| Rehabilitation Guidelines | Cerebral Palsy | Occupational Therapy |

Rehabilitation Guideline for the Management of Children with Cerebral Palsy

| Occupational Therapy Guideline |

Humanity & Inclusion
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Advancing Medical Care and Rehabilitation Education Project

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

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

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Foreword

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

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

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

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

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

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

On Behalf of Humanity & Inclusion,
Didier Demey
Country Director

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

Prof. Trần Trọng Hải, Prof. Cao Minh Châu, Associated Prof. Lương Tuấn Khanh, Dr. Nguyễn Thị Kim Liên, Dr. Hà Chân Nhân, Dr. Đinh Quang Thanh, Dr. Trịnh Quang Dũng, Lê Thanh Vân (MSc), ThS. Nguyễn Ngọc Minh (MSc), Dr. Phạm Thị Cẩm Hưng, Dr. Đinh Thị Hoa, Dr. Hoàng Khánh Chi, Lê Tường Giao (BSc), Đỗ Thị Bích Thuận (BSc).

List of Abbreviations

AAC	Augmentative and alternative communication
ADL	Activities of daily living
AOTA	American Occupational Therapy Association
CBR	Community-based rehabilitation
CFCS	Communication Function Classification System
COPM	Canadian Occupational Performance Measure
CVI	Cortical visual impairment
EBP	Evidence-based practice
EDACS	Eating and Drinking Ability Classification System
FEES	Flexible endoscopic evaluation of swallowing
GMFCS	Gross Motor Function Classification System
GMFM	Gross Motor Function Measure
HIE	Hypoxic-ischaemic encephalopathy
HINE	Hammersmith Infant Neurological Examination
IALD	Individualized Activities of Daily Living
ICF	International Classification of Function
MACS	Manual Abilities Classification Scale
QUEST	Quality of Upper Extremity Skills Test
WFOT	World Federation of Occupational Therapy
WHO	World Health Organization

1. Introduction

1.1. The Need for Guidelines

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

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

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

These guidelines consist of several components - a general rehabilitation guideline (this document), a technical guideline for physiotherapy and a technical guideline for occupational therapy. Collectively these documents make up a set of guidelines (known as 'the guidelines') for the holistic management of children with cerebral palsy. Specific technical guidelines for medical practitioners, nurses and speech pathologists are still to be developed.

The present **Occupational Therapy Guideline for Cerebral Palsy** provide recommendations and guidance on type of occupational therapy care to be provided as well as "cross-cutting" recommendations in regard of requirements for a system organization, multidisciplinary and comprehensive care, person-centred care, family support and involvement, care pathway and referrals, discharge and follow-up, community reintegration and social participation. The guideline acts as an adjunct to the General Rehabilitation Guidelines for Cerebral Palsy which have been developed recently.

1.2. Who Are the Guidelines For

The present guideline is primarily a practical resource tool for Occupational Therapist who are involved in rehabilitation with children with CP.

They are also useful to any other professional with an interest in rehabilitation for children with CP, including doctors, neurologists, rehabilitation doctors, nurses, occupational therapists,

speech and language therapists, dieticians, orthotists, pharmacists, psychologists, specialists in public health, social, community workers and stroke survivors and their family and carers.

1.3. Aim of the Guideline

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

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

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

1.4. Statement of Intent

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

1.5. What is CP

CP is an umbrella term that describes 'a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive

disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy and by secondary musculoskeletal problems.' (Rosenbaum et al., 2007).

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

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

- Mean age of diagnosis of CP was 20.7 months (range 1 month -13 years)
- CP type at diagnosis:
  - 66% spastic quadriplegia
  - 21% hemiplegia/monoplegia
  - 6.4% diplegia
- 1.5% had predominantly athetosis
- 54% the children had intellectual impairment and 12.7% had probable intellectual impairment
- Using the Gross Motor Function Classification System (GMFCS):
  - 16% had level V function
  - 27% Level IV (indicating requirement for a manual or powered wheelchair) yet none had access to a wheelchair
  - 13% had Level III function
  - 16% Level II function
  - 23% Level I function

1.6. Describing CP

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

1.6.1. Motor Type

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

(I) Spasticity

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

(II) Dyskinesia/Hyperkinesia

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

- **Dystonia** is characterised by sustained or intermittent muscle contractions causing repetitive or twisting movements.
- **Athetosis** is characterised by uncontrolled, slow and writhing movements that prevent maintenance of a stable posture. It involves continuous smooth movements that appear random and are not composed of recognisable sub-movements or movement fragments. Athetosis is made worse by attempts to move however it may also be present at rest. Athetosis is distinguished from dystonia by the lack of sustained postures, and from chorea by the lack of identifiable movement fragments (Sanger et al, 2010, page 1543).
- **Chorea** is an ongoing random-appearing sequence of one or more discrete involuntary movements or movement fragments. Chorea is distinguished from dystonia due to the apparently random, unpredictable, and continuously ongoing nature of the movements, compared with the more predictable and stereotyped movements or postures of dystonia. The movements of chorea often appear more rapid than those associated with dystonia. Although chorea may be worsened by movement, attempts at movement, or stress, particular movements are not triggered by voluntary attempts with the same degree of temporal specificity as in dystonia (Sanger et al, 2010, page 1542). Children with chorea present as fidgety or in constant motion.

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

(III) Ataxia

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

(IV) Mixed motor types

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

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

1.6.2. Topography

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

(I) Unilateral CP

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

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

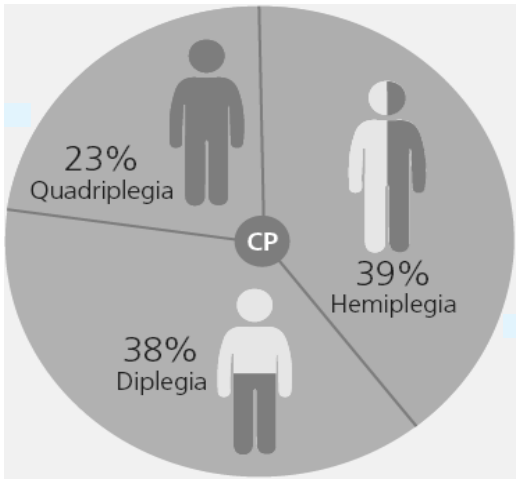


Figure 1: Image from Cerebral Palsy Diagnosis and Treatment infographic poster (www.worldcpday.org)

(II) Bilateral CP

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

1.6.3. Severity

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

1.7. Associated Conditions

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

- 3 in 4 will experience chronic pain
- 1 in 2 will have an intellectual impairment
- 1 in 3 will be unable to walk

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

(Novak et al., 2012)

1.8. What is Occupational Therapy

1.8.1. Definition

Occupational therapy is a client-centred health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement (World Federation of Occupational Therapy (WFOT), 2012).

1.8.2. Domain and Scope of Practice of Occupational Therapy

Occupations refer to the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations are central to a person's identity and sense of competence and have meaning and value to patients (AOTA 2014).

Achieving health, well-being, and participation in life through engagement in occupation is the overarching statement that describes purpose occupational therapy in its fullest sense. This statement acknowledges the profession's belief that active engagement in occupation promotes, facilitates, supports, and maintains health and participation.

These interrelated concepts include:

- *Health*—"a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity" (World Health Organization [WHO], 2006, p. 1).
- *Well-being*—"a general term encompassing the total universe of human life domains, including physical, mental, and social aspects" (WHO, 2006, p. 211).
- *Participation*—"involvement in a life situation" (WHO, 2001, p. 10). Participation naturally occurs when clients are actively involved in carrying out occupations or daily life activities

they find purposeful and meaningful. More specific outcomes of occupational therapy intervention are multidimensional and support the end result of participation.

- *Engagement in occupation*—performance of occupations as the result of choice, motivation, and meaning within a supportive context and environment. Engagement includes objective and subjective aspects of clients' experiences and involves the transactional interaction of the mind, body, and spirit. Occupational therapy intervention focuses on creating or facilitating opportunities to engage in occupations that lead to participation in desired life situations (AOTA, 2014).

Occupational therapists are skilled in evaluating all aspects of the domain of occupation, their interrelationships, and the client within his or her contexts and environments. Occupations are categorized as activities of daily living (ADLs), instrumental activities of daily living (IADLs), rest and sleep, education, work, play, leisure, and social participation.

Other healthcare professions use a similar process of evaluating, intervening, and targeting intervention outcomes, but only occupational therapists focus on the use of occupations to promote health, well-being, and participation in life.

2. Principles of Rehabilitation

2.1. Introduction

2.1.1. Rehabilitation

WHO describes rehabilitation as "a set of measures that assist individuals who experience, or are likely to experience, disability [resulting from impairment, regardless of when it occurred (congenital, early or late)] to achieve and maintain optimal functioning in interaction with their environments" "Rehabilitation measures target body functions and structures, activities and participation, environmental factors, and personal factors." (WHO, 2011)

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

Key aspects of rehabilitation care include:

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

2.1.2. Habilitation

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

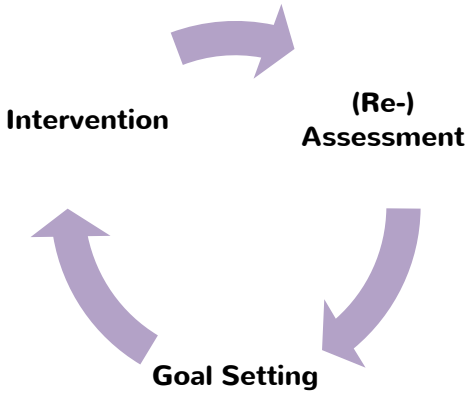
Examples include teaching an infant with CP how to roll, sit unsupported, stand, and walk for the first time. It can also include teaching an older child with CP to ride a bicycle, hold a pencil and write, and catch/throw a ball for the first time.

2.2. Rehabilitation Cycle

The conventional approach to rehabilitation is a cyclical process:

2.2.1. Assessment

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



2.2.2. Goal setting

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

2.2.3. Intervention

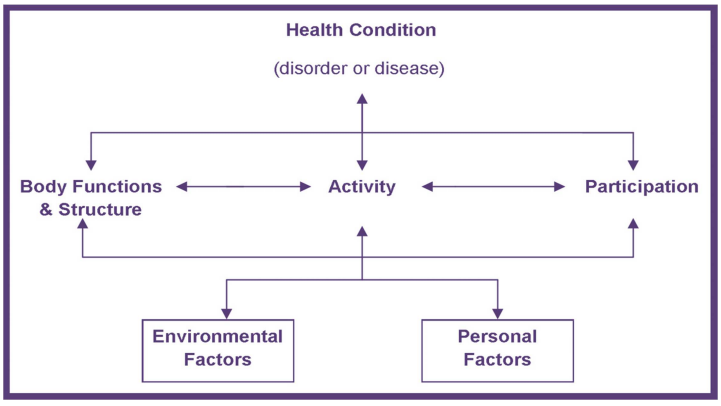
- Giving relevant treatment in order to achieve the goals;

2.2.4. Re-Assessment

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

2.3. ICF

2.3.1. What is the ICF



WHO (2001). ICF Model

Rehabilitation can be summarised in the ICF (International Classification of Functioning, Disability and Health) model developed by WHO (2001). The ICF conceptualises a person's level of functioning as a dynamic interaction between her or his health condition, environmental factors, and personal factors. It is a biopsychosocial model, based on an integration of the

social and medical models of disability. All components of disability are important and any one may interact with another. Environmental factors must be taken into consideration as they affect everything and may need to be changed.

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

For example:

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

2.3.2. The ICF, Rehabilitation and CP

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

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

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

2.4. Person Centred and Family Centred Care

2.4.1. Person-Centred Approach

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

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

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

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

- Each individual is unique
- Each individual is an expert in their own lives
- Partnerships are key
- There is a focus on an individual's strengths

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

2.4.2. Family-Centred Approach

Family-centred practice adopts a similar philosophy to person-centred practice and goes further to recognise that families and carers are pivotal decision makers when working with children with CP. Family-centred practice is made up of a set of values, attitudes, and approaches to

services for children with CP and their families. The family works with service providers to make informed decisions about the services and supports the child and family receive. In a family-centred approach, the strengths and needs of all family members and carers are considered. The family defines the priorities of the intervention and services. It is based on the premises that families know the child best, that optimal recovery outcomes occur within a supportive family and community environment and that each family is unique. Service provides support and respect each family's capacity and resources. Family capacity includes the knowledge and skills the family requires to support the child's needs and well-being. Capacity is the amount of physical, intellectual, emotional and spiritual energy necessary to support the child with CP, and it directly influences the sense of competency a family member experiences when caring for a child with CP.

2.4.3. Parent Empowerment

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

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

- Encourage parent decision-making in partnership with other team members (to utilise family empowerment strategies.)
- Assist families to identify their strengths and build their own resources.
- Inform, answer, and advise parents (to encourage informed choices).
- Work in partnership with parents and children and help them identify and prioritise their needs from their own perspective.
- Collaborate with parents at all levels (care of the individual child; program development, implementation and evaluation; policy formation).
- Provide accessible services that will not overwhelm families with paperwork and bureaucratic red tape.
- Share complete information about the child's care on an ongoing basis.
- Respect the values, wishes and priorities of families.
- Accept and support decisions made by families.
- Listen.
- Provide flexible and individualised services (and to respond to the changing needs of the family).
- Be knowledgeable about and accept diversity among families (racial, ethnic, cultural and socio-economic).
- Believe and trust parents.
- Communicate in a language understandable by parents.
- Consider and be sensitive to the psychosocial needs of all family members.
- Provide an environment that encourages the participation of all family members.
- Respect the family's own style of coping without judging what is right and what is wrong.

- Encourage family-to-family support and the use of natural community supports and resources.
- Recognise and build on family and child strengths.

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

2.4.4. Patient Centred Models of Occupational Therapy

Occupational therapists use several models to provide a framework for the assessment and treatment of patients. Models are client-centred and collaborative in nature engaging the patient in the occupational therapy process. Some models which can be used to guide occupational therapy services for children with CP and their families include:

1) The Person-Environment-Occupation-Performance Model – The model focuses on health, participation, and well-being of individuals, groups, and populations. Occupational performance is the doing of meaningful activities, tasks, and roles through complex interactions between the person and the environment.

2) The Person-Environment-Occupation Model – This model focuses on occupational performance and its link to people, occupation, roles, the environment, work, and play as a dynamic, interwoven process.

3) Occupational Adaptation Model – This model encourages the occupational therapist to assist the client to identify occupation to which he or she is interested in returning. The emphasis is on the use of meaningful occupations to allow the client to experience adaptation.

4) The Model of Human Occupation – Occupation is the action of doing in which people occupy their world. Occupational behaviors occur when a person makes a choice and acts. People are occupational by nature and need to act in accordance to valued goals and interests (volition). Habits and roles guide a person's occupational choices.

5) The Kawa Model – This model uses the natural metaphor of a river to depict one's life journey. The varying and chronological experience of life is like a river, flowing from the high lands down to the ocean. Along its meandering path, the quality and character of its flow will vary from place to place, from instance to instance. Occupational therapists try to enable, assist, restore and maximize their clients' life flows.

Recommendation -

> Occupational therapists should use common models and frameworks as tools to guide clinical reasoning skills needed to deliver evidence-based and client-centred occupational therapy services

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2.5. Multidisciplinary Teams and Interprofessional Team Approach

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

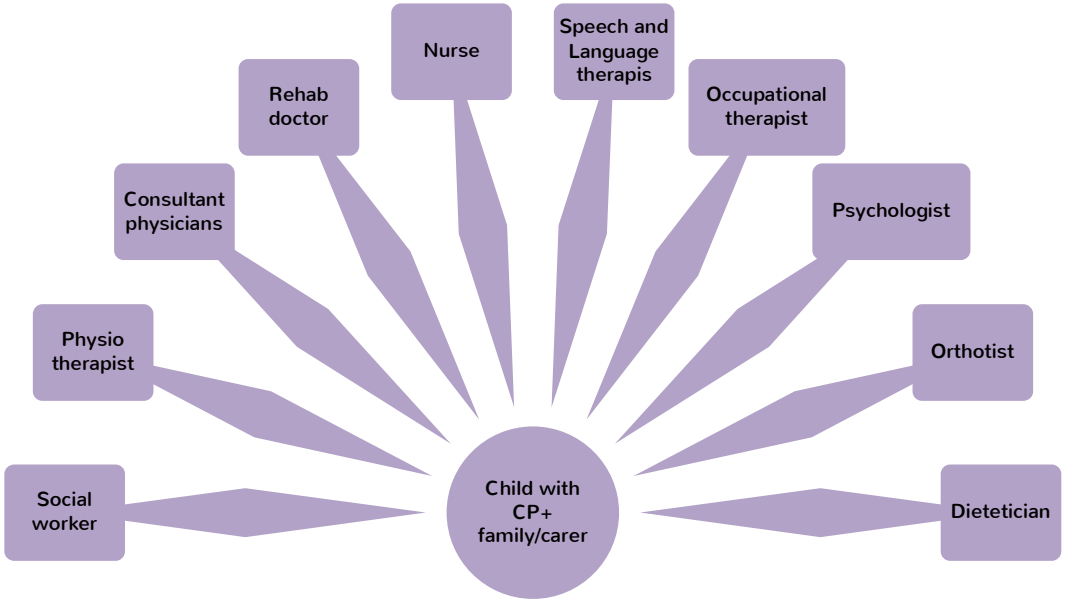
Rehabilitation team members may include:

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

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

In the interprofessional team approach, providers work independently, but recognise and value contributions of other team members. This approach requires interaction among the team members for the evaluation, assessment, and development of the intervention plan. The role of each team member is defined and there is an emphasis on regular and on-going communication among team members. Common goals are developed in collaboration with the child and family.

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


Nurse
Speech and Language therapis
Rehab doctor
Occupational therapist
Consultant physicians
Psychologist
Physio therapist
Orthotist
Social worker
Child with CP+ family/carer
Dietetician

3. The Rehabilitation Cycle

3.1. Screening for Children at Risk of Cerebral Palsy

Cerebral palsy is diagnosed by clinical presentation based upon the presence of a motor disorder caused by damage to, or maldevelopment of the infant brain. A diagnosis of CP is made by a medical professional (e.g. general practitioner, paediatrician, paediatric neurologist). Refer to the general rehabilitation guideline for more detailed information regarding diagnosing cerebral palsy.

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

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

3.1.1. Risk Factors for Cerebral Palsy

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

Maternal risk factors include

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

Infant risk factors include:

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

Additional risk factors have been identified in children born at term (in high resource countries). These include (McIntyre et al, 2012)

- Placental abnormalities
- Birth defects
- Meconium aspiration
- Instrumental/emergency caesarean delivery
- Birth asphyxia
- Respiratory distress syndrome

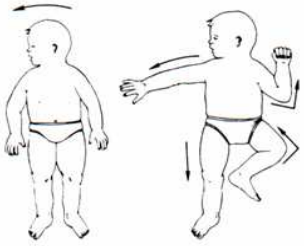
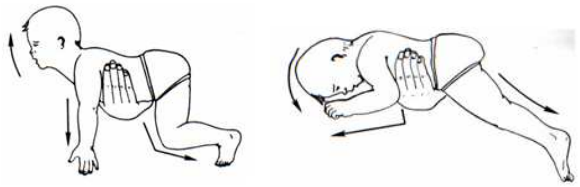
A small percentage of children acquire cerebral palsy after one month of age. This is generally a result of stroke, which may occur spontaneously or from complications associated with another condition or medical intervention (ACPR Group 2009).

3.1.2. Abnormal Reflexes

Occupational and physiotherapists should evaluate the presence of abnormal reflexes in infants at risk for CP (Hamer & Hadders-Algra, 2016):

- In early infancy, an absent Moro or plantar grasp response may be predictive for adverse developmental outcome including CP
- Persistence of the Moro response and asymmetric tonic neck reflex (ATNR) indicates a higher risk for poor developmental outcome
- Abnormal performances on the pull-to-sit manoeuvre and vertical suspension test have predictive significance throughout infancy

Reflex	Timeline when reflex is normally present	Testing procedure
1) Moro	> Birth to 4-5 months of age; > Strong persistence beyond 6 months of age may be a sign of neurologic dysfunction. > Integration of this reflex coincides with development of head control and protective extension response.	> Position: Placed child supine with head in the midline, arms on chest. > Procedure: Support infant's head and shoulders with hand, allow to drop back 20-30 degrees with respect to trunk, stretching neck muscles. > Response: Abduction of the upper extremities with extension of the elbows, wrists and fingers, followed by subsequent adduction of the arms at the shoulders and flexion at the elbows and cry.

2) Plantar Grasp	> Present at birth to 7 to 8 months of age. > Persistence beyond 1 year should be regarded with the child's total developmental picture. Can assist the child with early standing with support and often seen until child walks well.	> Position: Place child supine with head in midline and legs relaxed. > Procedure: Firm pressure against volar surface of infant's foot, directly below toes. > Response: Plantar flexion of all toes
3) Asymetrical Tonic Neck Reflex (ATNR)	> Present at 1-2 months of age; strongest at 2 months. Should be integrated by 4 months of age. > Persistence beyond 6 months may be a sign of neurologic dysfunction. > Integration coincides with the development of voluntary and controlled rolling abilities.	> Position: Place child supine with head in midline. > Procedure: Turn the head slowly to one side, and hold in this extreme position with jaw over the shoulder. > Response: Arm and leg on jaw side extend. Arm and leg on skull side flex. 
4) Symmetrical Tonic Neck Reflex (STNR)	> Present at 5 to 6 months of age. > Persistence beyond 7 months of age may be a sign of neurologic dysfunction. > Integration coincides with the development of reciprocal crawling.	> Position: Place child in prone position supported by the trunk, over the examiner's knee. > Procedure: Examiner passively first flexes then extends the child's head, or facilitates movement with toy. > Response: Flexion of the head (chin tuck) produces flexion of the upper extremities, extension of the lower extremities. Extension of the head produces extension of the upper extremities and flexion of the lower extremities. 

5) Righting reactions	> The infant should demonstrate righting responses in the head and neck starting at 4 months. > Abnormal or absent head righting responses by 7 months may be a sign of neurologic dysfunction.	> Position: This reflex can also be assessed during pull-to-sit manoeuvre and during vertical suspension test. > Procedure: * Pull to sit: Place infant in supine. Grasp the infant's wrists and slowly pull the infant up from supine into sitting position. * Vertical suspension test: Examiner holds child vertically in space under the arms and around chest. > Response: Head orients immediately to vertical position to align head with trunk.
6) Babinski sign	> Present at birth to approximately 2 years of age.	> Position: Place child supine. > Procedure: Examiner firmly strokes the sole of the foot. > Response: For children under 2 years of age, the big toe extends back toward the top of the foot and the other toes fan out. A normal response in individuals older than 2 years of age would be the big toe flexing downward (toward the sole of the foot) or no response.

3.1.3. Motor Assessment

(I) Ages and Stages Questionnaire (ASQ)

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

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

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

Use of developmental milestones as a marker for cerebral palsy alone, is insufficient information as there may be many causes for delayed development that are not related to cerebral palsy. Motor delay should always be supplemented with information related to neurological functioning (muscle tone and/or abnormal reflexes).

If there are concerns regarding the above signs and symptoms, physiotherapists should consider a possible diagnosis of cerebral palsy and refer to a medical practitioner.

3.2. Classification Tools

3.2.1. Functional Mobility Ability

(I) Gross Motor Function Classification System (GMFCS)

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

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

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

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

Administration

Assessor: Medical practitioners, physiotherapists, occupational therapists, nurses who are familiar with the child's gross motor function in conjunction with a parent or caregiver.
How: Clinician asks questions of the child, parent or caregiver to determine functional mobility. Done either via parent/caregiver report and/or observation during regular appointment.
Time: N/A
Availability: The GMFCS – ER (2007) can be sourced freely online by visiting the CanChild website at https://www.canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r

(II) Functional Mobility Scale (FMS)

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

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

Administration

Assessor: Medical practitioners, physiotherapists, occupational therapists, nurses. Clinician asks questions of the child, parent or caregiver who is familiar with the child's mobility (not direct observation).
How: questions asked during regular appointment.
Time: N/A
Availability: forms available from: http://ww2.rch.org.au/emplibrary/ortho/MOBILITYSCALE.pdf

3.2.2. Manual Ability

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

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

The Manual Ability Classification System (MACS) provides a systematic method of classifying how children with CP, aged 4 to 18 years use their hands when handling objects during daily activities. MACS is based upon self-initiated manual ability, with particular emphasis on handling objects in an individual's personal space (the space immediately close to one's body, as distinct from objects that are not within reach). The focus of MACS is on determining which level best represents the child's usual performance at home, school and in community settings. Distinctions between the levels are based on the child's ability to handle objects and their need for assistance or adaptations to perform manual tasks in everyday life. MACS is not designed to classify best capacity and does not mean to distinguish different capacities between the two hands. MACS does not intend to explain the underlying reasons for limitations of performance or to classify types of CP.

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

Administration

Assessor: Parent, caregiver or health professional who is familiar with the child's hand function.
How: MACS level must be determined by asking someone who knows the child well and not by conducting a specific assessment (Eliasson, et.al.2005). Done either via parent/caregiver report and/or observation during regular appointment.

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

3.2.3. Communication Ability

(I) Communication Function Classification System (CFCS)

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

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

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

Administration

Assessor: Parent, caregiver or professional who is familiar with the child's communication.
How: Completed either via parent/caregiver report and/or observation during regular appointment
Time: N/A
Availability: Can be accessed via:
http://www.therapybc.ca/eLibrary/docs/Resources/CFCS_2008_11_03.pdf

3.2.5. Eating and Drinking Ability

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

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

The Eating and Drinking Ability Classification System (EDACS) is a system for classifying eating and drinking ability in children with CP from age 3 years. It is complementary to the GMFCS, MACS and CFCS and its purpose is to be utilised both clinically and in research. The EDACS focuses on the aspects of eating and drinking such as chewing, swallowing, sucking, biting and

keeping food and liquid in the mouth. The distinctions between the five levels consider functional ability, requirement for adaptation to texture, techniques used and assistance required.

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

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

Administration

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

How: Completed either via parent/caregiver report and/or observation.

Time: N/A

Availability*:* Can be accessed via: www.EDACS.org

3.3. Goal Setting

Building authentic partnerships with families has positive implications for the rehabilitation process in general, and in particular, on determining which goals will be addressed during the rehabilitation process. All team members actively participate to reach consensus on the overall rehabilitation goals. This increases the likelihood of positive and sustainable outcomes, as everyone agrees as to which goals are particularly important for the family and child (Harty, Griesel, & van der Merwe, 2011).

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

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

3.3.1. Occupational Profile

The occupational profile is a summary of a client's occupational history and experiences, patterns of daily living, interests, values, and needs" (AOTA, 2014, p. S13). The information is obtained

from the client's perspective through both formal interview techniques and casual conversation and leads to an individualized, client-centered approach to intervention.

Administration

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

How: Completed through a semi-structured interview with the parent and/or child. The interview questions focus on determining the client's interests and goals for therapy.

Time: 30 minutes

Note: An Occupational Profile template (English) can be freely downloaded, but will require translation into Vietnamese:
https://www.aota.org/~/media/Corporate/Files/Practice/Manage/Documentation/AOTA-Occupational-Profile-Template.pdf

3.3.2. Canadian Occupational Performance Measure (COPM)

(Law, Baptiste, Carswell, McColl, Polatajko & Pollock, 1990)

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

(I) Administration

Assessor: This tool can be conducted by any rehabilitation team member.
How: Ensure that the version used is the paediatric modified version. Select parent or child report as appropriate. The assessment involves a 5-step process nested within a semi-structured interview that focuses on identifying activities within each performance domain that the client wants, needs, or is expected to perform.
Time: 15-30 minutes, semi-structured interview.
Note: The COPM has been translated into 24 different languages. It is not currently available in Vietnamese however it is likely that a translation will be available.

3.3.3. Goal Attainment Scaling (GAS)

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

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

(I) Administration

Assessor: This tool can be conducted by any rehabilitation team member however it is typically used by physiotherapists and occupational therapists to set therapy goals and evaluate intervention.

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

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

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

Note: Freely available from

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

Recommendation -

> Patient-centred therapy starts with the identification of the child's and parent's goals for occupational therapy. Occupational therapy assessment should begin with an Occupational Profile of the child. The COPM and GAS are internationally recognised tools for setting and evaluating goals and should be used to determine priority goals for therapy. The GAS requires extensive experience and training to use in a clinical setting and the capabilities of clinicians to utilise GAS will develop over time

3.4. Assessment

Occupational therapists will evaluate *performance skills which* are goal-directed actions that are observable as small units of engagement in daily life occupations. They are learned and developed over time and are situated in specific contexts and environments (AOTA, 2013). Various body structures, as well as personal and environmental contexts, converge and emerge as occupational performance skills. In addition, body functions, such as visual, sensory, neuromuscular, and movement-related functions, are identified as the capacities that reside

within the person and converge with structures and environmental contexts to emerge as performance skills. This description is consistent with WHO's (2001) *International Classification of Functioning, Disability and Health.*

The term *context* refers to elements within and surrounding a client that are often less tangible than physical and social environments but nonetheless exert a strong influence on performance. Contexts are cultural, personal, temporal, and virtual

Body Structure and Function Assessments

3.4.1. Assessment of Range of Motion (ROM)

Range of Motion (ROM) is the range through which a joint can be moved as determined by the type of joint, its articular surfaces, and that allowed by regional muscles, tendons, ligaments, joints and physiologic control of movements across the joint. ROM is divided into three main types:

- Passive range of motion (PROM) – the therapist passively moves the joint through the full arc of motion
- Active assisted range of motion (AAROM) – the therapist and the patient work together to move the joint through the full arc of motion
- Active range of motion (AROM) – the patient attempts to moves the joint through the full arc of motion

Measurement of ROM

The most common way to measure ROM is using a double-armed goniometer, a device used to measure joint angles in degrees. A stationary arm holding a protractor is placed parallel with a stationary body segment and a movable arm moves along a moveable body segment. The pin (axis of goniometer) is placed over the joint.

- The purpose of measure ROM is to determine if the patient has enough available ROM in specific joints (e.g. shoulder, wrist) to participate in daily activities (e.g. dressing, eating, bathing).
- ROM measurement can also be used to measure outcomes of stretch and muscle interventions (e.g. botox injections, casting and splinting).

Note: A template that can be used to record ROM measurements can be found at https://www.dshs.wa.gov/sites/default/files/FSA/forms/pdf/13-585a.pdf

3.4.2. Assessment of Motor Disorder and Muscle Tone

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

Points to remember:

- Hypertonia may still be evolving in the first two years of life with myelination

- Mixed presentations are common (spasticity/dystonia, dystonia/choreoathetosis)

(I) Manual Muscle Test (MMT)

Manual muscle testing measures muscle strength using a grading system, Grades 1-5. There are a number of different scales that are used for MMT (see table below).

Manual muscle testing is an assessment of performance not capacity.

> Administration

Assessor: This assessment is typically carried out by a physiotherapist, occupational therapist or medical practitioner.

How: The client is positioned in the most appropriate position to assess strength of specific muscles. The position will be dependent upon the level of strength present and the ability to move the limb against gravity.

Time: 15–30 minutes; Administrative time is dependent on the muscle (s) selected, the age and cooperation of the participant.

Medical Research Council	Explanation
5	**Holds test position against maximal resistance**
4+	Holds test position against moderate to strong pressure
4	**Holds test position against moderate resistance**
4-	Holds test position against slight to moderate resistance
3+	Holds test position against slight resistance
3	**Holds test position against gravity**
3-	Gradual release from test position
2+	Moves through partial ROM against gravity OR Moves through complete ROM with gravity eliminated and holds against pressure
2	**Able to move through full ROM with gravity eliminated**
2-	Moves through partial ROM with gravity eliminated
1	**No visible movement; palpable or observable tendon prominence / flicker contraction**
0	**No palpable or observable muscle contraction**

Recommendation -

> The Medical Research Council Manual Muscle Testing Scale is strongly recommended for use with Manual Muscle Testing.

(II) Assessment of Spasticity

Modified Tardieu Scale (MTS)

(http://www.rehabmeasures.org/Lists/RehabMeasures/PrintView.aspx?ID=1038)

> Purpose: To identify presence of spasticity.

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

> Administration:

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

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

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

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

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

Upper Limbs	Lower Limbs
Shoulder flexors	Hip flexors
Shoulder internal rotators	Hip extensors
Elbow flexors	Hip adductors
Elbow extensors	Knee flexors
Wrist flexors	Knee extensors
Wrist extensors	Ankle plantarflexors (m. Soleus)(knee joint flexed)
	Ankle plantarflexors (m. Gastrocnemius) (knee joint fully extended)

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

Ashworth Scale and Modified Ashworth Scale

(Ashworth, 1964; Bohannon & Smith, 1987)
(http://www.rehabmeasures.org/Lists/RehabMeasures/PrintView.aspx?ID=902)

> Purpose: to measure the presence of hypertonia.

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

Ashworth Scale

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

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

Time: Varies depending on the number of muscle groups assessed

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

> Purpose: to identify and discriminate between different forms of hypertonia.

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

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

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

How: Clinician completes ALL 6 items on one extremity before moving to the next next extremity. It is recommended that all four limbs are assessed. Items are listed in the suggested order of administration in the HAT manual. http://www.hollandbloorview.ca/research/scientistprofiles/documents/HATUserManual.pdf

Time: Approximately 5 minutes to conduct per limb assessed

(II) Assessment of Dystonia

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

Hypertonicity Assessment Tool (HAT)
See above.

Barry Albright Dystonia Scale (BAD)
(Barry et al, 1999)

> Purpose: to identify and quantify dystonia.

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

> Administration
Assessor: This assessment is carried out by an occupational therapist, physiotherapist or Physician experienced in secondary dystonia and cerebral palsy.

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

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

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

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

0	Absent
1	Slight: dystonia less than 10% of the time and does not interfere with speech and/or feeding
2	Mild: dystonia less than 50% of the time and does not interfere with speech and/or feeding
3	Moderate: dystonia more than 50% of the time and/or dystonia that interferes with speech and/or feeding
4	Severe: dystonia more than 50% of the time and/or dystonia that prevents speech and/or feeding
	Unable to assess mouth movements

Neck: signs of dystonia of the neck include pulling of the neck into any plane of motion: extension, flexion, lateral flexion or rotation

0	Absent
1	Slight: pulling less than 10% of the time and does not interfere with lying, sitting, standing and/or walking
2	Mild: pulling less than 50% of the time and does not interfere with lying, sitting, standing and/or walking
3	Moderate: pulling more than 50% of the time and/or dystonia that interferes with lying, sitting, standing and/or walking
4	Severe: pulling more than 50% of the time and dystonia that prevents sitting in a standard wheelchair (e.g. requires special head rest), standing and/or walking
	Unable to assess neck movements

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

0	Absent
1	Slight: pulling less than 10% of the time and does not interfere with lying, sitting, standing and/or walking
2	Mild: pulling less than 50% of the time and does not interfere with lying, sitting, standing and/or walking
3	Moderate: pulling more than 50% of the time and/or dystonia that interferes with lying, sitting, standing and/or walking
4	Severe: pulling more than 50% of the time and dystonia that prevents sitting in a standard wheelchair (e.g. requires adapted seating system), standing and/or walking
	Unable to assess trunk movements

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

0	Absent
1	Slight: dystonia less than 10% of the time and does not interfere with normal positioning and/or functional activities
2	Mild: dystonia less than 50% of the time and does not interfere with normal positioning and/or functional activities
3	Moderate: dystonia more than 50% of the time and/or dystonia that interferes with normal positioning and/or upper extremity function
4	Severe: dystonia more than 50% of the time and/or dystonia that prevents normal positioning and/or upper extremity function (e.g. arms restrained to prevent injury)
	Unable to assess upper extremity movements

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

0	Absent
1	Slight: dystonia less than 10% of the time and does not interfere with normal positioning and/or functional activities
2	Mild: dystonia less than 50% of the time and does not interfere with normal positioning and/or functional activities

3	Moderate: dystonia more than 50% of the time and/or dystonia that interferes with normal positioning and/or lower extremity weight bearing and/or function
4	Severe: dystonia more than 50% of the time and/or dystonia that prevents normal positioning and/or lower extremity weight bearing and/or function
	Unable to assess lower extremity movements

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

(III) Assessment of Athetosis/Choreoathetosis

Assessment for chorea, athetosis and choreoathetosis is by observation of involuntary movements characterised by:

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

3.4.3. Assessment of Functional Strength

Strength is important to engage in meaningful activities and is defined as a function of muscle power.

- Grip/hand strength can be measured using a handheld dynamometer, but since muscle tone is typically impaired in children with CP, it may be difficult to use standard tools to measure upper body strength.
- Strength is required to perform daily activities which include reaching, grasping, holding, and carrying and occupational evaluation should include clinical observation of how the patient interacts with and moves objects and self in his/her environment.
- Therapist should use a **checklist of functional daily activities** which require strength can provide important information about muscle power required to participate in daily occupations.

Examples of daily activities which require strength:

- Pulling shirt and pants on and off body
- Maintaining grasp and hold on feeding utensils
- Grasping and holding a cup with liquid
- Picking up and holding toys of various weight
- Pushing and pulling handles on toys
- Opening containers
- Screwing and unscrewing lids
- Opening zip-loc bags
- Maintaining grasp and hold writing tools (pencil, marker)
- Using scissors to cut

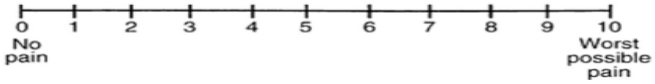
3.4.4. Assessment of Pain

(I) Visual Analogue Scale (VAS)

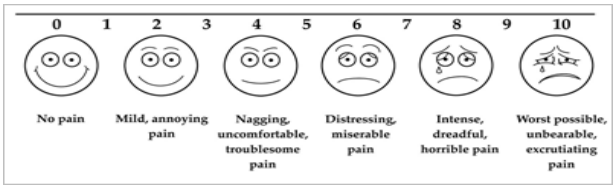
VAS is a measurement instrument that helps to determine pain that a patient feels ranges across a continuum from none to an extreme amount of pain. Validated in children 10 to 18 years of age.

This scale is a child report of pain and the choice of terms is specific to the type of scale. VAS can be presented in several ways, including:

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



Types of visual analogue scales:



Types of visual analogue scales

> Administration

Assessor: The screening can be carried out by an occupational therapist, physiotherapist, nurse or medical practitioner.

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

Time: Approximately 5 minutes

Available: http://www.blackwellpublishing.com/specialarticles/jcn_10_706.pdf

(II) Paediatric Pain Profile (PPP)

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

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

How: Each of the items of the PPP can by observed by the provider and parents can answer specific questions to rate their child's behaviours or reaction during specific activities. The PPP is a 20-item behavioural response scale with each question scored from "0" (not at all) to "3" (a great deal), except for the first two questions in which the scoring is reversed. Responses to all

questions are summed to give a total score between 0 and 60. Cut-off scores are used to determine pain severity: scores of 14/60 indicate clinically significant pain and can be additionally grouped into levels of severity mild (10-19), moderate (20-29), severe (30-39) and very severe (40 or greater).

Time: Approximately 20 minutes

Available: http://www.ppprofile.org.uk/ppptooldownload.php?s=209

3.4.5. Assessment of Sensation

Tactile impairment impacts on upper limb function in a significant proportion of children with CP. These deficits may occur in tactile registration and/or tactile perception (which may be spatial, temporal, or textural) and over 77% of children with unilateral CP have tactile perception deficits and over 40% have concomitant registration and perception deficits (Auld, 2011 & 2012).

(I) Tests of sensation:

Reliable assessment of sensation using these measures requires the patient to accurately respond to the evaluators questions. These assessments may not be reliable for children with intellectual impairments (Auld, 2011 & 2012).

1) Tactile registration can be measured using the full 20-item Semmes-Weinstein monofilaments kit. Starting with the monofilament of value 2.83 (lower side of normal sensation), the monofilament is applied to the skin surface of the four fingers three times in a random order, with one response out of three taken as an affirmative response, as indicated by the original test methodology.

2) Intensity/Texture Tactile Perception can be tested using the Perspex board (AsTex) that displays tactile gratings of reducing tactile discrimination index. Starting at the rough end of the board, the therapist guides the child's index finger, then thumb, then 5th finger was guided by the examiner along the board at a constant speed in a standardized manner. Children are instructed to stop immediately when the texture of the board feels smooth (gratings became too close together to determine their separation).

3) Motor-enhanced tactile perception: Stereognosis. Nine common objects are placed to the side of the child within the child's view. These objects include 3 unrelated objects (peg, key, spoon) and six objects that come in associative pairs (a coin and a button of similar size, a pen and a pencil, a paperclip and a safety pin). The examiner has an identical set of objects that are placed in the child's testing hand one at a time in a random order. The child is asked to manipulate the object and/or was assisted to touch the object and to either name or point to the object that was identical to the one placed in his/her hand. The total score is the number of correct responses out of a possible maximum of 9.

3.4.6. Assessment of Vision

(see General Guidelines for further information about Associated Visual Impairments)

Visual impairments and visual processing disorders will impact the patient's ability to participate in daily activities. Occupational therapists should evaluate the patient's ability to use functional visual skills including visual fixation, scanning, attention, and discrimination in everyday activities. For patients who are in school, an occupational therapist may need to evaluate higher level visual perceptual and visual motor skills required for reading and writing.

(I) Screening for visual impairment

1) **Ophthalmological examination** which focuses on visual acuity, refractive state of the eyes, ocular health, and, visual field assessments.

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

(II) Assessment specific to visual impairments

The CVI Questionnaire screens for or cortical visual impairment in children suspected of CVI (Ortibus et al, 2011).

Assessor: The CVI Questionnaire is a parent-report questionnaire which can be carried out by an occupational therapist, physiotherapist, nurse or medical practitioner.

How: The 47 questions can be given to a parent to complete independently or discussed as a semi-structured interview. CVI characteristics are rated as present/not present. The clinician should be responsible for calculating the sum scores and the information shared with the child's medical practitioner.

Time: Approximately 15 minutes

Available:
http://download.lww.com/wolterskluwer_vitalstream_com/PermaLink/COOP/A/COOP_2012_05_31_LEHMAN_656_SDC1.pdf

The Functional Visual Questionnaire assesses daily visual performance in children with CP who are difficult to assess due to sever ere motor, cognitive, and communication impairments (Ferziger et al., 2011).

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

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

Time: Approximately 20 minutes

Available: https://www.ncbi.nlm.nih.gov/pubmed/21309767

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

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

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

Time: Approximately 10 minutes

Available: https://www.ncbi.nlm.nih.gov/pubmed/17880645

Activity and Participation Assessments

3.4.7. Box and Blocks

Assessor: The Box and Blocks is a capacity assessment of upper extremity reach and grasp using a common toy (block) which can be completed by an occupational therapist or physiotherapist.

How: The test includes a box with 150 blocks. A partition(divider) is placed lengthwise in the middle of the box to divide the box into two sides. Directions give to patient "I want to see how quickly you can pick up one block at a time with your right (or left) hand [point to the hand]. Carry it to the other side of the box and drop it. Make sure your fingertips cross the partition. Watch me while I show you how." Following the demonstration and practice, the patient is given 1-

minute to transfer blocks from one side to the other. The examiner records how many blocks are successfully transferred in 1-minutes.

Time: 5-10 minutes

Available: Instruction for the Box and Block test are available at http://www.rehabmeasures.org/PDF%20Library/Box%20and%20Blocks%20Test%20Instructions.pdf

3.4.8. Quality of Upper Extremity Skills Test (QUEST)

Assessor: The QUEST is a capacity assessment of the quality of hand and arm movement patterns and function in children with CP who are 18 months to 8 years of age. There are four sections: 1) dissociated movement, 2) grasp, 3) weightbearing, and 4) protective extension. The assessment can be completed by an occupational therapist or physiotherapist.

How: The examiner encourages the child to complete movement activities in each section through verbal encouragement, toys, demonstration, and/or handling the child as necessary. The child must demonstrate the required position without physical assistance, e. g., the therapist cannot hold the arm in extension against gravity, but may facilitate this through weight bearing, placing, etc. The child must hold the position for at least 2 seconds. The order of administration can be changed to suit the child and therapist. If a child has a fixed contracture, the contracted position should be considered full range (e.g., if the child is lacking 10 degrees of extension due to a contracture, that position is considered full extension for that child).

Time: Approximately 45 minutes to administer all four sections

Available: The English version of the QUEST is available, but can be translated into Vietnamese: https://canchild.ca/en/shop/19-quality-of-upper-extremity-skills-test-quest

3.4.9. Pediatric Motor Activity Log (PMAL)

Assessor: The PMAL is a parent-report questionnaire measuring real-world use of impaired upper limb in common daily activities, capturing both perceived amount of use and quality of use. The assessment can be administered by an occupational therapist or physiotherapist.

How: The PMAL is completed through a semi-structured interview with the parent. The parent is asked specific questions about the way the child uses his/her upper limbs from a list of 22 real-world activities. It is important to determine what the child does outside the treatment or hospital setting. The parent is asked to rate the "How Often" and "How Well" the child completes each specific activity using a 6-point scale. After administering the full PMAL, the mean PMAL scores are calculated for the two scales (How Often & How Well) by adding the rating scores on each of the scales and dividing by the number of items asked.

Time: Approximately 20-30 minutes

Available: The English version of the Revised-PMAL is available but can be translated into Vietnamese. https://www.uab.edu/citherapy/images/pdf_files/CIT_PMAL_Manual.pdf

3.4.10. Assessment of ability to manage routine tasks requiring both upper extremities – (ABILHAND-Kids)

Assessor: The ABILHAND-Kids is a parent completed questionnaire that assesses manual abilities of children 6 to 15 years of age who have impaired upper limb functions.
How: The assessment consists of 21 items covering both unimanual and bimanual self-care activities. Each item is rated as 0=impossible, 1=difficult, 2=each, yielding a score range of 0 to 42. The parent is asked to estimate the child's ease or difficulty in performing each activity without assistance, irrespective of using right or left upper limb, and using whatever means necessary (compensation is allowed).
Time: Approximately 20 minutes
Available: The English version of the ABILHAND-Kids is available but can be translated into Vietnamese
http://www.rehab-scales.org/abilhand-kids-downloads.html

Environmental Assessments

Children with cerebral palsy live and carry out activities in many environments including home, preschool/school and the community. For many children, environmental barriers will exist that significantly impact upon the achievement of their goals, particularly goals related to social and community participation, inclusion and learning. Examples of environmental barriers that may exist include:

- Physical barriers (e.g. lack of ramps, uneven roads and footpaths, steep inclines/hills/mountains, river/creek/stream crossings etc.)
- Lack of suitable adaptive and assistive equipment (e.g. poor seating options, no wheelchair/walking aid, no/limited access to learning materials such as adapted writing utensils or accessible computer/technology/software etc.)
- Attitudinal barriers (e.g. lack of understanding of cerebral palsy and disability resulting in stigmas leading to people with cerebral palsy being excluded and not accepted into their community etc.)
- Governmental/policy barriers (e.g. limited access to health/rehabilitation services outside of medical facilities such as hospitals or clinics, cost of certain medical/rehabilitation interventions etc.)

3.5. Evidence-Based Practices in CP - OT

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

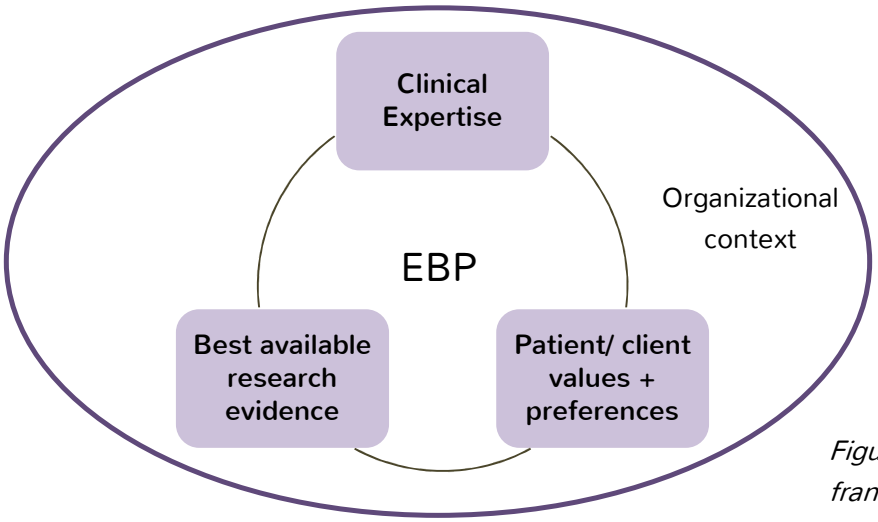


Figure 3. EBP framework

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

The ICF guides evidence-based practice in the management of children with CP. Research findings demonstrate that interventions for CP are only effective for one domain of the ICF. That is, interventions targeting the body functions and structure impairments will have outcomes at the body functions and structure domain only. If outcomes are desired at the activities and participation domains of the ICF, interventions that are proven to impact these domains are directed at the activity and participation limitations (Table 1, Novak et al., 2013)

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

Table II: Green light interventions (and their other indications) by level of ICF

Intervention	ICF level				
	Body structures and function	Activity	Participation	Environment	Personal factors
Body structures and function interventions					
1. Anticonvulsants	G				
2. Botulinum toxin	G				
3. Bisphosphonates	G				
4. Casting (ankle)	G	Y			
5. Diazepam	G				
6. Fitness training	G	Y	Y		
7. Hip surveillance	G				
8. Pressure care	G				
9. Selective dorsal rhizotomy	G	Y	Y		
Activities interventions					
10. Bimanual training		G			
11. Constraint-induced movement therapy		G			
12. Context-focused therapy		G			
13. Goal-directed training/functional training		G			
14. Home programmes		G	Y		
15. Occupational therapy post botulinum toxin (upper limb)		G			

G=green intervention when aimed at this level of the International Classification of Functioning, Disability and Health (ICF); Y=yellow intervention when aimed at this level of the ICF.

Table 1. Green light interventions for children with CP from Novak et al, 2013

The following factors are important when reviewing the evidence-based for interventions for the management of children with CP.

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

Intervention studies must first demonstrate effectiveness in achieving a meaningful outcome then follow with carefully designed studies to determine the minimal dose required to elicit or maintain the same desired functional outcome.

To date, the minimum doses for changing structure and function, activity, and participation in children with CP are unknown and determining the effective *dose* of specific interventions is a focus of future intervention studies.

Maximising outcomes in children with cerebral palsy will most often require a combination of therapy approaches targeting different levels of the ICF – body structure and function interventions, activity and participation interventions and interventions targeting the environment. The relative contribution of each of these approaches will vary according to each individual child's presentation and identified needs and goals. As such, an integrated care approach should be promoted to enable children to receive appropriate interventions in a timely and efficient manner.

For example, the presence of a muscle contracture in the gastrocnemius or elbow flexors may require serial casting (a body structure and function intervention) to reduce the contracture followed by a motor learning based intervention such as goal directed therapy or constraint induced movement therapy (activity and participation interventions) to gain or maintain functional skills.

Body Structure and Function Interventions

3.5.1. Stretch Interventions

Stretch interventions are widely utilised for the treatment of contractures in children with CP with the aim of maintaining or increasing range of motion at a specific joint. Stretch can be applied in three main forms:

- The application of orthoses
- Serial casting
- Positioning program

Stretch interventions aim to elongate soft tissue. Low load prolonged stretch is more effective than short held, passive stretches.

(I) Splinting and Orthoses

The prescription and manufacture of upper and lower limb orthoses is common practice with children with CP. A splint or orthosis is a removable external devices designed to support a weak or ineffective joint or muscle.

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).

Functional Orthoses

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

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

Non-functional Orthoses

Positional orthoses aim to maintain corrected anatomical alignment of the joint and maintain range of motion around that joint (such as after botox or surgery). 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

Clear dosage information around wearing regimes for orthoses is currently lacking. Decisions around wearing regimes need to be made with consideration to the individual goals identified by each child and family.

Upper Extremity Orthoses

Upper limb deformities caused by spasticity in the elbow, wrist, and digits can lead to several significant contractures. Splints and serial casting may be used to passively stretch contracted and spastic muscles and are most effective when used in conjunction with botulinum toxin A injections (Kanellopoulos et al., 2009)

- Elbow movement is affected by spastic biceps, brachialis anterior and brachioradialis muscles.
- Forearm movement is affected by spastic pronator teres, pronator quadratus, and flexor carpi ulnaris muscles.
- Wrist movement is affected by ulnar deviation due to spastic flexor carpi ulnaris.
- Finger movement is affected by spastic flexor digitorum, and the flexor digitorum profundus.
- An indwelling or "thumb-in-palm" deformity is due to spastic adductor pollicis longus or flexor pollicus brevis muscles.

Splints can also be used to support a weak or ineffective joint or muscle, prevent or correct joint, deformities, improve functional use of the upper limb, and improve position for hygiene and/or outward appearance.

- Although there is little published evidence to support the use of hand or elbow splints in children with neurologic conditions, splints continue to be widely prescribed for all MACS levels to improve upper limb skills and functional activities (Shierk, Lake, & Haas, 2016).
- There is evidence to support the use of thumb opponens splints to improve hand function in children with unilateral CP and bracing of the wrist and thumb to improve spontaneous use of the affected upper limb in bimanual activities (Ten Berge et al., 2012).

(II) Casting

Casting is the application of individually moulded casts made of either plaster or synthetic casting materials with the **aim of increasing passive range of movement of tight or contracted muscles,** by applying a prolonged low load stretch across a joint or joints to lengthen affected muscles.

Serial casting involves applying a number of casts in succession to gradually increase passive range of movement.

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 particularly as children undergo a growth spurt. Casting is unlikely to be an effective intervention for long term contractures where bony changes might be limiting ROM.

Rationale for Use of Serial Casting

Biomechanically, casting imposes a continuous stretch on a muscle/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 5-7 days as there is evidence to support the loss of sarcomeres if a joint is left immobilised in a cast for too long.

When casting is being considered the impact of the current level of soft tissue contracture on function must be determined. For example, a 10° knee flexion contracture in a child at GMFCS Level III who walks with a Kaye walker is problematic as the contracture will impact on their gait, whereas in a child at GMFCS Level V this degree of contracture will not impact on their seating and positioning. Similarly a 20° flexion contracture at the elbow is not likely to impact functionally on a child's day to day activities such as dressing or even reaching but may impact on their ability to participate in sport or on overall cosmesis when walking, as arm swing may not look natural.

Who

Serial casting for the upper limb and lower limb should only be applied by therapists 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.

How

Casting may be considered following assessment and the determination that muscle contracture is limiting the achievement of the identified goals. Casting material required includes appropriate stockinette, under-padding, casting material (plaster of paris or synthetic). The advantages of synthetic materials include ease of application, speed of drying (in comparison to plaster of paris) and decreased overall weight on the limb. Disadvantages of synthetic materials include the need to remove rigid casting material with a cast saw (this prevents the ability of the family to remove the cast at home if required), some materials contain fibreglass which require personal protective equipment (eye glasses and nose/mouth masks) to decrease risk of airborne particles being ingested.

The limb to be cast is held at the desired position, usually at the tolerable end point of passive range, and in the optimal biomechanical alignment. The ankle should be cast in subtalar neutral. When casting the wrist, consider the alignment of the fingers and thumb.

The under-padding is applied followed by the casting material. Care should be given to ensure that the joint does not move during and after application. Ensure that circulation has not been compromised.

Each cast is left on for between 3-5 days before it is removed. Reassessment of the range of movement is carried out to determine the effectiveness of the casting intervention.

3.5.2. Muscle Tone Interventions

Please refer to the General Guidelines for specific interventions to treat motor disorders and muscle tone. These may include, but are not limited to: 1) botulinum toxin A (BoNT-A) injections, 2) medications, 3) intrathecal baclofen (ITB), and surgical procedures such at Selective Dorsal Rhizotomy (SDR).

There is a high level of evidence to support the use of BoNT-A as an adjunct to managing the upper limb in children with spastic CP. BoNT-A should not be used in isolation but should be accompanied by planned occupational therapy (Hoare, et al., 2010).

3.5.3. Pain Interventions

Please refer to the General Guidelines for specific interventions to treat pain.
Pain Management and the treatment of pain may vary depending on the cause of pain.

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

- For musculoskeletal pain, regular active movement and exercise is the key to strength and will often reduce pain.

3.5.4. Oral Motor and Feeding Interventions

Eating and feeding occur within the social environment and often include family members and other caregivers in the process. Occupational therapists addressing feeding, eating, and swallowing issues must collaborate and work closely with family members and caregivers who take part in mealtimes. In addition, therapists must consider psychosocial, cultural, and environmental factors which may strongly influence feeding behaviors.

- Feeding – the term used to describe the process of setting up, arranging, and bringing food (or liquids) from the plate or cup to the mouth. Also considered self-feeding.
- Eating – the term defined as the ability to keep and manipulate food or fluid in the mouth and swallow it.
- Swallowing – involves a complex act in which food, fluid, medication, or saliva is moved from the mouth through the pharynx and oesophagus into the stomach.

Occupational therapy interventions for the comprehensive management of oral motor, eating, feeding, and swallowing disorders includes:

1) Training in use of adaptive feeding equipment (e.g. modified eating utensils)
2) Intervention for physical problems which restrict a child from bringing food or liquid to the mouth (e.g. children with upper limb contractures may have limited ability self-feed or bring food to mouth).
3) Intervention for oral motor and mechanical issues which impact the child's ability to chew and manage food or liquid during the oral phase of eating. Children with CP who have abnormal oral-facial muscle tone may require special oral motor exercises for hypo or hypertonicity of oral-facial muscles.
4) Intervention for sensory issues which impact desire to eat (e.g. oral sensory defensiveness).
5) Behaviorally based feeding disorders (e.g. refusal to eat).
6) Positioning problems which may impact feeding, eating, and swallowing. For example, poor head control and inability to hold head at midline can impact functional and safe swallowing.

3.5.5. Acupuncture

Acupuncture involves the insertion of fine needles into the skin to stimulate certain parts of the body.

Evidence for acupuncture:

- A systematic review by Zhang et al (2010) found that the use of acupuncture with or without additional interventions such as conventional therapy may benefit children with CP but lacks sufficient evidence. A systematic review by Yang et al. (2015) reviewed the efficacy and safety of acupuncture for children and found:

- Acupuncture may be a promising intervention for cerebral palsy to improve ADLs scores when used as adjunct with conventional treatment (e.g. rehabilitation with occupational and physical therapy, medications, surgical interventions).
- Acupuncture may be a promising intervention for nocturnal enuresis, tic disorders, amblyopia, and pain reduction in neonates receiving a heel prick during blood draws.
- The efficacy of acupuncture for hypoxic–ischaemic encephalopathy, attention deficit hyperactivity disorder, mumps, and myopia remains unclear.
- The efficacy of acupuncture for asthma and nausea/vomiting is controversial.

Current evidence does not support the use of acupuncture for paediatric epilepsy

Recommendation -

> Clear treatment goals should be identified before undertaking acupuncture and all treatment should be evaluated to determine if it has been effective.

Activity and Participation Interventions

3.5.6. Goal Directed Therapy / Task-Oriented Therapy

Goal-directed and task-oriented therapy focuses on everyday skills in the child's natural environment with the goal of improving performance and increasing independence with daily activities.

- The therapist, child, and family collaborate to set goals with the therapist providing strategies for task specific practice to utilize a motor learning approach
- This intervention has been used for children with CP of all MACS levels and is effective for improvement of basic motor abilities, increased independence with selfcare, and goal attainment.
- Overall, goal-directed therapy is effective in improving hand function and self-care skills. It is frequently combined with other intervention strategies including CIMT, bimanual training, and home programs.
- It is important to understand the developmental timeline when specific gross-motor, fine-motor, and self-care skills are typically mastered to identify age appropriate goals for patients.

3.5.7. Constraint Induced Movement Therapy (CIMT)

CIMT is a rehabilitation strategy to increase functional use of the weaker or affect upper limb through repetitive and adaptive task practice while the strong or non-affected upper limb is restrained (Ramey et al, 2013). It is primarily used with children with unilateral motor deficits, such as children with hemiplegic CP.

There are five essential elements for paediatric CIMT (Pidcock, 2017; Ramey et al, 2013)

- Constraint of the non-affected or stronger upper limb

- High dosage of therapy (30 hours or greater)
- Use of repetitive and adaptive task practice (massed practice)
- Sessions take place in the child's natural environment if possible (e.g. home/school) although clinic/hospital models have been found to be effective also
- Transition or discharge program to start when CIMT is completed

Adaptive task practice, or shaping, involves breaking a task into several smaller, more manageable components to improve the child's overall efficiency in performing the task. Massed practice, or high-density repetition of motor movements, helps integrate new motor skills into everyday behaviours. CIMT is effective for development of unimanual actions brought about by this type of implicit motor learning. Therapy activities target motor patterns and functional skills in the weaker, affected upper limb. These movement patterns can include increased reach to objects, improved grasp and variation in grasp, increased grip strength, and improved and timely release of objects. CIMT can be provided in individual or in group therapy formats.

Evidence for the use of CIMT:
There are over 100 published studies on paediatric CIMT and 27 systematic reviews which reveal a modest to large effects of CIMT on improving efficiency and quality of movement of the impaired arm/hand compared with usual/customary care (Pidcock, 2017; Sakzewski, et al., 2015).

3.5.8. Bimanual Therapy

Bimanual therapy retains the intensive structure and task practice at CIMT, but the focus is improving the ability to perform bimanual activities. While CIMT appears to be an effective treatment strategy for many children with CP, CIMT may not necessarily be effective for children who have mild or severely affected hand function (MACS Level I or V) (Hoare & Greaves, 2017).

Bimanual therapy uses carefully planned, repeated practice of two-handed, or bimanual, games and activities to improve a child's ability to use their hands together in daily activities. It involves intensive, massed practice, similar to the dosage required for CIMT (> 30 hours) and can be provided during individual or group therapy formats.

Using bimanual therapy, object properties can be adapted to trigger goal-related perceptual and cognitive processes required for children to learn to recognise when two hands are required for task completion (Gordon 2011; Gordon & Magill, 2012).

- The therapist encourages the child to use both hands during bimanual tasks and discourages unimanual skills using only the stronger non-affected upper limb.
- Therapy activities target bimanual movements such as those required to play with toys with two hands, transfer items between hands, remove or put on clothing, or carry or move toys.

3.5.9. Activities of Daily Living (ADLs)

Motor learning is the primary approach for learning new motor skills. Occupational therapists should use motor learning strategies when training children to complete basic activities of daily living (ADLS=s) which involve self-care skills such as 1) dressing, 2) self-feeding, 3) oral hygiene, 4) bathing, and 5) toileting (including management of clothing) and 6) grooming. The role of the occupational therapist is to facilitate functional independence in all ADLs and support participation in basic self-care that are meaningful to the child with CP and the family.

When providing therapy for children with CP, it is important to consider the typical developmental timeline in which children complete basic self-care tasks and to set age appropriate goals to maximise the developmental windows of time when children are motivated to become independent in basic self-care.

See the General Guidelines for the theory and evidence for current best-practice for maximising functional abilities and performance of activities of daily living using child-active approaches (Novak, 2014). These approaches promote active practice of real-life tasks (preferably in real-life environments). Child-active approaches are consistent with current neuroscience evidence about harnessing neuroplasticity.

- **Task or activity analysis** is an important part of using a motor learning approach to training patients to learn new motor skills.
- **Therapists will also evaluate functional cognition during the child's completion of ADLs.** Functional cognition refers to the thinking and processing skills that are used to accomplish everyday activities in clinical, home, and community environments.
- A therapist performs a task analysis to break complex tasks into a sequence of smaller steps or actions (ie. steps required to put on a shirt or pair of pants). The therapist then teaches or trains the patient to complete the smaller steps to reach the goal of completing the full task independently.
    - Task/activity analysis addresses the typical demands of an activity, the range of skills involved in its performance, and the various cultural meanings that might be ascribed to it.
    - Occupation-based activity analysis places the person in the foreground. It considers the person's interests, goals, abilities, and contexts, as well as the demands of the activity itself.
    - These considerations shape the practitioner's efforts to help the person reach his/her goals through carefully designed evaluation and intervention.

3.5.10. Instrumental Activities of Daily Living (IDALs)

IADLs are defined as activities that are oriented toward interaction with the environment and that are the sequence and steps are to complete these tasks are more complex than basic activities of daily living The activity demands of IADLs may require more effort, energy, cognitive, and perceptual demands than basic ADLs.

Examples of IADLS include:

- Home management
- Meal preparation
- Shopping
- Financial management
- Community mobility
- Communication devise use
- Care of others (ie. role of mother/father and care of infant/child)
- Care of pets
- Health management
- Safety and emergency responses

Occupational therapists should evaluate the ability of older children and young adults with CP to complete IADLs. Therapists will also evaluate functional cognition during the child's completion of IADLs. Functional cognition refers to the thinking and processing skills that are used to accomplish everyday activities in clinical, home, and community environments.

The role of the occupational therapist is to facilitate functional independence in all IADLs and support participation in life roles that are meaningful to the child with CP and the family. In addition, the therapist should determine the role that context and environment play in performance of IADLs. Some older children may be more receptive to the assistance of others (e.g. family members) to assist with daily activities, therefore, may not be as receptive to learning new techniques to advance independence.

3.5.11. Home Programs

Occupational therapists routinely use home programs for children with CP of all MACS levels as an adjunct to concurrent ongoing outpatient therapy, as well as, when outpatient therapy is not available, feasible or affordable (Shierk, Lake, & Haas, 2016).

Home programs are individualized multimodal interventions that target body structure, activities, and participation problems identified collaboratively by the child, parents and the occupational therapist.

- Home programs can be clinically effective to improve upper limb function and goal attainment if implemented approximate 20 times per month for an average of approximately 20 minutes per session. This equates to roughly an hour a week of home program intervention (Novak, Cusick, & Lannin, 2009; Novak, 2010).
- When multiple healthcare providers are providing home programs, it is important to coordinate activities to reduce workload for family and improve overall efficiency of care.
- Before developing home programs, it is important to understand the child's and parent's goals to target the most important activities for the program.
- It is important to continuously monitor and update home programs to assure that the current needs of the child and family are met.

3.5.12. Context-Focused Therapy

Context includes the cultural, personal, temporal, virtual, physical, and social influences which impact an individual's participation in daily activities. Context-focused therapy shares concepts described in other 'functional', 'task-oriented', or 'activity-focused' interventions, such as involvement of parents, identification of functional goals, and a 'top-down' activity-based approach to assessment and intervention.

A unique aspect of the context-focused therapy is that therapists are trained to change the characteristics of the task and/or environment rather than focus on remediation of the child's abilities (Darrah et al., 2011).

- The assumption of this approach is that changes to the task and/or environment will enable the child to perform an activity that they were unable to do previously.
- Tenets of family-centred theory are also integrated into the development of the context-focused therapy protocol, particularly the concept of a collaborative partnership between families and health care providers (Darrah et al., 2011).
- The parents participate in the identification therapy goals and of intervention strategies for the child.
- Context-focused therapy starts with goal identification and specific assessment of how the child's performance of the goal-related task. Therapists used a strength-based approach, first identifying factors within the task and environment that supported a child's attempt to complete the identified goal before identifying task and environmental constraints.
- After identifying the important task and environment factors amenable to change, the therapist and parent agreed on the intervention strategies.
- In the context-focused therapy approach, therapists are trained to consider all movement solutions, even those traditionally thought to represent 'abnormal' movement patterns (e.g. W-sitting, 'bunny-hopping' to crawl), and to build on the movement solution that the child was trying to use.
- Therapists ask parents to show how they were currently managing the task and to consider this as a 'starting point' for adaptations. Therapists are cautioned against assuming a hierarchy of 'best solutions', such as if a child should move by crawling rather than commando creeping or that a mature pencil grasp was preferred over an immature grasp.

3.5.13. Social Participation

The World Health Organization defines social participation for the lifespan as "the nature and extent of an individual's involvement in life situations" (WHO, 2001). Methods of social participation interventions can be occupation-based and/or use purposeful activities that may be preparatory, education, and or consultative in nature.

- Occupational therapists and physiotherapists must first identify the individual's goals to maximise social participation in all context and environments
- Assessment involves gathering data on the child's skills and patterns of performance that are required for social participation
- Occupational therapists must also assess the individual's habits, routines, rituals, and roles used in the process of engaging in social environments
- Social activities are analysed to understand the specific demands of the activity and the match to the individual's factors and performance abilities
- Social participation should be considered within the family, with peers/friends, and, later in life, during dating or a relationship with a significant other
- Interventions for social participation can take place in home, school, or community settings. Interventions may include:
    - Remediation of performance skills to increase social participation
    - Compensation/adaptation of an activity to increase social participation (e.g. the use of adaptive sporting equipment to allow child to participate in youth recreation leagues)
    - Environmental adaptation to increase social participation (e.g. providing ramp access to a school or community building for child who uses a wheelchair for mobility)
    - Maintenance of successful performance through parent and child education
    - A combination of intervention approaches

3.5.14. Hydrotherapy/Aquatic Therapy

Hydrotherapy refers to a wide range of activities, of which most pertain to therapeutic and exercise activities carried out in heated pools (aquatic physiotherapy services, water exercise services, aquatic fitness activities and swimming activities).

Aquatic therapy refers to treatments and exercises performed in water for relaxation, fitness, physical rehabilitation, and other therapeutic benefit.

Benefits of aquatic therapy/hydrotherapy include:

- Allows independence of movement not possible on land
- Decreases weight bearing, enabling easier walking and general mobility
- Reduces muscle spasm allowing relaxation
- Decreases swelling, improves circulation and reduces pain
- Improves water confidence, water skill and basic swimming skills
- Encourages fitness

Hydrotherapy involves working, in a heated pool, with an exercise physiologist or physiotherapist on exercises tailored to individual's unique needs. Along with improving strength and mobility, hydrotherapy is also frequently used as part of rehabilitation programs following surgery. While a person with CP is recovering from their surgery, hydrotherapy can help to gradually increase movement and their ability to put weight through their feet.

Specialist hydrotherapy pools are heated to 32-34 degrees Celsius, as warm water can help increase a person's circulation, reduce their muscle spasms and relieve pain.

The unique properties of water mean that hydrotherapy has the potential to benefit people with CP right across the severity spectrum. Exercising in water may provide greater physical activity opportunities for people with more significant movement limitations when compared with land-based activities.

For some people, the special flotation devices used in hydrotherapy may be essential for safety and independence in the pool. For others, exercise equipment is used instead to provide additional support or resistance in their program.

Precautions and contraindications for hydrotherapy:

Precautions	Contraindications
Epilepsy - 1:1 client/carer ratio & management plan	Open/infected wounds/skin conditions – cover wounds with waterproof dressing
PEG tubes and other external medical devices	All bacterial infections and infectious diseases
Tracheotomy: use floatation devices to maintain safe airway	Increase temperature
High blood pressure	Faecal Incontinence (some clients can be toilet timed prior to pool entry which is a management strategy to decrease risk)
Haemophilia	Recent diarrhoea - the person should not swim until at least a week after symptoms have ceased
Hepatitis B, C and HIV/AIDS - monitor for wounds / airborne infections	High risk obstetric patients (if any bleeding, or complicated pregnancy)
Severe Peripheral Vascular Disease	Active TB, flu and other airborne viral infections
Ear infections, grommets – use ear plugs/ headbands. If repeated infections consider excluding from pool	Unstable medical conditions, e.g. recent CVA, cardiac or kidney failure
Cytomegalovirus (CMV) - usual infection control procedures apply e.g. hand washing, cleaning change tables etc.	Tinea, ringworms

Altered sensation - wear protective clothing/ shoes to protect against hitting/rubbing the pool surface	Perforated eardrum
	Menstruating Hep B, C and HIV/AIDS
	Unprotected menstruation
	Alcohol/drug consumption
	Recent deep x-ray treatment
	Chemotherapy - medical clearance required. Possibly wait 24-48 hours after dose.

3.5.15. Emerging Therapies – Robotics and Virtual Reality

The field of paediatric neurorehabilitation has rapidly evolved with the introduction of robotics, computer-assisted systems, and virtual reality which may complement conventional physiotherapeutics or occupational therapies. These systems appear promising, especially the exciting and challenging virtual reality scenarios which can increase motivation to train intensely in a playful therapeutic environment. Despite promising experiences and a large acceptance by the patients and parents, so far, few robotic, computer-assisted systems, and virtual reality programs have been rigorously evaluated in children with CP and well-designed randomised controlled studies in this field are lacking. It is unclear which systems are effective for specific types of CP and the best application for this technology (e.g. duration, frequency, and intensity) to generate the best results (Meyer-Heim & van Hedel, 2013; Peri et al., 2016).

Prescribing Adaptive and Assistive Technology (AAT)

3.5.16. Adaptive and Assistive Equipment

Adaptive and assistive technology is a widely used intervention for people with cerebral palsy and other disabilities (Novak et al, 2012). Assistive technology is any "item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (US Govt, 1988). Assistive technology is routinely prescribed to support individuals to achieve their movement, communication and participation goals as well as to reduce caregiver burden.

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

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

- Wheelchairs and strollers
- Walking aids
- Standing frames
- Beds and mattresses
- Pressure care
- Adaptive mealtime equipment (cutlery,

- Splints and orthoses (upper limb and lower limb)
- Bath/shower aids
- Positioning equipment including seating systems, chairs, side lyers and bed positioning
- Toileting aids
- bowels, plates, cups etc)
- Transfer aids including hoists
- Ramps
- Low tech communication aids
- High tech communication aids
- Accessible toys

Sources for adaptive and assistive technology include:

- Hospital workshops
- Private health-related workshops
- Local commercial workshops (wood work and iron work)
- Adaptive and assistive technology supply companies
- NGOs
- Adaptations made by families

Best practice prescription of adaptive and assistive technology involves:

- A comprehensive assessment that considers all levels of the ICF
- Trial of identified options (wherever possible)
- Intervention strategies to support implementation of device(s) including skill development and parent/carer education
- Follow up and review of adaptive and assistive technology to evaluate impact of the device(s) on goal achievement and to identify challenges with use of the device(s)

(I) Assessment

Having a clear understanding of each individual's unique needs is essential when exploring, trialling and prescribing AAT. It is therefore necessary to ensure a thorough assessment has been completed to provide information about:

- The individual's movement disorder (Body Structure and Function assessments)

Including: assessment of spasticity and dyskinesia (see 7.1).

- The individual's musculoskeletal status (Body Structure and Function assessments)

Including: assessment of range of motion, posture, leg length and pain (see 7.1).

- The individual's functional abilities and how the individual performs certain tasks and activities(Activity and Participation assessments)

Including: assessment of walking function, hand function, activities of daily living and transfers (see 7.2).

- The environment in which the individual performs the tasks and activities (Environmental assessments)

Including: assessment of the physical environment and individual/family/carer perceptions of AAT (see 7.3).

(II) Trial and prescription of AAT

Wherever possible, trial of the recommended device should be carried out before confirming the prescription. This is to ensure that the recommended device meets the individual child's needs and is suitable for their home/community environment.

Trial of certain types of AAT may not be possible, such as custom made orthoses.

(III) Follow-up of AAT prescription

Whenever AAT has been prescribed, every effort should be made to ensure that adequate follow-up is provided. Follow-up provides the opportunity to evaluate if the device continues to meet the child's/family's needs and understand any difficulties that might be experienced by the child/family with regards to using the device. Follow-up can be provided during face to face appointments, via phone or via email.

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

Recommendation -

> Local rehabilitation departments should identify strategies for increasing access to AAT and post-prescription follow up of AAT. The use of telerehabilitation may offer one strategy for increasing follow up.

3.6. Rehabilitation Needs Across Lifespan

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

Gait and Functional Decline

3.6.1. Adolescence

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

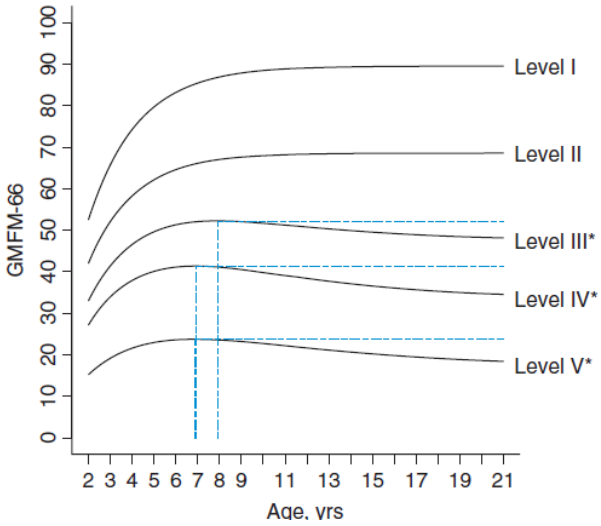


Figure 6. Gross motor curves for CP

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

Prognosis of walking function

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

3.6.2. Adulthood

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

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

In addition to gait decline, declines in the performance of activities of daily living, eating and drinking, and cognitive functioning are common in people with CP.

3.6.3. Transition

Transitioning between paediatric and adult rehabilitation services is an important aspect of the care of individuals with CP.

The following overarching principles should guide transition planning (NICE, 2017)

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

Recommendations – for transition planning

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

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

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

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

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

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

3.7. Parent, Family and Caregiver Support

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

- Families whose child is diagnosed with CP experience complex care responsibilities, financial hardship, limits to occupational attainments, relationship distress, grief and social

isolation. They may experience significant stress and anxiety about the future and a lack of understanding from the broader community.

- Parents of children with CP need to be proactive, skilled and conscious of their parenting choices to provide their children with optimal developmental support.
- Parenting a child with CP, and optimising their development, involves forward thinking, a commitment to long-term support, patience, compassion, behavioural management skills and effort above and beyond the parenting of typically developing children. Further, all of this requires a strong and loving emotional bond and parental psychological resilience.

Recommendations for ways to empower and support families:
(See also Parent Empowerment in the General Guideline)

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

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

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

Glossary

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

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

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

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

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

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

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

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

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

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

Cortical Visual Impairment (CVI) - defined as a bilateral loss of central visual function

(visual acuity) caused by neurological damage to the visual cortex and/or visual pathway structures. It most commonly results from hypoxic ischaemia causing periventricular leukomalacia
in the preterm infant.

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

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

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

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

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

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

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

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

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

Gross Motor Function Measure (GMFM) – a clinical tool designed to evaluate change in gross motor function in children with CP. There are two versions of the GMFM - the original 88-item measure (GMFM-88) and the more recent 66-item GMFM (GMFM-66). Items on the GMFM-88

span the spectrum from activities in lying and rolling up to walking, running and jumping skills. The GMFM-66 is comprised of a subset of the 88 items identified (through Rasch analysis) as contributing to the measure of gross motor function in children with CP.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Scoliosis - abnormal lateral curvature of the spine.

Spasticity - velocity-dependent resistance to stretch by the muscles. It is characterised by an excessive stiffness in the muscles when the child attempts to move or maintain a posture against gravity.

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

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Disclaimer

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