson RD. Identification of malnutrition in children with cerebral palsy: poor performance of weight-for-height centiles. *Dev Med Child Neurol*. 2000;42(3):162-8.
78. Addo OY, Himes JH. Reference curves for triceps and subscapular skinfold thicknesses in US children and adolescents. *Am J Clin Nutr*. 2010;91(3):635-42.
79. Arrowsmith FE. Nutritional assessment and rehabilitation of children with quadriplegic cerebral palsy: The University of Sydney, Australia; 2006.
80. Gurka MJ, Kuperminc MN, Busby MG, Bennis JA, Grossberg RI, Houlihan CM, et al. Assessment and correction of skinfold thickness equations in estimating body fat in children with cerebral palsy. *Dev Med Child Neurol*. 2010;52(2):e35-41.
81. Samson-Fang L, Bell KL. Assessment of growth and nutrition in children with cerebral palsy. *Eur J Clin Nutr*. 2013;67 Suppl 2:S5-8.
82. Samson-Fang L, Fung E, Stallings VA, Conaway M, Worley G, Rosenbaum P, et al. Relationship of nutritional status to health and societal participation in children with cerebral palsy. *J Pediatr*. 2002;141(5):637-43.
83. Lark RK, Williams CL, Stadler D, Simpson SL, Henderson RC, Samson-Fang L, et al. Serum prealbumin and albumin concentrations do not reflect nutritional state in children with cerebral palsy. *J Pediatr*. 2005;147(5):695-7.
84. Coleman Y. Medications & Nutrition a Quick Reference for Busy Clinicians. Melbourne, Australia: Nutrition Consultants Australia; 2015a.

85. Coleman Y. Medications & Nutrition Favourite Fifty General. Melbourne, Australia: Nutrition Consultants Australia; 2015b.
86. Hebra A, Hoffman MA. Gastroesophageal reflux in children. *Pediatr Clin North Am.* 1993;40(6):1233-51.
87. Fishman LN, Bousvaros A. Gastrointestinal Issues in the Child with Cerebral Palsy. *International Seminars in Pediatric Gastroenterology and Nutrition.* 1999;8(2):1-15.
88. Somerville H, Tzannes G, Wood J, Shun A, Hill C, Arrowsmith F, et al. Gastrointestinal and nutritional problems in severe developmental disability. *Dev Med Child Neurol.* 2008;50(9):712-6.
89. Sullivan PB, Juszczak E, Lambert BR, Rose M, Ford-Adams ME, Johnson A. Impact of feeding problems on nutritional intake and growth: Oxford Feeding Study II. *Dev Med Child Neurol.* 2002;44(7):461-7.
90. Sullivan PB, Lambert B, Rose M, Ford-Adams M, Johnson A, Griffiths P. Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study. *Dev Med Child Neurol.* 2000;42(10):674-80.
91. Henderson RC. Bone density and other possible predictors of fracture risk in children and adolescents with spastic quadriplegia. *Dev Med Child Neurol.* 1997;39(4):224-7.
92. Henderson RC, Kairalla J, Abbas A, Stevenson RD. Predicting low bone density in children and young adults with quadriplegic cerebral palsy. *Dev Med Child Neurol.* 2004;46(6):416-9.
93. Henderson RC, Kairalla JA, Barrington JW, Abbas A, Stevenson RD. Longitudinal changes in bone density in children and adolescents with moderate to severe cerebral palsy. *J Pediatr.* 2005;146(6):769-75.
94. Roberts CD, Vogtle L, Stevenson RD. Effect of hemiplegia on skeletal maturation. *J Pediatr.* 1994;125(5 Pt 1):824-8.
95. Lin PP, Henderson RC. Bone mineralization in the affected extremities of children with spastic hemiplegia. *Dev Med Child Neurol.* 1996;38(9):782-6.
96. Munns CF, Cowell CT. Prevention and treatment of osteoporosis in chronically ill children. *J Musculoskelet Neuronal Interact.* 2005;5(3):262-72.
97. Paxton GA, Teale GR, Nowson CA, Mason RS, McGrath JJ, Thompson MJ, et al. Vitamin D and health in pregnancy, infants, children and adolescents in Australia and New Zealand: a position statement. *Med J Aust.* 2013;198(3):142-3.
98. Holick MF. Environmental factors that influence the cutaneous production of vitamin D. *Am J Clin Nutr.* 1995;61(3 Suppl):638S-45S.
99. Caulton JM, Ward KA, Alsop CW, Dunn G, Adams JE, Mughal MZ. A randomised controlled trial of standing programme on bone mineral density in non-ambulant children with cerebral palsy. *Arch Dis Child.* 2004;89(2):131-5.
100. Hammond MI, Lewis MN, Johnson EW. A nutritional study of cerebral palsied children. *J Am Diet Assoc.* 1966;49(3):196-201.
101. Berg K, Isaksson B. Body composition and nutrition of school children with cerebral palsy. *Acta Paediatr Scand Suppl.* 1970;204:Suppl 204:41+.
102. Karle IP, Bleiler RE, Ohlson MA. Nutritional status of cerebral-palsied children. *J Am Diet Assoc.* 1961;38:22-6.
103. Leamy CM. A study of the food intake of a group of children with cerebral palsy in the Lakeville Sanatorium. *Am J Public Health Nations Health.* 1953;43(10):1310-7.
104. Peeks S, Lamb MW. Comments on the dietary practices of cerebral palsied children. *Journal of the American Dietetic Association.* 1951;27:870-6.
105. Stallings VA, Zemel BS, Davies JC, Cronk CE, Charney EB. Energy expenditure of children and adolescents with severe disabilities: a cerebral palsy model. *Am J Clin Nutr.* 1996;64(4):627-34.
106. Arrowsmith FE, Allen JR, Gaskin KJ, Somerville H, Birdsall J, Barzi F, et al. Nutritional rehabilitation increases the resting energy expenditure of malnourished children with severe cerebral palsy. *Dev Med Child Neurol.* 2012;54(2):170-5.
107. Walker JL, Bell KL, Boyd RN, Davies PS. Validation of a modified three-day weighed food record for measuring energy intake in preschool-aged children with cerebral palsy. *Clin Nutr.* 2013;32(3):426-31.

108. Kuperminc MN, Gottrand F, Samson-Fang L, Arvedson J, Bell K, Craig GM, et al. Nutritional management of children with cerebral palsy: a practical guide. *Eur J Clin Nutr.* 2013;67 Suppl 2:S21-3.
109. Azcue MP, Zello GA, Levy LD, Pencharz PB. Energy expenditure and body composition in children with spastic quadriplegic cerebral palsy. *J Pediatr.* 1996;129(6):870-6.
110. Schofield WN. Predicting basal metabolic rate, new standards and review of previous work. *Human Nutrition - Clinical Nutrition.* 39 Suppl 1:5-41.
111. Bell KL, Samson-Fang L. Nutritional management of children with cerebral palsy. *Eur J Clin Nutr.* 2013;67 Suppl 2: S13-6.
112. Arrowsmith F, Allen J, Gaskin K, Somerville H, Clarke S, O'Loughlin E. The effect of gastrostomy tube feeding on body protein and bone mineralization in children with quadriplegic cerebral palsy. *Dev Med Child Neurol.* 2010;52(11):1043-7.
113. Wittenbrook W. Nutritional Assessment and Intervention in Cerebral Palsy. *Practical Gastroenterology.* 2011;32(16): 21-32.
114. Veugelers R, Benninga MA, Calis EA, Willemsen SP, Evenhuis H, Tibboel D, et al. Prevalence and clinical presentation of constipation in children with severe generalized cerebral palsy. *Dev Med Child Neurol.* 2010;52(9):e216-21.
115. Children's Health Queensland Hospital and Health Service. Fluid needs of children with cerebral palsy. In: Service QPR, editor. 2016.
116. Schoendorfer N, Boyd R, Davies PS. Micronutrient adequacy and morbidity: paucity of information in children with cerebral palsy. *Nutr Rev.* 2010;68(12):739-48.
117. National Health and Medical Research Council. Nutrient Reference Values for Australia and New Zealand. In: Ageing AGDoHa, editor. 2005.
118. Harvey A, Robin J, Morris ME, Graham HK, Baker R. A systematic review of measures of activity limitation for children with cerebral palsy. *Dev Med Child Neurol.* 2008;50(3):190-8.
119. Russell DJ, Avery LM, Rosenbaum PL, Raina PS, Walter SD, Palisano RJ. Improved scaling of the gross motor function measure for children with cerebral palsy: evidence of reliability and validity. *Phys Ther.* 2000;80(9):873-85.
120. Russell DJ, Rosenbaum PL, Avery LM, Lane M. Gross Motor Function Measure (GMFM-66 and GMFM-88) User's Manual. London, UK: MacKeith Press; 2002.
121. Russell DJ, Rosenbaum PL, Wright M, Avery LM. Gross Motor Function Measure (GMFM-66 and GMFM-88) User's Manual. London, UK: MacKeith Press; 2013.
122. Wei S, Su-Juan W, Yuan-Gui L, Hong Y, Xiu-Juan X, Xiao-Mei S. Reliability and validity of the GMFM-66 in 0- to 3-year-old children with cerebral palsy. *American Journal of Physical Medicine & Rehabilitation.* 2006;85(2):141-7.
123. Leunkeu NA, Shephard RJ, Ahmaidi S. Six-minute walk test in children with cerebral palsy gross motor function classification system levels I and II: reproducibility, validity, and training effects. *Arch Phys Med Rehabil.* 2012;93(12):2333-9.
124. American Thoracic Society. ATS statement: guidelines for the six-minute walk test. *American Journal of Respiratory Critical Care Medicine.* 2002;166(1):111-7.
125. Zaino CA, Marchese VG, Westcott SL. Timed up and down stairs test: preliminary reliability and validity of a new measure of functional mobility. *Pediatr Phys Ther.* 2004;16(2):90-8.
126. Krumlinde-Sundholm L, Holmefur M, Kottorp A, Eliasson AC. The Assisting Hand Assessment: current evidence of validity, reliability, and responsiveness to change. *Dev Med Child Neurol.* 2007;49(4):259-64.
127. Coleman A, Weir KA, Ware RS, Boyd RN. Relationship between communication skills and gross motor function in preschool-aged children with cerebral palsy. *Arch Phys Med Rehabil.* 2013;94(11):2210-7.
128. Andersen G, Mjoen TR, Vik T. Prevalence of speech problems and the use of augmentative and alternative communication in children with cerebral palsy: a registry-based study in Norway. *Perspectives on Augmentative and Alternative Communication.* 2010;19(1):12-20.

129. Msall ME, DiGaudio K, Duffy LC, LaForest S, Braun S, Granger CV. WeeFIM. Normative sample of an instrument for tracking functional independence in children. *Clin Pediatr (Phila)*. 1994;33(7):431-8.
130. Msall ME, Ottenbacher K, Duffy L, Lyon N, Heyer N, Phillips L, et al. Reliability and validity of the WEEFIM in children with neurodevelopmental disabilities. *Pediatric Research*. 1996;39(S4):378-.
131. Ottenbacher KJ, Taylor ET, Msall ME, Braun S, Lane SJ, Granger CV, et al. The stability and equivalence reliability of the functional independence measure for children (WeeFIM). *Dev Med Child Neurol*. 1996;38(10):907-16.
132. Brien M, Sveistrup H. An intensive virtual reality program improves functional balance and mobility of adolescents with cerebral palsy. *Pediatr Phys Ther*. 2011;23(3):258-66.
133. Franjoine MR, Gunther JS, Taylor MJ. Pediatric balance scale: a modified version of the berg balance scale for the school-age child with mild to moderate motor impairment. *Pediatr Phys Ther*. 2003;15(2):114-28.
134. Bartlett DJ, Chiarello LA, McCoy SW, Palisano RJ, Rosenbaum PL, Jeffries L, et al. The Move & PLAY study: an example of comprehensive rehabilitation outcomes research. *Phys Ther*. 2010;90(11):1660-72.
135. Chapparo C, Ranka J. The Model of Occupational Performance: Definition of Terms. In: Ranka CCJ, editor. *Occupational Performance Model (Australia): Monograph 1*. Sydney: Total Print Control; 1997. p. 58-60.
136. Wynter M, Gibson N, Kentish M, Love SC, Thomason P, Graham HK. The Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care. *Journal of Pediatric Rehabilitation Medicine*. 2011;4(3):183-95.
137. Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM). Australian Hip Surveillance Guidelines [Available from: <https://ausacpdm.org.au/professionals/hip-surveillance/australian-hip-surveillance-guidelines/>].
138. Katalinic OM, Harvey LA, Herbert RD, Moseley AM, Lannin NA, Schurr K. Stretch for the treatment and prevention of contractures. *Cochrane Database Syst Rev*. 2010(9):CD007455.
139. Wallen M, Stewart K. The evidence for abandoning upper limb stretch interventions in paediatric practice. *Dev Med Child Neurol*. 2013;55(3):208-9.
140. Jackman M, Novak I, Lannin N. Effectiveness of hand splints in children with cerebral palsy: a systematic review with meta-analysis. *Dev Med Child Neurol*. 2014;56(2):138-47.
141. Pohl M, Rückriem S, Mehrholz J, Ritschel C, Strik H, Pause MR. Effectiveness of serial casting in patients with severe cerebral spasticity: a comparison study. *Arch Phys Med Rehabil*. 2002;83(6):784-90.
142. Dodd KJ, Taylor NF, Damiano DL. A systematic review of the effectiveness of strength-training programs for people with cerebral palsy. *Arch Phys Med Rehabil*. 2002;83(8):1157-64.
143. Verschuren O, Darrah J, Novak I, Ketelaar M, Wiat L. Health-enhancing physical activity in children with cerebral palsy: more of the same is not enough. *Phys Ther*. 2014;94(2):297-305.
144. Stewart K, Wallen M. There is little evidence on the effect of upper limb strengthening in children with cerebral palsy. *A Critically Appraised Topic*. 2009.
145. Council on Sports Medicine and Fitness. Strength Training by Children and Adolescents. *Pediatrics*. 2008;121(4):835-40.
146. Faigenbaum AD, Kraemer WJ, Blimkie CJ, Jeffreys I, Micheli LJ, Nitka M, et al. Youth resistance training: updated position statement paper from the national strength and conditioning association. *J Strength Cond Res*. 2009;23(5 Suppl):S60-79.
147. Cauraugh JH, Naik SK, Hsu WH, Coombes SA, Holt KG. Children with cerebral palsy: a systematic review and meta-analysis on gait and electrical stimulation. *Clinical Rehabilitation*. 2010;24(11):963-78.
148. Cleary E, Waite A, Asher K. There is low level evidence to support the use of functional electrical stimulation to enhance function in the upper limb of children with neurological conditions. *A Critically Appraised Topic*. 2011.
149. Delgado MR, Hirtz D, Aisen M, Ashwal S, Fehlings DL, McLaughlin J, et al. Practice parameter: pharmacologic treatment of spasticity in children and adolescents with cerebral palsy (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society. *Neurology*. 2010;74(4):336-43.

150. Novak I, McIntyre S, Morgan C, Campbell L, Dark L, Morton N, et al. A systematic review of interventions for children with cerebral palsy: state of the evidence. *Dev Med Child Neurol*. 2013;55(10):885-910.
151. Albright AL, Ferson SS. Intrathecal baclofen therapy in children. *Neurosurg Focus*. 2006;21(2):e3.
152. Hoving MA, van Raak EP, Spincemille GH, Palmans LJ, Sleyten FA, Vles JS, et al. Intrathecal baclofen in children with spastic cerebral palsy: a double-blind, randomized, placebo-controlled, dose-finding study. *Dev Med Child Neurol*. 2007;49(9):654-9.
153. Josenby AL, Wagner P, Jarnlo GB, Westbom L, Nordmark E. Motor function after selective dorsal rhizotomy: a 10-year practice-based follow-up study. *Dev Med Child Neurol*. 2012;54(5):429-35.
154. Koy A, Hellmich M, Pauls KA, Marks W, Lin JP, Fricke O, et al. Effects of deep brain stimulation in dyskinetic cerebral palsy: a meta-analysis. *Mov Disord*. 2013;28(5):647-54.
155. Truven Health Analytics Inc. Micromedex Solutions
[Available from: <http://www.micromedexsolutions.com/micromedex2/librarian>].
156. Burrige N, Symons K. Australian don't rush to crush handbook: Therapeutic options for people unable to swallow solid oral medicines. Collingwood, Victoria: Society of Hospital Pharmacists of Australia; 2015.
157. MIMS Australia. MIMS Online [Available from: <https://www.mimsonline.com.au/Search/Search.aspx>].
158. Vernon-Roberts A, Sullivan PB. Fundoplication versus post-operative medication for gastro-oesophageal reflux in children with neurological impairment undergoing gastrostomy. *Cochrane Database Syst Rev*. 2007(1):CD006151.
159. Western Child Health Network. Paediatric Home Enteral Nutrition (HEN): Tube Feeding - A Multidisciplinary Resource for Health Professionals. In: Health N, editor. First edition ed2013.
160. NSW Agency for Clinical Innovation. ACI Guidelines for Home Enteral Nutrition (HEN) Services (2nd Edition). Sydney, Australia: NSW Agency for Clinical Innovation; 2012.
161. Brun AC, Størdal K, Johannesdottir GB, Bentsen BS, Medhus AW. The effect of protein composition in liquid meals on gastric emptying rate in children with cerebral palsy. *Clin Nutr*. 2012;31(1):108-12.
162. Savage K, Kritas S, Schwarzer A, Davidson G, Omari T. Whey- vs casein-based enteral formula and gastrointestinal function in children with cerebral palsy. *JPEN J Parenter Enteral Nutr*. 2012;36(1 Suppl):118S-23S.
163. Schoenfeld L. The Use of Blenderized Tube Feeding in Pediatric Patients: Evidence and Guidelines for Dietetic Practice. 2013.
164. Pentiuk S, O'Flaherty T, Santoro K, Willging P, Kaul A. Pureed by gastrostomy tube diet improves gagging and retching in children with fundoplication. *JPEN J Parenter Enteral Nutr*. 2011;35(3):375-9.
165. Goncalves GK, Carmagnani FG, Correa MS, Duarte DA, Santos MT. Dental erosion in cerebral palsy patients. *Journal of Dentistry for Children (Chicago, Ill)*. 2008;75(2):117-20.
166. Santos MT, Biancardi M, Guare RO, Jardim JR. Caries prevalence in patients with cerebral palsy and the burden of caring for them. *Spec Care Dentist*. 2010;30(5):206-10.
167. Guare RdO, Ciampioni AL. Prevalence of Periodontal Disease in the Primary Dentition of Children with Cerebral Palsy. 2004;71(1):27-32.
168. Scannapieco FA. Role of oral bacteria in respiratory infection. *J Periodontol*. 1999;70(7):793-802.
169. Rodrigues dos Santos MT, Masiero D, Novo NF, Simionato MR. Oral conditions in children with cerebral palsy. *J Dent Child (Chic)*. 2003;70(1):40-6.
170. Abanto J, Carvalho TS, Bönecker M, Ortega AO, Ciampioni AL, Raggio DP. Parental reports of the oral health-related quality of life of children with cerebral palsy. *BMC Oral Health*. 2012;12:15.
171. Dos Santos MT, Nogueira ML. Infantile reflexes and their effects on dental caries and oral hygiene in cerebral palsy individuals. *J Oral Rehabil*. 2005;32(12):880-5.
172. Santos MT, Guare RO, Celiberti P, Siqueira WL. Caries experience in individuals with cerebral palsy in relation to oromotor dysfunction and dietary consistency. *Special Care in Dentistry*. 2009;29(5):198-203.

173. Walsh LJ. Preventive dentistry for the general dental practitioner. 2000;45(2):76-82.
174. Balakrishnan M, Simmonds RS, Tagg JR. Dental caries is a preventable infectious disease. Aust Dent J. 2000;45(4):235-45.
175. Young WG. Tooth wear: diet analysis and advice. Int Dent J. 2005;55(2):68-72.
176. Ahokas JT, Demos L, Donohue DC, Killalea S, McNeil J, Rix CJ. Review of Water Fluoridation and Fluoride Intake from Discretionary Fluoride Supplements: Review for NHMRC. 1999.
177. Children's Hospital at Westmead Paediatric Dentists and Speech Pathologists. A Clean Mouth is Crucial for Children with Special Needs. 2013.
178. Dougherty NJ. A review of cerebral palsy for the oral health professional. Dent Clin North Am. 2009;53(2):329-38, x.
179. Hoare B. Functional hand use in hemiplegia: Evidence based treatment for children with cerebral palsy Instructional Course, March 2012: Melbourne. 2012.
180. Sakzewski L, Ziviani J, Boyd RN. Efficacy of upper limb therapies for unilateral cerebral palsy: a meta-analysis. Pediatrics. 2014;133(1):e175-204.
181. Sakzewski L, Boyd R, Ziviani J. Clinimetric properties of participation measures for 5- to 13-year-old children with cerebral palsy: a systematic review. Dev Med Child Neurol. 2007;49(3):232-40.
182. Mutlu A, Livanelioglu A, Gunel MK. Reliability of Ashworth and Modified Ashworth scales in children with spastic cerebral palsy. BMC Musculoskelet Disord. 2008;9:44.
183. Pennington L, Goldbart J, Marshall J. Interaction training for conversational partners of children with cerebral palsy: a systematic review. Int J Lang Commun Disord. 2004;39(2):151-70.
184. Baxter S, Enderby P, Evans P, Judge S. Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: a systematic review and qualitative synthesis. Int J Lang Commun Disord. 2012;47(2):115-29.
185. Speech Pathology Australia. Augmentative and Alternative Communication Clinical Guideline. Melbourne: The Speech Pathology Association of Australia Limited; 2012.
186. Cerebral Palsy Alliance. Assistive Technology, Mobility and Customised Seating 2016 [Available from: <https://www.cerebralpalsy.org.au/services/all-programs-and-services/assistive-technology/>].
187. Northcott. Assistive Technology [Available from: <https://www.northcott.com.au/services/assistive-technology>].
188. Educate Autism. Social Stories [Available from: <http://www.educateautism.com/social-stories.html>].
189. Gray C. Social Stories 2016 [Available from: <http://carolgraysocialstories.com/social-stories/>].
190. Blair SN, Kampert JB, Kohl HW, Barlow CE, Macera CA, Paffenbarger RS, et al. Influences of cardiorespiratory fitness and other precursors on cardiovascular disease and all-cause mortality in men and women. JAMA. 1996;276(3):205-10.
191. Caspersen CJ, Powell KE, Christenson GM. Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. Public Health Rep. 1985;100(2):126-31.
192. Novak I. Parent experience of implementing effective home programs. Phys Occup Ther Pediatr. 2011;31(2):198-213.
193. Novak I, Cusick A, Lannin N. Occupational therapy home programs for cerebral palsy: double-blind, randomized, controlled trial. Pediatrics. 2009;124(4):e606-14.
194. Darrah J, Law MC, Pollock N, Wilson B, Russell DJ, Walter SD, et al. Context therapy: a new intervention approach for children with cerebral palsy. Dev Med Child Neurol. 2011;53(7):615-20.
195. Law MC, Darrah J, Pollock N, Wilson B, Russell DJ, Walter SD, et al. Focus on function: a cluster, randomized controlled trial comparing child- versus context-focused intervention for young children with cerebral palsy. Dev Med Child Neurol. 2011;53(7):621-9.
196. Independent Living Centres Australia. Independent Living Centres Australia 2011 [Available from: <http://ilcaustralia.org.au/>].

197. Northcott. Equipment and Technology
[Available from: <https://www.northcott.com.au/service-categories/equipment-and-technology>.
198. NSW Government. EnableNSW 2015 [Available from: <http://www.enable.health.nsw.gov.au/>.
199. TAD Disability Services. TAD Disability Services 2016 [Available from: <http://tadnsw.org.au/>.
200. TranSPOT The Transport Seating Group. Transport Safety Guidelines for People with a Disability. 2010.
201. SPOT on DD. TranSPOT [Available from: http://spotondd.org.au/?page_id=17.
202. Zhang Y, Liu J, Wang J, He Q. Traditional Chinese Medicine for treatment of cerebral palsy in children: a systematic review of randomized clinical trials. *J Altern Complement Med*. 2010;16(4):375-95.
203. Dursun E, Dursun N, Alican D. Effects of biofeedback treatment on gait in children with cerebral palsy. *Disabil Rehabil*. 2004;26(2):116-20.
204. Bloom R, Przekop A, Sanger TD. Prolonged electromyogram biofeedback improves upper extremity function in children with cerebral palsy. *J Child Neurol*. 2010;25(12):1480-4.
205. Queensland Facilitated Communication Training Incorporated. Qld Facilitated Communication Training Inc
[Available from: <http://www.qldfctinc.com.au/>.
206. Anne McDonald Centre Victoria. <http://www.annemcdonaldcentre.org.au/facilitated-communication-training>
[Available from: <http://www.annemcdonaldcentre.org.au/facilitated-communication-training>.
207. Blohm D. Effectiveness of aquatic intervention for children with cerebral palsy: systematic review of the current literature. *Journal of Aquatic Physical Therapy*. 2011;19(1):19-29.
208. International Aquatic Therapy Faculty. Water Specific Therapy Network
[Available from: <http://www.halliwicktherapy.org/en/>.
209. International Aquatic Therapy Faculty. Bad Ragaz Ring Method Network
[Available from: <http://www.badragazringmethod.org/en/>.
210. McDonagh MS, Morgan D, Carson S, Russman BS. Systematic review of hyperbaric oxygen therapy for cerebral palsy: the state of the evidence. *Dev Med Child Neurol*. 2007;49(12):942-7.
211. Weerapong P, Hume PA, Kolt GS. The mechanisms of massage and effects on performance, muscle recovery and injury prevention. *Sports Med*. 2005;35(3):235-56.
212. Bennett C, Underdown A, Barlow J. Massage for promoting mental and physical health in typically developing infants under the age of six months. *Cochrane Database Syst Rev*. 2013(4):CD005038.
213. Bailes AF, Greve K, Burch CK, Reder R, Lin L, Huth MM. The effect of suit wear during an intensive therapy program in children with cerebral palsy. *Pediatr Phys Ther*. 2011;23(2):136-42.
214. Patel DR. Therapeutic interventions in cerebral palsy. *Indian Journal of Pediatrics*. 2005;72(11):979-83.
215. Franki I, Desloovere K, De Cat J, Feys H, Molenaers G, Calders P, et al. The evidence-base for conceptual approaches and additional therapies targeting lower limb function in children with cerebral palsy: a systematic review using the ICF as a framework. *J Rehabil Med*. 2012;44(5):396-405.
216. Rauch F. Vibration therapy. *Dev Med Child Neurol*. 2009;51 Suppl 4:166-8.
217. Ruck J, Chabot G, Rauch F. Vibration treatment in cerebral palsy: A randomized controlled pilot study. *J Musculoskeletal Neuronal Interact*. 2010;10(1):77-83.
218. American Veterinary Medical Association. Animal-Assisted Interventions: Definitions 2016
[Available from: <https://www.avma.org/KB/Policies/Pages/Animal-Assisted-Interventions-Definitions.aspx>.
219. Matuszek S. Animal-facilitated therapy in various patient populations: systematic literature review. *Holist Nurs Pract*. 2010;24(4):187-203.
220. Peto Association. The Principle and Aim of Conductive Education 2012
[Available from: <http://www.petoassociation.hu/index.php/en/news/73-the-principle-and-aim-of-conductive-education>.

221. Pedersen AV. Conductive Education - A Critical Appraisal. *Advances in Physiotherapy*. 2000;2(2):75-82.
222. Darrah J, Watkins B, Chen L, Bonin C, AACPDM. Conductive education intervention for children with cerebral palsy: an AACPDM evidence report. *Dev Med Child Neurol*. 2004;46(3):187-203.
223. Peto Institute. Andras Peto College [Available from: <http://www.peto.hu/start/en/>].
224. Cerebral Palsy Alliance. Conductive Education Learning Centre 2016
[Available from: <https://www.cerebralpalsy.org.au/services/for-children/group-skills-classes-for-children/>].
225. Whalen CN, Case-Smith J. Therapeutic effects of horseback riding therapy on gross motor function in children with cerebral palsy: a systematic review. *Phys Occup Ther Pediatr*. 2012;32(3):229-42.
226. Park ES, Rha DW, Shin JS, Kim S, Jung S. Effects of hippotherapy on gross motor function and functional performance of children with cerebral palsy. *Yonsei Medical Journal*. 2014;55(6):1736-42.
227. Vygotsky L. Play and its role in the mental development of the child. In: J. Burner AJKS, editor. *Plays, its Role in Development and Evolution*. Middlesex, UK: Penguin Books; 1976. p. 537-54.
228. Stagnitti K, Unsworth C. The Importance of Pretend Play in Child Development: An Occupational Therapy Perspective. *The British Journal of Occupational Therapy*. 2000;63(3):121-7.
229. Stewart KS. Information processing strategy application: A longitudinal study of typically developing preschool and school aged children. Sydney: University of Sydney; 2010.
230. My Child at Cerebralpalsy.org. Play Therapy 2016
[Available from: <http://www.cerebralpalsy.org/about-cerebral-palsy/treatment/therapy/play-therapy>].
231. Cochran N, Nordling W, Cochran J. *Child Centred Play Therapy: A practical guide to developing therapeutic relationships with children*. New Jersey: John Wiley and Son; 2010.
232. Pfeifer LI, Pacciulio AM, Santos CA, Santos JL, Stagnitti KE. Pretend play of children with cerebral palsy. *Phys Occup Ther Pediatr*. 2011;31(4):390-402.
233. Association of Child Life Therapists Australia. Association of Child Life Therapists Australia 2016
[Available from: <http://childlife.org.au/>].
234. Nestle Australia Ltd. Australian Standards for Texture Modified Foods and Fluids. 2015.
235. NSW Health. *Feeding Difficulties in Children - A Guide for Allied Health Professionals*. Sydney: Office of Kids and Families; 2016.
236. NSW Health. Children's Healthcare Network (CHN) 2016
[Available from: <http://www.health.nsw.gov.au/kidsfamilies/paediatric/Pages/childrens-healthcare-networks.aspx>].

APPENDIX ONE: CEREBRAL PALSY CLINICAL PRACTICE GUIDELINE WORKING PARTY MEMBERSHIP

Significant contributions were provided by many clinicians, in particular:

Sonia Hughes (Co-chair)	Allied Health Educator	Children's Healthcare Network, Northern Region
Carmel Blayden (Co-chair)	Allied Health Educator	Children's Healthcare Network, Western Region
Aimee Taylor	Dietitian	Cerebral Palsy Alliance
Ann Leonard	Physiotherapist	John Hunter Children's Hospital
Antonia Trollip	Dietitian	Sydney Children's Hospital
Belinda Denver	Occupational Therapist	Sydney Children's Hospital
Cathy Morgan	Physiotherapist	Cerebral Palsy Alliance
Christine Porter	Speech Pathologist	EnhanceABILITY
Erin Ralph	Physiotherapist	John Hunter Children's Hospital
Fiona Arrowsmith	Dietitian	Children's Hospital at Westmead
Gloria Tzannes	Speech Pathologist	Children's Hospital at Westmead
Jenny Lewis	Physiotherapist	Children's Hospital at Westmead
Jenny Wood	Speech Pathologist	Sydney Children's Hospital
Joanne Morrell	Physiotherapist	Wollongong Hospital
Johanna Korkalainen	Consultant for Speech Pathology	Cerebral Palsy Alliance
Kerry Hanns	Physiotherapist	Sydney Children's Hospital
Kirsty Stewart	Occupational Therapist	Children's Hospital at Westmead
Michelle Jackman	Occupational Therapist	John Hunter Children's Hospital
Mignon Halford	Dietitian	Child & Family Health, NNSW LHD Northern Community Access Team, Ageing, Disability and Home Care
Prue Golland	Consultant for Physiotherapy	Cerebral Palsy Alliance
Tamis Pin	Physiotherapist	Children's Hospital at Westmead
Virginia McRory	Dietitian	John Hunter Children's Hospital

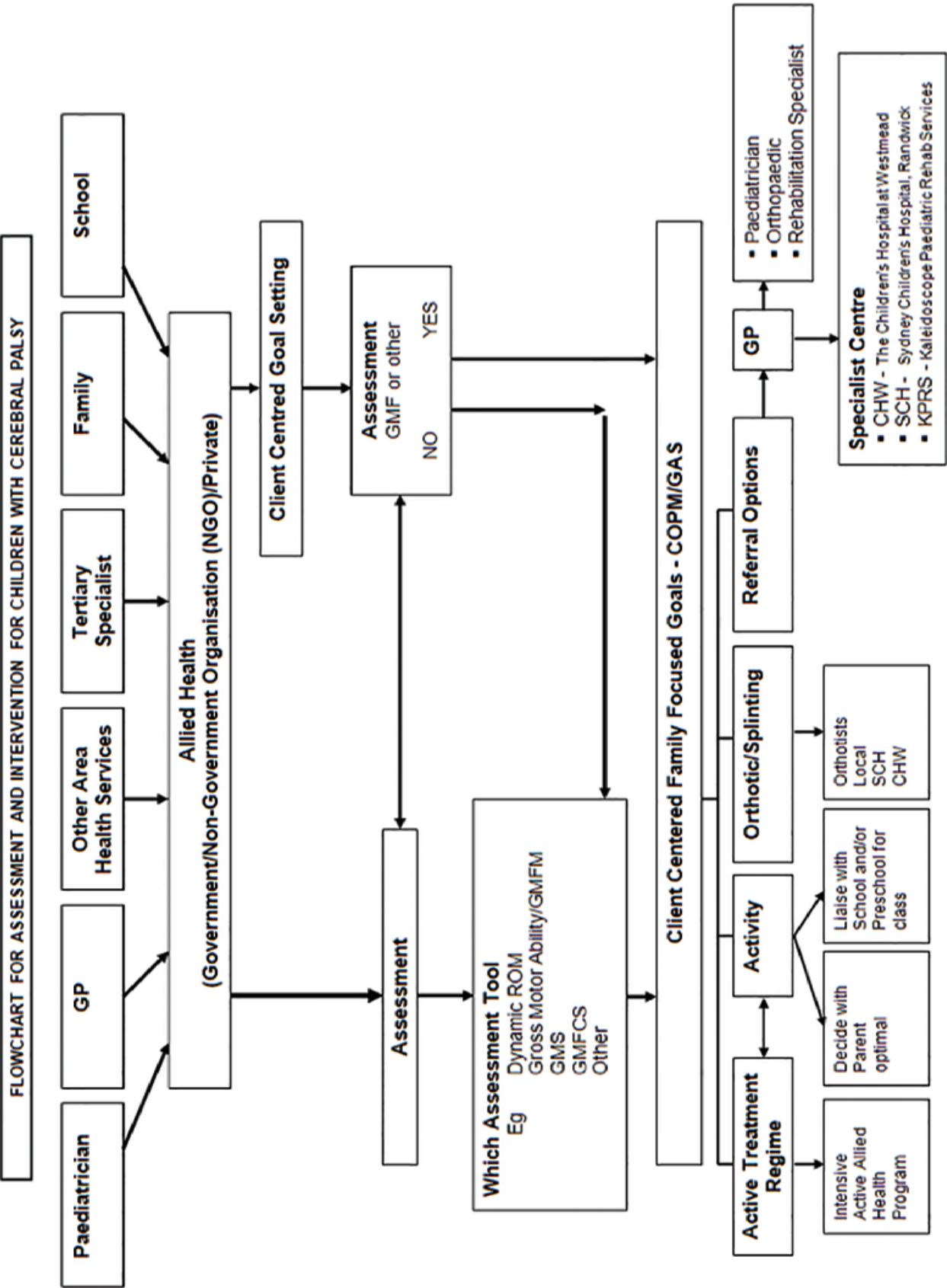
Contributions and reviews were also provided by:

Alison Waite	Occupational Therapist	Sydney Children's Hospital
Catherine Arndell	Physiotherapist	Ageing, Disability and Home Care
Cathy Kohlenberg	Physiotherapist	Ageing, Disability and Home Care
Corinne Browne	Occupational Therapist	Port Kembla Hospital
Denise Wong See	Dietitian	John Hunter Children's Hospital
Dianne Muniz	Dietitian	Sydney Children's Hospital
Fiona Arrowsmith	Dietitian	Children's Hospital at Westmead
Fiona Carstairs	Occupational Therapist	Ageing, Disability and Home Care
Leigha Dark	Speech Pathologist	Cerebral Palsy Alliance
Melissa Hayles	Speech Pathologist	John Hunter Children's Hospital
Pathma Joseph	Pharmacist	Children's Hospital at Westmead
Ruth Baker	Orthotist	Sydney Children's Hospital
Stephanie Ong	Physiotherapist	Sydney Children's Hospital
Trudy Wilson	Occupational Therapist	Ageing, Disability and Home Care
Vicki Cavanagh	Orthotist	Children's Hospital at Westmead

Illustrations (figures 2, 3, 4 & 5; figures contained within tables 1 & 2) provided by:

Janice Latham	Images 4U
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APPENDIX TWO: FLOWCHART FOR ASSESSMENT AND INTERVENTION FOR CHILDREN WITH CEREBRAL PALSY



APPENDIX THREE: PAEDIATRIC VIDEOFLUOROSCOPIC SWALLOW STUDY SERVICES IN NSW

Specialist clinics are available at a number of tertiary and non-tertiary facilities across NSW. These clinics may or may not provide services to children with cerebral palsy.

It is recommended that clinicians make contact initially with local services and then proceed to specialist clinics and tertiary children's hospitals.

The list below provides details of established paediatric feeding teams and clinics in NSW but is not exhaustive and additional services may be available at other sites across the state.

Facility	Contact Details	Tertiary Children's Hospital	Feeding Team	VFSS Service
John Hunter Children's Hospital, Newcastle	Lookout Road NEW LAMBTON HEIGHTS, NSW 2305 Ph: 02 4921 3727 Fax: 02 4921 3599 http://www.hnekidshealth.nsw.gov.au/site/jhch	✓	✓	✓
Sydney Children's Hospital, Randwick	High Street RANDWICK, NSW 2031 Ph: 02 9382 1021 Fax: 02 9382 1200 www.schn.health.nsw.gov.au	✓	✓	✓
Children's Hospital at Westmead Speech Pathology	Cnr Hawkesbury Road & Hainsworth Street WESTMEAD, NSW 2145 Ph: 02 9845 2076 Fax: 02 9845 2078 www.schn.health.nsw.gov.au	✓	✓	✓
Liverpool Hospital Speech Pathology	Elizabeth Street LIVERPOOL, NSW 2170 Ph: 02 9828 4765 Fax: 02 9828 4744		✓	✓
St George Hospital Speech Pathology	Belgrave Street KOGARAH, NSW 2217 Ph: 02 9113 1360 Fax: 02 9113 1382		✓	✓

APPENDIX FOUR: NUTRITION ASSESSMENT FORM

Cerebral Palsy Nutrition Assessment Form						
Patient name						
MRN						
DOB		Age				
Parent/Carer name						
Date of appointment						
Appointment type	☐ New			☐ Review		
Date of last review						
Referred by						
Reason for referral						
Medical History						
GMFCS Level	I	II	III	IV	V	Unknown
Current & past medical issues						
Growth History						
Comments: (record measurements in table on page 4 of the Nutrition Assessment Form and plot on growth chart)						
Feeding History						
Feeding type	☐ Oral		☐ Gastrostomy/tube		☐ Both	
Date of gastrostomy/tube		Fundoplication		☐ Yes	☐ No	
Does your child require assistance with eating?					☐ Yes	☐ No
How long do meals take? (>30 mins)						
Are mealtimes stressful to you or your child?						
How does illness impact on your child's intake e.g. weight loss, dehydration						
Name of formula and/or supplements?						
Diet history/other notes:						
Checklist	Comments					
☐ Energy & protein intake						
☐ Fluid intake						
☐ Fibre intake						
☐ Micro-nutrient intake						

Biochemistry

Swallowing Skills/VFSS (MBS) Results				
Diet consistency	Full	Texture A – soft	Texture B – minced	Texture C – puree
Fluid consistency	Thin	Level 1 – mild	Level 2 – moderate	Level 3 – extreme
Does your child cough or choke on food and/or fluids?				☐ Yes ☐ No
Has the child had a Videoflouroscopic Swallow Study (VFSS/MBS)?				☐ Yes ☐ No

Details:

Reflux and vomiting

Chest health e.g. number of chest infections per year

Bowels (type/frequency) refer to Bristol Stool Chart (http://www.sthk.nhs.uk/library/documents/stoolchart.pdf)

Medications

Bone health/vitamin D

Other
E.g. relevant social history, dental health or other health professionals involved
Overall assessment and summary
Plan/goals
1.
2.
3.
4.

HEN Checklist	Comments
☐ Update HEN Registration	
☐ HEN/nutrition plan (page 5 of the Nutrition Assessment Form)	
☐ Registered with Enable	

Date of next review	
---------------------	--

Dietitian (print/sign)	
------------------------	--

Copy of report to	
-------------------	--

Home Enteral Nutrition Plan for:				
Date:	MRN:		DOB:	
Feeding Device				
Type of feeding device:		Name of device:		
Size:		Date inserted/last changed:		
Feeding Plan				
Oral Feeding:	☐ Yes	☐ No	☐ Tastes only	
Food Texture:	☐ As desired	☐ Soft	☐ Minced & moist	☐ Puree
Fluid Texture:	☐ Thin	☐ Mildly thick	☐ Moderately thick	☐ Extremely thick
Notes:				
Tube Feeding: *See recipe (if using powdered formula)*				
Name of formula:				
Concentration:		kCal/100ml:		
Regimen:	☐ Gravity bolus	☐ Syringe bolus	☐ Pump bolus	
	☐ Continuous pump	☐ Intermittent pump _____ hrs/day		
Details:				
Water flushes:				
Additional water:				
Tube feed provides:			% estimated requirement	
Energy:	kCal/day			
Protein:	g/day			
Fluid:	ml/day			

Estimated Requirements based on a weight of _____ kg		
Energy:	kCal/day	Equ:
Protein:	g/day	g/kg/day
Fluid:	ml/day	ml/kg/day

Growth:		Date of measurement:
Weight:	kg	%ile
Height/length:	cm	%ile
Goal weight:	kg	%ile
Wheelchair:	kg	%ile
Triceps skinfold:	mm	%ile

Goals of this feeding plan:	
1.	
2.	
Health Professional's Contact Details:	
Facility:	Phone:
Dietitian:	Phone:
Nurse/CNC:	Phone:
Speech Pathologist:	Phone:

Review Details: All tube fed children should be reviewed by their Dietitian every 6-12 months				
Date of next review:	With:			
Date of next review:	With:			
For follow up appointments please contact your Dietitian, Speech Pathologist and Nurse				
cc:	☐ Medical file	☐ Parent/carer	☐ Paediatrician	☐ Dietitian
	☐ Speech Pathologist	☐ Nurse/CNC	☐ School	☐ Respite

Australian Standards for Texture Modified Foods and Fluids

The provision of thickened fluids and texture modified foods is a routine part of the assessment and management of feeding and swallowing difficulties (dysphagia).

If you need assistance with the level of fluid and food texture modification required, contact your Speech Pathologist.

To find a Speech Pathologist, go to www.speechpathologyaustralia.org.au

If you require support to determine whether a textured modified diet is meeting nutrition and hydration needs, contact your dietitian.

To find an Accredited Practising Dietitian (APD), go to www.daa.asn.au

FLUID		
Mildly Thick Level 150  Fluid runs freely off the spoon but leaves a mild coating on the spoon.	Moderately Thick Level 400  Fluid slowly drips in dollops off the end of the spoon.	Extremely Thick Level 900  Fluid sits on the spoon and does not flow off it.
FOOD		
Texture A - Soft  Food may be naturally soft or may be cooked or cut to alter its texture.	Texture B - Minced and Moist  Food is soft, moist and easily mashed with a fork; lumps are smooth and rounded.	Texture C - Smooth Pureed  Food is smooth, moist and lump free; may have a grainy quality.



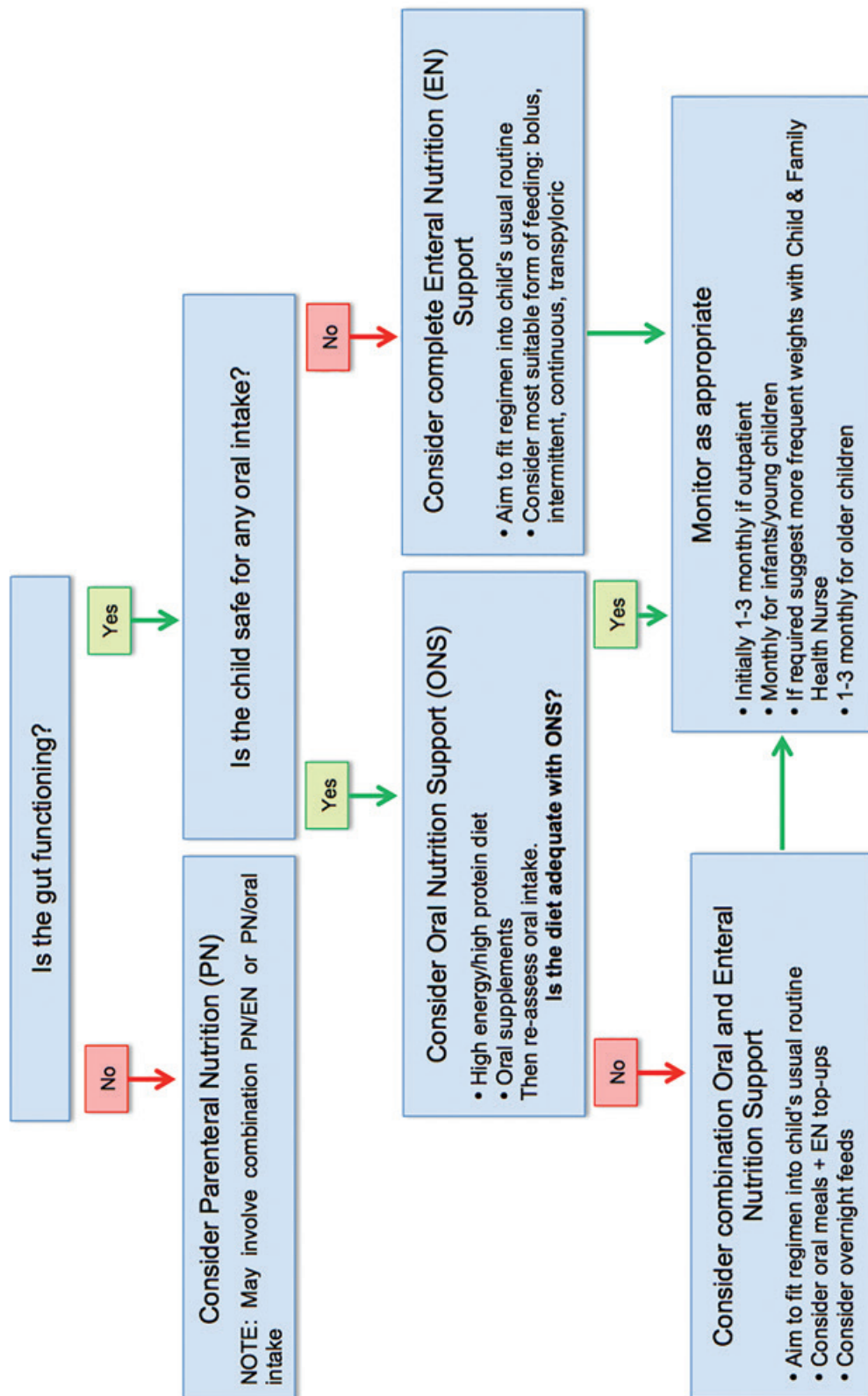
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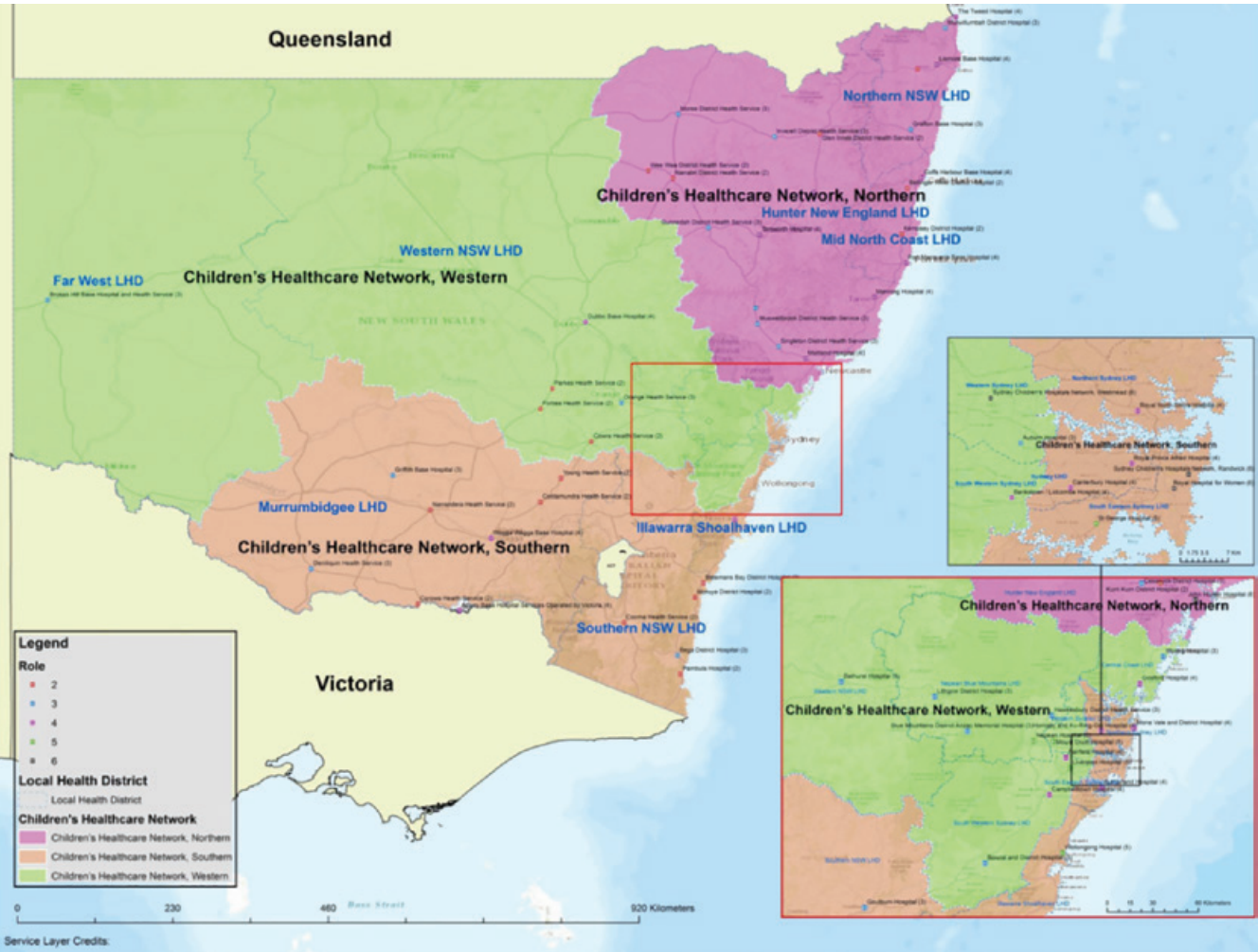
Adapted from: NSW Health (2016). *Feeding Difficulties in Children - A Guide for Allied Health Professionals*, p50.

APPENDIX SIX: TERTIARY HOSPITALS – RESOURCES AND REFERRALS

There are three tertiary paediatric hospitals in NSW with designated Children’s Healthcare Networks that have specialist departments that manage children with cerebral palsy. These are:

Hospital	Department	Service	Children’s Healthcare Network	Contact Details
Children’s Hospital at Westmead	Kids Rehab	Cerebral Palsy & Movement Disorders Service	Western	02 9845 2819
Sydney Children’s Hospital, Randwick	Rehab 2 Kids	Cerebral Palsy Service	Southern	02 9382 0178
John Hunter Children’s Hospital, Newcastle	Kaleidoscope Paediatric Rehabilitation Service	Cerebral Palsy & Movement Disorders Service	Northern	02 4925 7868

Figure 6: NSW Children’s Healthcare Networks ²³⁷



The tertiary children's hospitals all offer specialist clinical care for children with cerebral palsy within their Children's Healthcare Network boundaries. Further information regarding the specialist services offered at each of the tertiary children's hospitals is listed below:

- **Children's Hospital at Westmead**

- Cerebral Palsy & Movement Disorder clinics
- Botulinum Toxin clinics
- Orthopaedic clinics – lower limb surgery, upper limb surgery and spinal surgery
- Intrathecal Baclofen Therapy – NSW service
- Selective Dorsal Rhizotomy – NSW service
- Deep Brain Stimulation – NSW service.

- **Sydney Children's Hospital, Randwick**

- Cerebral Palsy clinics
- Botulinum Toxin clinics
- Orthopaedic clinics – lower limb surgery, upper limb surgery and spinal surgery.

- **John Hunter Children's Hospital, Newcastle**

- Cerebral Palsy & Movement Disorder clinics
- Botulinum Toxin clinics.

