CDI Clinical Practice Guidance Document Cover Sheet

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National Clinical Programme for People with Disability (NCPPD)

Disability Regional Enhanced Services and Supports for Motor Management

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1.0 Generic Key Features of Disability Regional Enhanced Supports Services (DRESS)

Please refer to the National Clinical Programme for People with Disability's (NCPPD) document on "Generic Key Features of Disability Regional Enhanced Supports Services (DRESS)". This document describes the general pathways to DRESS's, the importance of a human rights-based approach, being person-centred, appropriate terminology, the layered and general framework for services, leadership, staffing, supervision, and management of DRESS's.

Readers are also referred to the National Disability Authority's (2022) "Advice Paper on Disability Language and Terminology" (https://nda.ie/publications/nda-advice-paper-on-disability-language-and-terminology)

1.1 Introduction

The purpose of this document is to support CHOs and Lead Agencies in implementing a consistent approach to the delivery and development of Motor Management services and supports for children with disabilities. The context being post reconfiguration of services under the Progressing Disability Services for Children and Young People (PDS) programme and aligning to this policy. A recent survey by the National Clinical Programme for People with Disability (NCPPD) highlights variation in approaches regionally and reported deficits in motor management competencies. This national guidance builds on the Guidance on Specialist Supports 2016 and will focus on enhanced regional Motor Management Services and Supports to support Primary Care Teams (PCTs) and Children's Disability Network Teams (CDNTs) in the management of Children with complex motor management presentations (Level 3 Services and Supports, ref. Figure 2).

The **Guidance on Specialist Supports 2016** document states the following:

In line with the National Policy on Access to Services for Children and Young People with Disability:

- Children with non-complex needs will receive their services at Primary Care services level
- Children with complex needs will receive their services at Children's Disability Network Team level
- It is recognised that specialised services and supports will be needed at times for a small number of children whose specific needs require a level of expertise which may not solely be met by these teams.

Specialised services and supports are required to provide;

- Training and consultation for Primary Care services and Children's Disability Network Teams (CDNTs) and/or
- Assessment and direct interventions for children where and when necessary to respond to the exceptional complexity or specialised nature of their needs.

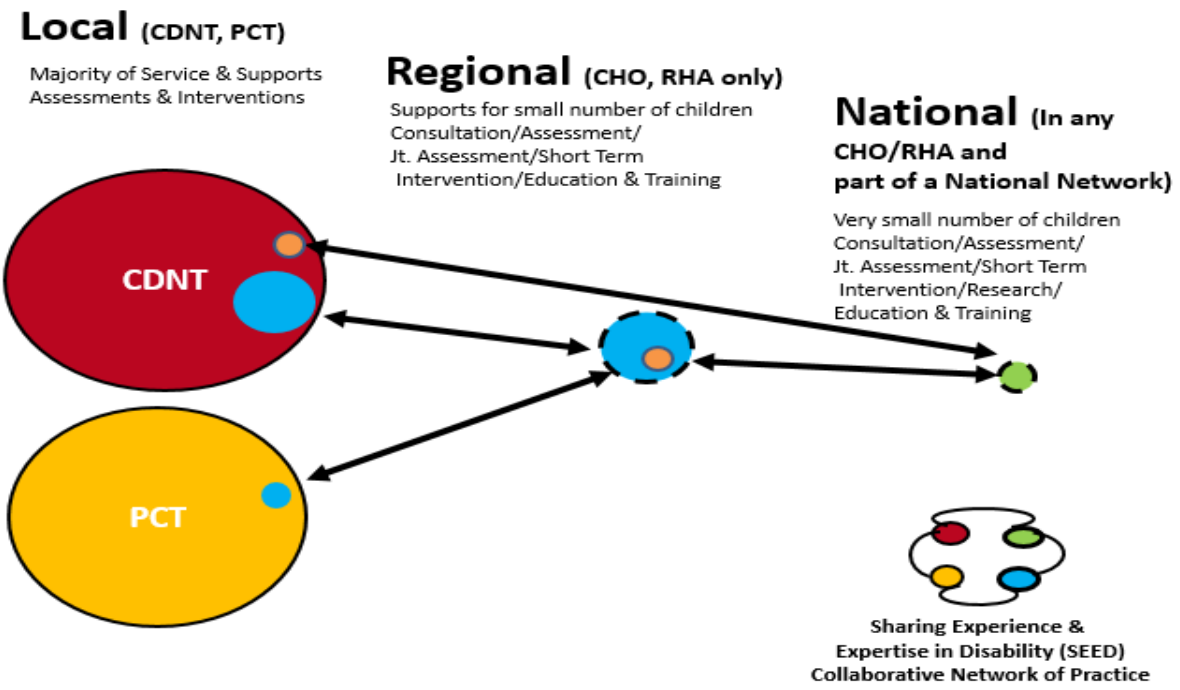
The Children's Disability Network Team or Primary Care services will remain the primary service provider for these children with a disability and their families.

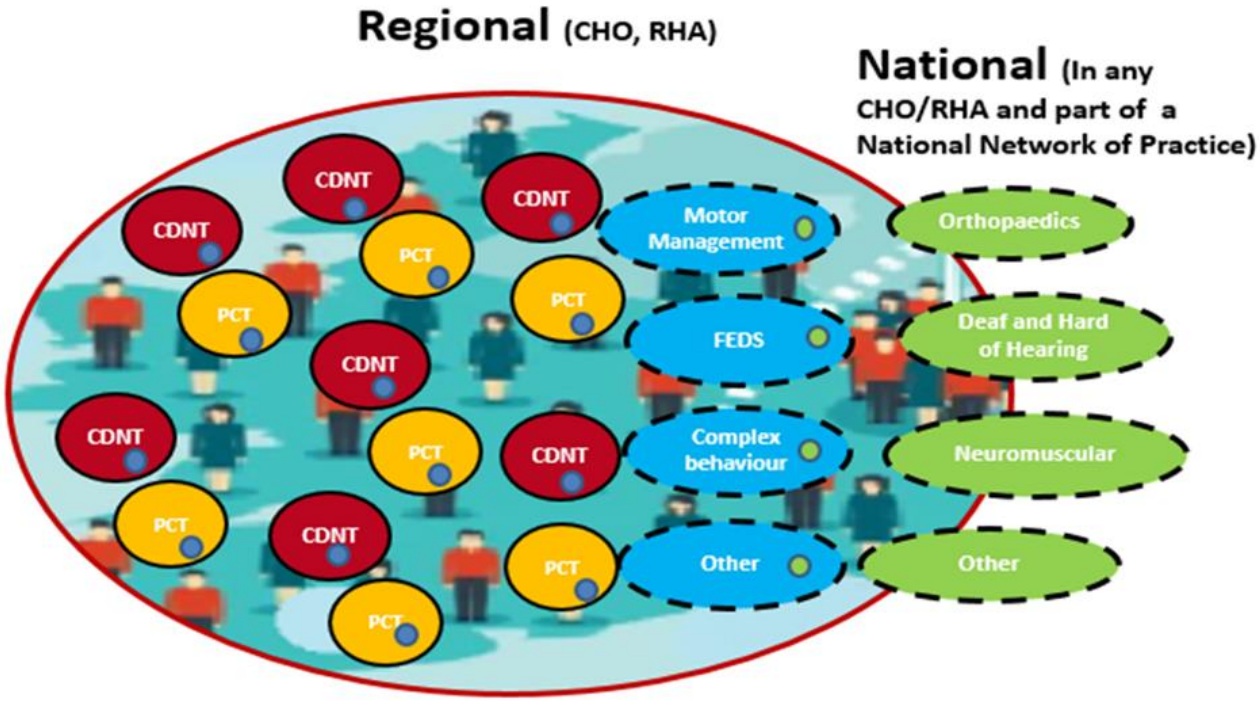
A more detailed description of the role of Specialised Services and Supports is available in the Guidance on Specialist Supports 2016 document.

2.0 Model for Specialised Services and Supports

Figure 1 outlines a conceptual model for Specialised Services and Supports for children with disabilities.

Figure 1. Model for Specialised Services & Supports





Local – In line with Slaintecare and PDS policy services for children with disabilities shall be available on a needs-basis as close as possible to where children and their families live. PCTs and CDNTs are established on a local geographical basis in line with these policies delivering the majority of services to children with disabilities as outlined above.

Regional – A number of children with greater complexity and rarer presentations will require access to specialised services and supports. By their nature in terms of; population demand, critical mass of throughput needed to maintain competencies and required technical expertise/infrastructure, some of these services will be organised on a regional level, e.g. Motor Management Support Services, Therapy-led clinics like upper limb clinics, complex casting, medical review. Many tertiary specialist services will also be available in some but not all regions, e.g. Orthopaedics, Spasticity Management.

National – Some tertiary specialised services will only be available nationally, e.g. Selective Dorsal Rhizotomy Service, while others will be available in more than one region but we envisage that these will be increasingly organised nationally as a network of practice around a specific functional area of expertise or practice, e.g. Motor Management, FEDs. We expect that these networks will be supported to collaborate and take a national perspective in terms of population cover, standards, education, service development and policy advice. It is expected that these networks will have academic and international linkages. The National Clinical Programme for People with Disabilities terms these networks of practice as SEED Networks (Sharing Experience and Expertise in Disability). SEEDs will pull together and serve all parts of the service delivery network (local, regional and national) and serve as a source of sustainable knowledge, education, research and focus on specific functional areas or cohorts.

3.0 Motor Management Context

Motor management is an important aspect of care of the child with physical and sensory disability/impairment. Clear service and support pathways and appropriately-skilled staff must be in place to deliver a quality, efficient service and to facilitate the cultivation of important therapist-child/family partnerships.

There are significant physical, sensory and psychological complications that can evolve as part of the natural course of a child/young person with disability. The clinician's role is to both optimize function throughout childhood and to prevent avoidable motor complications.

Every child with motor impairment must have regular comprehensive timely assessments and interventions in order to optimize participation and independence.

The following sections take a holistic view of total Motor Management Needs. **A significant quantity of the needs outlined below will be addressed at PCT and CDNT level.** In line with complexity and the competencies required for some service elements, a small cohort of children will require additional services and supports beyond local level as outlined in Figure 2 below.

3.1 Categories of need requiring Motor Management Support (all levels of service)

There is a wide spectrum of presentations ranging from straight forward presentations requiring basic competencies in the management of physical disability issues to complex presentations and issues requiring specialised tertiary level services.

Areas of need related to physical disability include:

- **Tone**
  - Low tone
  - High tone – Spasticity and Dystonia
  - Mixed one
  - Dyskinetic tone

- **Medical needs related to Motor deficits**
  - Pain Management
  - Spasticity Management

- **Posture**
  - Hip and Spine surveillance
  - Secondary impairments - Contracture risk – muscle length / joint position
  - Orthotics / Prosthetics / Casting / splinting / bracing

- **Function and Activity (24 Hr Postural Management)**
  - Positioning and equipment to support function and access in all environments
    - Lying / Sitting / Standing / Mobility e.g. wheeled mobility/ trike / walkers
  - Gait atypical patterns and impact on function
    - Detailed gait analysis to support clinical decision making – 2d / Complex (3-d Gait Lab)
  - Upper limb functioning

- **Access needs in multiple environments to maximise participation and independence**
  - At home – housing accessibility needs, housing adaptations e.g. hoists, ramps, etc.
  - At school – school adaptations
  - In the community

3.2 Population Prevalence

It is estimated that approximately 3.5% of children will require access to Children's Disability Network Teams, although early indications post reconfiguration suggest that this may be higher and closer to 5 % with a variable range depending on population profile. The estimated prevalence of physical disability is 0.5% of the child population. This means that an estimated 14% of the children with complex needs attending a Children's Disability Network Team (approximately 3.5 % of the total child population) will have physical disability (Guidance on Specialist Services 2016).

3.3 List of services/interventions for motor management

The services and intervention types outlined in Table 1 below are not exhaustive but represent the broad service/intervention profile for those with physical disability and motor management needs.

Table 1: Services and Intervention Profile for Motor management

Physiotherapy and Occupational Therapy Programmes
Medical consultation relating to Motor Management Needs • Diagnosis – including early identification • Pain Management • Spasticity Management - Therapeutic interventions - Oral drugs Botulinum toxin type A - Intrathecal Baclofen - Selective Dorsal Rhizotomy
Orthopaedics • Hip and spine surveillance • Upper limb orthopaedic surgery • Lower limb orthopaedic surgery • Spine orthopaedic surgery
24 Hour Postural Management • Sitting • Standing • Lying - Night positioning • Mobility assistance and supports including powered mobility
Casting/Splinting/ Bracing • Lower limb • Upper limb • Spine
Orthotics / Prosthetics
Gait analysis
Assistive Technology
Assessment and Interventions specific to Brachial Plexus
Assessment and Interventions specific to Spina Bifida
Assessment and Interventions specific to Neuromuscular, rare and other conditions

3.4 Likely conditions that may present with motor management needs that may need to meet through a variety of access pathways including tertiary service providers

- High risk/ low birth weight pre term infant
- Cerebral palsy
- Physical difficulties with risks related to the acquisition of secondary impairments in person with complex physical health needs / multiple disabilities
- Hereditary spastic paraparesis
- Acquired brain injury
- Syndromic diagnosis (e.g. chromosomal) with risks related to the acquisition of secondary impairments
- Metabolic condition with risks related to the acquisition of secondary impairments
- Skeletal dysplasia
- Osteogenesis Imperfecta
- Congenital spinal condition
- Acquired spinal injury

- Spina Bifida
- Neuro-progressive condition / Neuro-muscular disorders
- Brachial plexus injury
- Amputee

3.5 Risk

Without judicious service provision risks with health and cost implications include:

- Diagnosis delay
- Early identification and intervention of high risk infant
- Fixed contractures needing Orthopaedic surgery
- Incorrect prescription of equipment / orthotics
- Timely provision of equipment / orthotics
- Hip dislocation
- Scoliosis
- Fractures
- Chronic pain
- Tissue viability issues
- Obesity
- Cardiovascular complications
- Mental ill-health of child
- Carer/family strain (physical/psychological)
- Inability to access education
- Inability to access home
- Inability to access community
- Retention and recruitment issues
- Access to services e.g. waitlisted for PCT / CDNT
- Some categories of need involve timely responsive input to meet presenting issues – for example Brachial Plexus injury, timely interventions after surgery, deterioration in function with neuromuscular condition, need for equipment/ housing adaptations.

4.0 Structure of Services/Levels of Service

Motor management services and supports shall be provided at most appropriate level of complexity, with responsive, connected services built around child and family need, to support and empower children and families to optimise their health and actively address and minimise their risk factors.

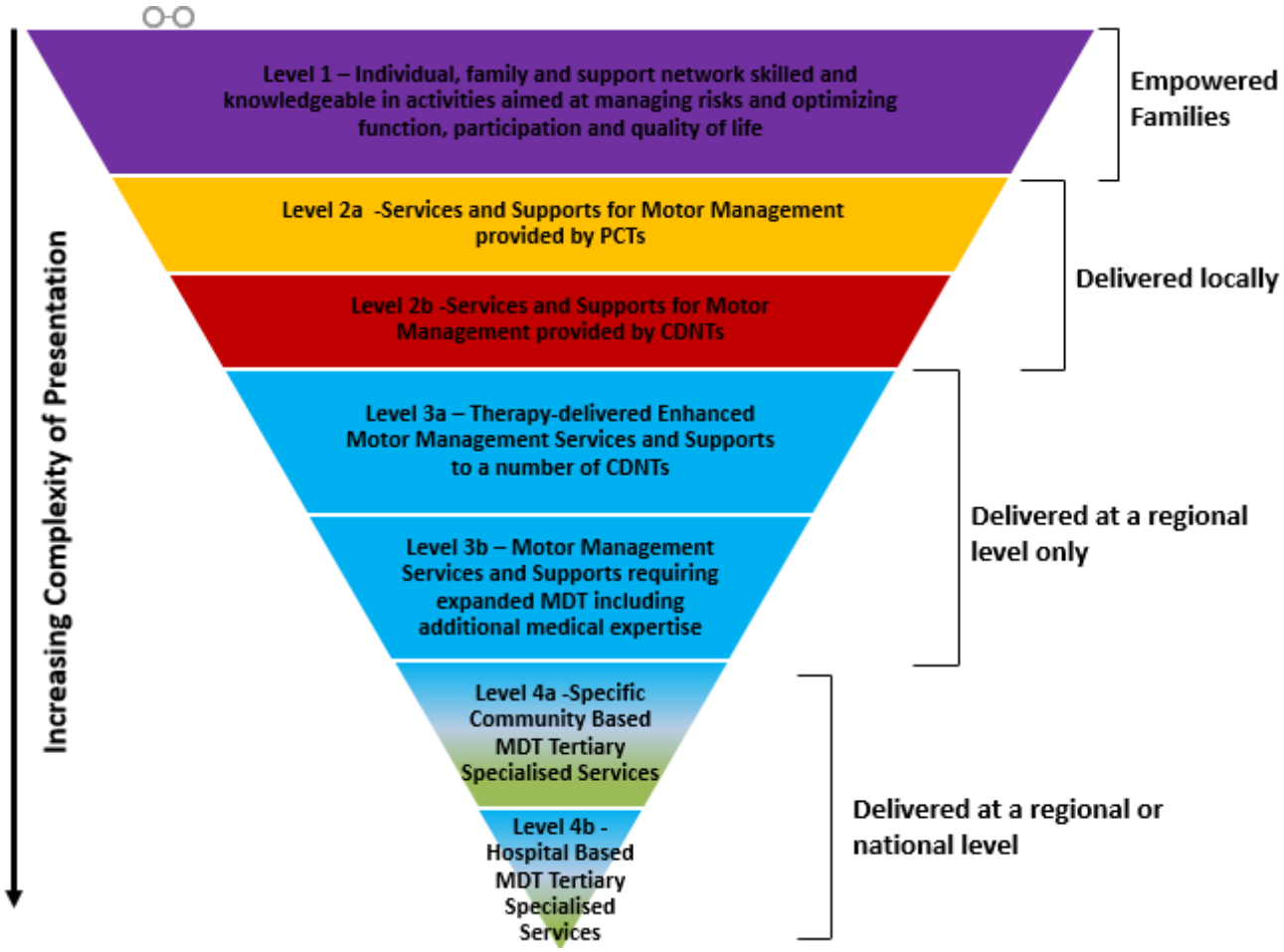
Figure 2 outlines a Framework for the delivery of Services and Supports to those with Physical Disability and Motor Management needs in line with increasing complexity of presentation.

4.1 Layered rather than Stepped Approach

Several existing models of service and extant literature recognise the value of a tiered approach to service provision. In some instances, this is described as “stepped-care”. However this can be misleading as it is sometimes understood that different levels – steps – can only be provided once lower steps have been tried. In fact, a layered model, where people may receive services and supports on different “steps” – e.g. a CDNT and tertiary specialised service at the same time with

teams working together on a coordinated shared care plan - is preferred and avoids the cessation of one “step” and waiting for another “step” to commence, which may also mean that people are put on waiting lists for the next step. This model allows for children to have the majority of services and supports delivered locally but importantly, when required, to have access to regional and tertiary services and supports from appropriate personnel working with the local teams to manage more complex issues.

Figure 2. Framework for the delivery of Services and Supports for Motor Management



Level 1 - Individual and family activities aimed at optimizing function, participation and quality of life

This level reflects the principles and policy of PDS in term of empowering families and children, in so far as possible, to develop skills and mechanisms which will allow them to manage and minimise the impact of impairments, societal and environmental barriers which contribute to the experience of disability. The focus here is to build self-efficacy and leverage family and personal strengths to optimise function and participation for children with disability, from childhood through adolescence and transitioning to life as an adult.

Levels 2a & 2b - Primary Care Teams and Children's Disability Network Teams

The first point of contact for the child and family will be the Children's Disability Network Team CDNT (if complex needs) or Primary Care Services (if non-complex needs) in accordance with the National Policy on Access to Services for Children & Young People with Disability & Developmental Delay.

The majority of the child and family's needs related to the child's physical disability (motor management) should be addressed at this level by the PCT or CDNT, in partnership with the family, at home or at local service and at their school, preschool etc. This is in the spirit of family centred practice where the CDNT works in partnership with the family and others to support the needs of the child in their own environment. These teams are responsible to set and implement goals which include motor management goals, and in the case of CDNTs within the model of Family Centred Practice and Interdisciplinary Team working.

The PCT and CDNT will require the competencies to address motor management needs in multiple environments (at home, school, or local service location). Typically these services and supports will include assessment and the delivery of therapy programmes and interventions (universal, targeted and specific individual) in multiple environments, posture and orthotics management, assessing for and organising assistive equipment across environments and based on functional needs, involvement in hip and spine surveillance, coordinating additional aspects of motor management and related service not provided by the local team as required, transition planning to adult services, engaging and working closely with specialised services as necessary around increased complexity.

Depending on presenting complexity and locally available competencies (which are envisaged to grow and develop in time post reconfiguration) a PCT or CDNT may need to engage with other levels of motor management service or support. This may range from a simple consultation to a joint assessment and care planning, to referral for a specialised component of service such as a spasticity management clinic or an orthopaedic clinic.

Referrals to and engagement with services and supports beyond the local teams shall always be conducted in the most streamlined manner possible for children and families through direct engagement with the appropriate level of service.

Level 3 – Enhanced Motor Management Services and Supports

CDNTs and PCTs, depending on complexity of presentation and competency within teams, may require access to specific Motor Management expertise in an area. This will range from therapy-delivered services and supports (Level 3a) to a more expanded structure requiring medical competencies, most commonly a Paediatrician (Level 3b).

Typical Level 3a services and supports will include:

- Motor management therapy-led assessment clinics
- Motor Management therapist-delivered consultation service and referral on to tertiary specialist services as required
- Targeted information and education on motor management, coordinated regionally and nationally linking with Level 4 Services and Supports and SEED network.
- Specific therapy-led clinics for short term interventions - Casting /Splinting /Orthotics/Upper Limb/Hand/Posture/ Seating/Therapy Recommendations
- Coordination and advice on Hip and Spinal Surveillance Pathways including referral for X-rays to Paediatricians or Orthopaedic Surgeons as relevant

- 2 D Gait Analysis

Level 3 Motor management therapy personnel will have additional expertise and experience to address complex motor management needs, to coordinate specific motor management clinics and to facilitate pathways for children accessing other Level 3 and Level 4 services regionally and nationally where required (See Competencies Section below).

If required by CDNTs or PCTs engagement with Level 3 motor management services and supports shall be for the appropriate level of complexity required and in as streamlined a fashion as required. This may range from;

- A simple phone call or virtual consultation being be the first choice of engagement, to;
- A scheduled joint assessment and care planning, to;
- Delivery of specific interventions with expertise, to;
- Referral to and preparation for attendance at a regional or national specialised service.

At all stages the primary duty of care will lie with the PCT or CDNT for ongoing management with **agreed individual service and intervention responsibilities clearly documented in an overall service and support plan.**

Level 3 motor management therapists will have the competencies needed to recognise the need for additional specific interventions.

Level 3b - Specialised Motor Management Services and Supports requiring expanded MDT including additional medical expertise

Level 3b requires an expanded team including motor management therapists (from 3a) and medical expertise, usually a Paediatrician with a special interest in Community Child Health and/or Special Interest in Neurodisability. (Note: Currently, access to these supports is variable in regions with some teams having access to dedicated expertise and working closely with Paediatric Consultants and other teams availing of primarily local hospital-based paediatricians with a mixture of community and acute commitments. The NCPPD is currently engaged with the National Clinical Programme for Paediatrics and Neonatology to review and design a more structured approach to these supports in the medium to longer term).

Typically, support at this level will involve MDT approach and specific clinics for assessment, diagnostics, coordination of aspects of motor care such as hip and spine surveillance and spasticity management, referral to other Level 3 and Level 4 specialised services and/or referral to general Paediatrics or other clinicians for non-motor management related issues.

Level 4

Level 4 covers a range of tertiary specialist motor management services and supports which involve multiple disciplines with a range of more advanced expertise, experience and technical capabilities in specific specialised areas. Many of these services can be delivered in community-based settings (Level 4a) outside of the acute hospital. There are however regional variations and some of these services continue to be delivered in a hospital environment in some regions.

Level 4a

Typical Level 4a tertiary specialised MDT services and supports delivered in community based settings include:

- Upper Limb Orthopaedic Clinics
- Lower Limb and Spine Orthopaedic Clinics
- Tone and spasticity management including Botulinum toxin, oral medication, Baclofen refills, SDR considerations
- Intrathecal Baclofen Clinics
- Selective Dorsal Rhizotomy Assessment and Suitability Clinics
- Neuromuscular Clinics (Currently Community and Hospital settings)
- Specific Rare Disease Clinics
- Hereditary Motor Sensory Neuropathy Clinics (HMSN)
- Brachial Plexus Injury Clinics
- 3-d Gait Analysis
- Video Vector clinics
- Specialised Seating/Power Mobility
- Complex Orthotics/Prosthetics
- Complex Assistive Technology

Level 4b

Some tertiary specialist motor management services must be hospital-based by their very nature, e.g. orthopaedic surgery. Others services may have components of service delivered across both acute and community, some in an integrated way, e.g. Baclofen dosing and refills. These services again involve a range of more advanced expertise, experience and technical capabilities and facilities in specific specialised areas. Typically these include:

- Orthopaedic and Spinal Surgery
- Neurosurgery including Selective Dorsal Rhizotomy Surgery
- Some Spina Bifida Clinics – Temple Street
- Some Neuromuscular Clinics – Tallaght Hospital
- Some Rare Condition Clinics e.g. Osteogenesis Imperfecta.
- Some Botulinum Injection Services
- Some Orthopaedic clinics
- NRH Acquired Spinal and Brain Injury Rehabilitation Services
- Radiology
- Pain Management (some aspects)

5.0 Level 3 Motor Management

5.1 *Competencies*

In relation to Level 3 specific motor management services and supports, competencies for Physiotherapists and Occupational Therapists are outlined in Appendix 1. Paediatric competencies are outlined in Appendix 2. Other professionals involved in the delivery of Motor Management Services and Supports are outlined in the 2016 document “Guidance on Specialist Supports”.

5.2 Pathways

It is acknowledged that the structures to deliver specialised motor management pathways may vary slightly in regions related to existing capacity and service arrangements. However, every child with motor management needs should have access to the motor management services and supports

outlined in Table 1 above and all future service developments shall be in accordance with the models outlined in this document.

To assist CHOs, sample working pathways from different regions are provided in Appendices 3, 4, 5 and 6.

As outlined in the 2016 Guidelines on Specialist Supports and above it is the responsibility of CHOs to ensure that pathways are in place for Motor Management Services and Supports. Where deficits exist, CHOs are expected to engage with relevant stakeholders in terms of pathways development and access.

5.3 Service Configuration and Governance

The NCPPD will engage with the overarching Specialised Services and Supports Task Group and relevant other stakeholders in relation to potential challenges around configuration, governance and management of specialised services and supports that have been raised and develop a common and strategic approach to implementation planning and service development.

Therapy capacity providing Level 3 enhanced Specialised Services and Supports to CDNTs and PCTs shall be structured in such a way to ensure service quality and sustainability. This entails dedicated WTE posts, delivered by therapists with competencies in motor management, who are supported to maintain and develop these competencies on an ongoing basis (including increased clinical specialist capacity).

The exact determination of the allocation and spread of Enhanced Motor Management structures for a particular cluster of network teams or region will depend on local mapping and profiling. This will require a pragmatic approach with factors such as geographical spread, service delivery logistics and population profile being relevant.

Operational management and clinical governance arrangements for these structures shall be clearly outlined.

6.0 Acknowledgements

In addition to the overarching Task Group and Motor Management Working Group for this work (Appendices 7 & 8) the National Clinical Programme for People with Disabilities (NCPPD) would like to acknowledge the many individuals who worked on and developed sample draft pathways in different CHO areas presented in the Appendices.

7.0 References

National Disability Authority's (2022) "Advice Paper on Disability Language and Terminology" (https://nda.ie/publications/nda-advice-paper-on-disability-language-and-terminology)

Guidance on Specialist Supports 2016 - (https://www.hse.ie/eng/services/list/4/disability/progressing-disability/guidance-on-specialist-reports.pdf)

National Policy on Access to health Services for Children with Disability or Developmental Delay 2019 (https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/national-policy-on-access-to-services-for-disabilities-and-developmental-delay.pdf)

8.0 Review

The NCPPD recommends a review of the implementation of the recommendations of this document within 2 years of formal approval.

Appendix 1 – Sample Job Descriptions/Competencies for PT and OT for Level 3 Motor Management Supports

Physiotherapist

Job Title and Grade	**Senior Physiotherapist, Motor Management Lead CHOX**
Location of Post	This post is based in ……. The post holder will have to travel to other sites from time to time in accordance with service needs.
Details of Service	**Service Overview** The purpose of this regional specialist service is to provide support to the Children's Disability Network Teams (CDNTs) and Primary Care Teams (PCTs) in terms of the motor and postural management of children with a range of conditions resulting in physical disability. Lack of access to expertise for these children can lead to the development of secondary impairments and deformities resulting in loss of function. The PCTs and CDNTs require specialist support in certain instances to fully address these children's needs. The team will consist of xx WTE PTs and xx WTE OTs across xx network areas and will work closely together in the delivery of a coordinated and holistic service. Support will be provided in the form of: **Direct Services:** • Consultation, direct assessment and short-term interventions such as casting and splinting which are required to support PCTs and CDNTs. • Joint assessment, care planning and working with CDNTs, PCTs, other agencies and specialist service providers in the provision of collaborative and coordinated care. • Differential diagnosis and second opinion assessments. • Providing advice regarding therapy provision for children with physical disabilities to CDNT and primary care physios • Screening for onward referral to regional and national specialist clinics **Indirect Services:** • Information resource to enhance knowledge and skills of members of CDNTs and PCTs. • Education and training for CDNTs and PCTs to support the achievement of required competencies.

	• Clinical audit and research to ensure the maintenance and support of best practice and evidence-based practice. • Pathology surveillance and monitoring of motor management service needs regionally. • Monitoring of demand and need for specialist skills regionally. • Contribution to planning of services for children and families regionally and nationally. Children with physical disabilities may need access to some or all of the following motor and postural management inputs: (depending on competence of the primary / network physio) • ***Specialist assessment and consultation –*** Including medical diagnostics. • ***Management of Posture –*** Including equipment advice, night positioning, parental education. • ***Management of Tone or Spasticity Management*** - Splinting and casting, Oral medications for use in spasticity reduction, Administration of Botulinum Toxin, Intrathecal Baclofen Pump programme, Selective Dorsal Rhizotomy programme, Orthopaedic clinic referral, Neuro-Muscular Clinic collaboration. • ***Casting*** • ***Upper Limb Management*** • ***Hip and spinal surveillance*** • ***Orthopaedics*** *- Including advice on pre- and post-operative programmes.* • ***Gait and Motion Analysis*** • ***Orthotics service*** • ***Specialised Seating/Assistive Technology*** • ***Clinics for children with rare conditions:*** e.g. Spina bifida, Osteogenesis imperfecta, Brachial plexus injury (Erb's palsy), Neuromuscular conditions The motor management service will serve as provider of aspects of these services (e.g. casting, splinting, equipment advice) and as an important link to other regional and national specialist service providers of the services outlined above. This will ensure coordinated and integrated care between local, regional and national services as defined by the agreed motor and postural management pathways for the xx region.
Reporting Relationship:	The post holder will report to the xxx

Key Working Relationships:	The post holder will: • Work with other members of the Motor Management/Postural Management Service. • Work closely with the Lead Agency management, CDNT managers, disability managers, Heads of therapy and primary care managers in the region to ensure coordinated and integrated service provision. • Liaise with and build good working relationships with therapists from relevant Children's Disability Network Teams (CDNTs), Primary Care teams (PCTs) and other specialist service teams involved in the care pathway. • Collaborate with other regional and National service providers of care.
Qualifications/Experience	**<u>Essential</u>** • Be employed as a senior physiotherapist • Minimum of 3 years' experience working in the area of paediatric (0-18 years) physical disability • Minimum of 3 years' experience working in the area of management of tone and postural management for children **<u>Desirable</u>** • Experience of delivering education and/or conducting research • Advanced CPD or postgraduate education in a relevant area (e.g. Gait course, Seating technology course, Postural management course, NDT course, Baby course, Ambulant CP course) • Experience in service development and practice standards development • Experience in coordinating clinics and leading and working at a consultative level in clinics alongside consultant and other lead therapists • Experience in managing databases such as hip surveillance, surgery, Botulinum Toxin, etc. and conducting audits
Professional Knowledge and Skill	• Demonstrate knowledge of typical and atypical development, and specifically the impact of a disability on a child's motor and functional development with implications for participation. • Be up to date with evidence-based practice in the area of management of tone and postural management • Evidence of continuous professional development

	• Knowledge of management of pain both acute and long term and appropriate pathway for same • Experience with lower limb casting for children with motor disorders • Application of ICF Model in the assessment process including upper and lower limb ROM, Strength, Dynamic Tone, Motor Function plus clinically reasoning implications of same on motor management to come up with a concise problem list and intervention plan that can be communicated effectively to family and primary treating therapist • Knowledge on best practice treatment guidelines/ pathways for specific conditions – i.e. appropriate frequency of therapy interventions along trajectory relevant to specific condition • Applied knowledge in the various treatment options available i.e. neurodevelopmental therapy, spasticity management – Botox, ITB, SDR, casting, orthotic prescription, orthopaedic interventions, aids and appliances, Lycra garments, taping • Applied knowledge in conducting and scoring GMFM assessments in combination with GMFCS classification for intervention planning • Trained and using CPIPS on a regular basis • Competent at identifying common gait abnormalities in neurodevelopmental disorders - in particular CP and following appropriate intervention pathways for each • Competent in assessment and prescribing for 24-hour postural management to include aids and appliances for the ambulant child including indicators for ongoing referral to more specialist clinics • Competent in spasticity management including pre and post botulinum toxin injections assessment and intervention as well as knowledge of appropriate adjuncts including Oral medication, ITB, SDR programmes • Competent in working with clients undergoing orthopaedic surgery including full process from: pre-operative assessments and planning, joint decision making regarding type of surgery and post-operative interventions • Competent in clinical reasoning for appropriate orthotic prescription in relation to the ambulant child with physical disability with complex presentation.
Duties and Responsibilities	**<u>Overall</u>** The therapist will provide a comprehensive physiotherapy input to support the work of the regional motor/postural management service as outlined above.

	<u>Other specific duties include:</u> • Ensure that professional standards are met and that a quality and equitable service is provided at all times across all service sites. • Keep abreast of current best practice and new clinical developments, by attending appropriate post graduate courses/conferences, reviewing published material and carrying out research or clinical audit in the area in order to maintain a high standard of service. • Be responsible for the education and supervision of professional and ancillary staff as required. • Participate in and organise continued professional development, including in-service training, attending and presenting at conference/ courses relevant to practice etc, as agreed by your professional line manager. • Assist in the development, and be responsible for the day-to-day running and evaluation of the service • Review and allocate resources within the designated area, in collaboration with your line manager and relevant other. • Promote quality by reviewing and evaluating the service regularly, identifying changing needs and opportunities to improve services, in collaboration with line manager and relevant others • Develop and implement service plans, quality initiatives, audits etc. and report on outcomes in collaboration with professional line manager • Collect and evaluate data about the service user group and demonstrate the achievement of the objectives of the service • Oversee the upkeep of accurate records in line with best clinical governance, organisational requirements and the Freedom of Information Act, and render reports and other information/ statistics as required • Represent the Service at meetings and conferences as appropriate • Promote good team working and a culture that values diversity within the Service and relevant teams • Participate in the management of stock and equipment • Engage in IT developments within the organisation and the Irish Health Service. ***These duties and responsibilities are a reflection of the predicted service requirements and may be subject to review and amendment by your line manager to meet the emerging needs***

	within the CHO X region. The post holder will be expected to contribute to the development of the post while in office.
Core Competencies for role	• Effective communication (oral and written) and interpersonal skills • Effective caseload management skills • Good time management skills • Ability to work in high pressure, fast paced environments • Ability to work independently with good problem-solving skills • Ability to provide high quality written reports in a timely manner and do follow up admin communicating with local therapist • Be ICT competent having experience in the use of MS Word, Excel and PowerPoint along with other desktop software • Understand and be able to implement risk assessment for casting and equipment provision, as well as non-provision of service • Able for and committed to working in partnership with children/families/other agencies and understanding important transition stages in life for children and families • Ability to develop and deliver training to parents, young adults and peers • Ability to support, supervise and mentor staff in relation to management of tone and/or postural management

Occupational Therapist

Job Title and Grade	**Senior Occupational Therapist, Motor Management Lead CHO X**
Location of Post	This post is currently based in……. The post holder will have to travel to other sites from time to time in accordance with service needs.
Details of Service	**Service Overview** The purpose of this regional specialist service is to provide support to the Children's Disability Network Teams (CDNTs) and Primary Care Teams (PCTs) in terms of the motor and postural management of children with a range of conditions resulting in physical disability. Lack of access to expertise for these children can lead to the development of secondary impairments and deformities resulting in loss of function. The PCTs and CDNTs require specialist support in certain instances to fully address these children's needs. The team will consist of X WTE OT and 2X WTE PT across X Networks

	and will work closely together in the delivery of a coordinated and holistic service. Support will be provided in the form of: **Direct Services:** • Consultation, direct assessment and short-term interventions such as casting and splinting which are required to support PCTs and CDNTs. • Joint assessment, care planning and working with CDNTs, PCTs, other agencies and specialist service providers in the provision of collaborative and coordinated care. • Differential diagnosis and second opinion assessments. • Providing advice regarding therapy provision for children with physical disabilities to CDNT and primary care physios • Screening for onward referral to regional and national specialist clinics **Indirect Services:** • Information resource to enhance knowledge and skills of members of CDNTs and PCTs. • Education and training for CDNTs and PCTs to support the achievement of required competencies. • Clinical audit and research to ensure the maintenance and support of best practice and evidence-based practice. • Pathology surveillance and monitoring of motor management service needs regionally. • Monitoring of demand and need for specialist skills regionally. • Contribution to planning of services for children and families regionally and nationally. Children with physical disabilities may need access to some or all of the following motor and postural management inputs: (depending on competence of the primary / CDNT OT) • ***Specialist assessment and consultation*** **–** Including medical diagnostics. • ***Management of Posture*** **–** Including equipment advice, night positioning, parental education. • ***Management of Tone or Spasticity Management*** - Splinting and casting, Oral medications for use in spasticity reduction, Administration of Botulinum Toxin, Intrathecal Baclofen Pump programme, Selective Dorsal Rhizotomy

	programme, Orthopaedic clinic referral, Neuro-Muscular Clinic collaboration. • ***Casting*** • ***Upper Limb Management*** • ***Hip and spinal surveillance*** • ***Orthopaedics*** *- Including advice on pre- and post-operative programmes.* • ***Gait and Motion Analysis*** • ***Orthotics service*** • ***Specialised Seating/Assistive Technology*** • ***Clinics for children with rare conditions:*** e.g. Spina bifida, Osteogenesis imperfecta, Brachial plexus injury (Erb's palsy), Neuromuscular conditions The motor management service will serve as provider of aspects of these services (e.g. casting, splinting, equipment advice) and as an important link to other regional and national specialist service providers of the services outlined above. This will ensure coordinated and integrated care between local, regional and national services as defined by the agreed motor and postural management pathways for the XX region.
Reporting Relationship:	The post holder will report to XXX
Key Working Relationships:	The post holder will: • Work with other members of the Motor Management/Postural Management Service. • Work closely with the Lead Agency management, CDNT managers, disability managers, Heads of therapy and primary care managers in the region to ensure coordinated and integrated service provision. • Liaise with and build good working relationships with therapists from relevant Children's Disability Network Teams (CDNTs), Primary Care teams (PCTs) and other specialist service teams involved in the care pathway. • Collaborate with other regional and National service providers of care.
Qualifications/Experience	**<u>Essential</u>** • Be employed as a senior occupational therapist • Minimum of 3 years experience working in the area of paediatric (0-18 years) physical disability • Minimum of 3 years' experience working in the area of management of tone and postural management for children

	• Experience in upper limb assessment and interventions • Experience in the manufacture and monitoring of splints and casts **Desirable** • Experience of delivering education and/or research in upper limb management and/or related areas in physical disability • Advanced CPD or postgraduate education in a relevant area (e.g. Seating technology course, Postural management course, Night time positioning course, Mini-Assisting Hand Assessment rater, Hand assessment for infants rater, NDT course, Management of upper limb course, taping, etc.) • Experience in assessment for and provision of specialised seating devices • Experience in service development and practice standards development • Experience in coordinating clinics and leading and working at a consultative level in clinics alongside consultant and other lead therapists • Experience in managing databases such as surgery/intervention database, etc. and conducting audits
Professional Knowledge and Skill	• Demonstrate knowledge of typical and atypical development, and specifically the impact of a disability on a child's motor and functional development with implications for participation. • Have up to date knowledge on children's disability conditions and relevant assessments and interventions • Be up to date with evidence-based practice in the area of management of tone and postural management • Be able to comprehensively assess all aspects of the child's occupational performance areas with particular reference to physical / motor aspects, demonstrate analysis, clinical reasoning, goal setting and treatment planning in a person centred holistic manner. • Evidence of continuous professional development • Experience in Functional upper limb assessment, interpretation of findings and goal setting • Proficient in implementing some or all of the following upper limb management modalities; bimanual therapy, constraint induced therapy, strength training programmes, kinesio taping • Knowledge of prescribing appropriate postural interventions for children with complex physical needs. • Demonstrate knowledge of appropriate functional tasks that child might have as goal such as use of controls for powered mobility including access options and ensure

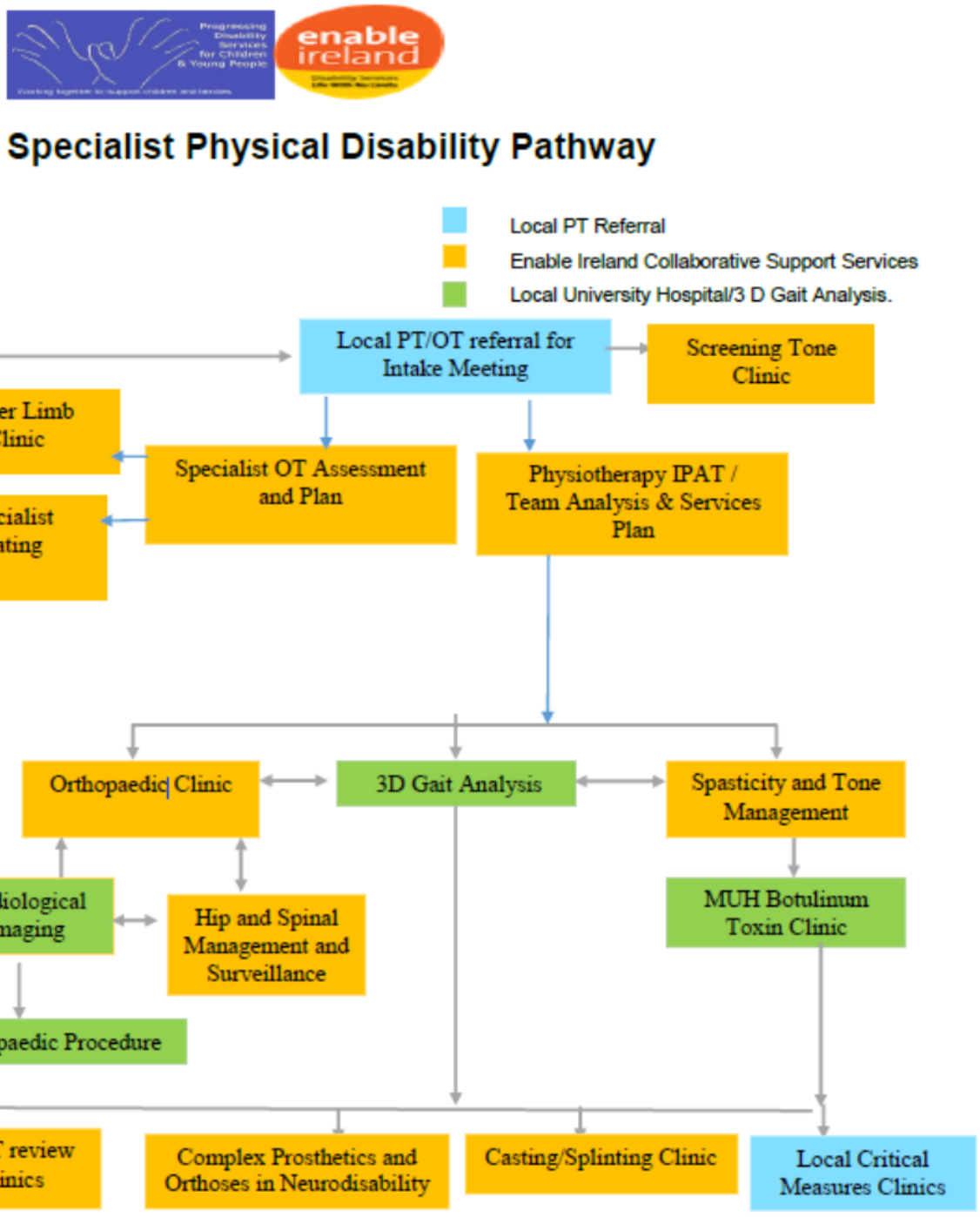
	these are considered in application of motor management interventions • Assess for and manufacture splints and casts and give correct guidance on their use, based on clinical need and individual child and family situation. • Assess for and recommend appropriate splints, second skin, Lycra garments and other off the shelf items which address tone and impact function. • Demonstrate knowledge of funding mechanisms and grants systems for provision of supportive equipment and making applications and recommendations.
Duties and Responsibilities	**<u>Overall</u>** The therapist will provide a comprehensive occupational therapy input to support the work of the regional motor/postural management service as outlined above. **<u>Other specific duties include:</u>** • Ensure that professional standards are met and that a quality and equitable service is provided at all times across all service sites. • Keep abreast of current best practice and new clinical developments, by attending appropriate post graduate courses/conferences, reviewing published material and carrying out research or clinical audit in the area in order to maintain a high standard of service. • Be responsible for the education and supervision of professional and ancillary staff as required. • Participate in and organise continued professional development, including in-service training, attending and presenting at conference/ courses relevant to practice etc, as agreed by your professional line manager. • Assist in the development of, and be responsible for the day-to-day running and evaluation of the service • Review and allocate resources within the designated area, in collaboration with your line manager and relevant other. • Promote quality by reviewing and evaluating the service regularly, identifying changing needs and opportunities to improve services, in collaboration with line manager and relevant others • Develop and implement service plans, quality initiatives, audits etc. and report on outcomes in collaboration with professional line manager • Collect and evaluate data about the service user group and demonstrate the achievement of the objectives of the service • Oversee the upkeep of accurate records in line with best clinical governance, organisational requirements and the

	Freedom of Information Act, and render reports and other information/ statistics as required • Represent the Service at meetings and conferences as appropriate • Promote good team working and a culture that values diversity within the Service and relevant teams • Participate in the management of stock and equipment • Engage in IT developments within the organisation and the Irish Health Service. ***These duties and responsibilities are a reflection of the predicted service requirements and may be subject to review and amendment by your line manager to meet the emerging needs within the xxx region. The post holder will be expected to contribute to the development of the post while in office.***
Core Competencies for role	• Effective communication (oral and written) and interpersonal skills • Effective caseload management skills • Good time management skills • Ability to work in high pressure, fast paced environments • Ability to work independently with good problem-solving skills • Be ICT competent having experience in the use of MS Word, Excel and PowerPoint along with other desktop software • Understanding of and ability to implement risk assessment for splinting, postural management and equipment prescription • Able for and committed to working in partnership with children/families/other agencies and understanding important transition stages in life for children and families • Ability to develop and deliver training to parents, young adults and peers • Ability to support, supervise and mentor staff in relation to management of tone and/or postural management

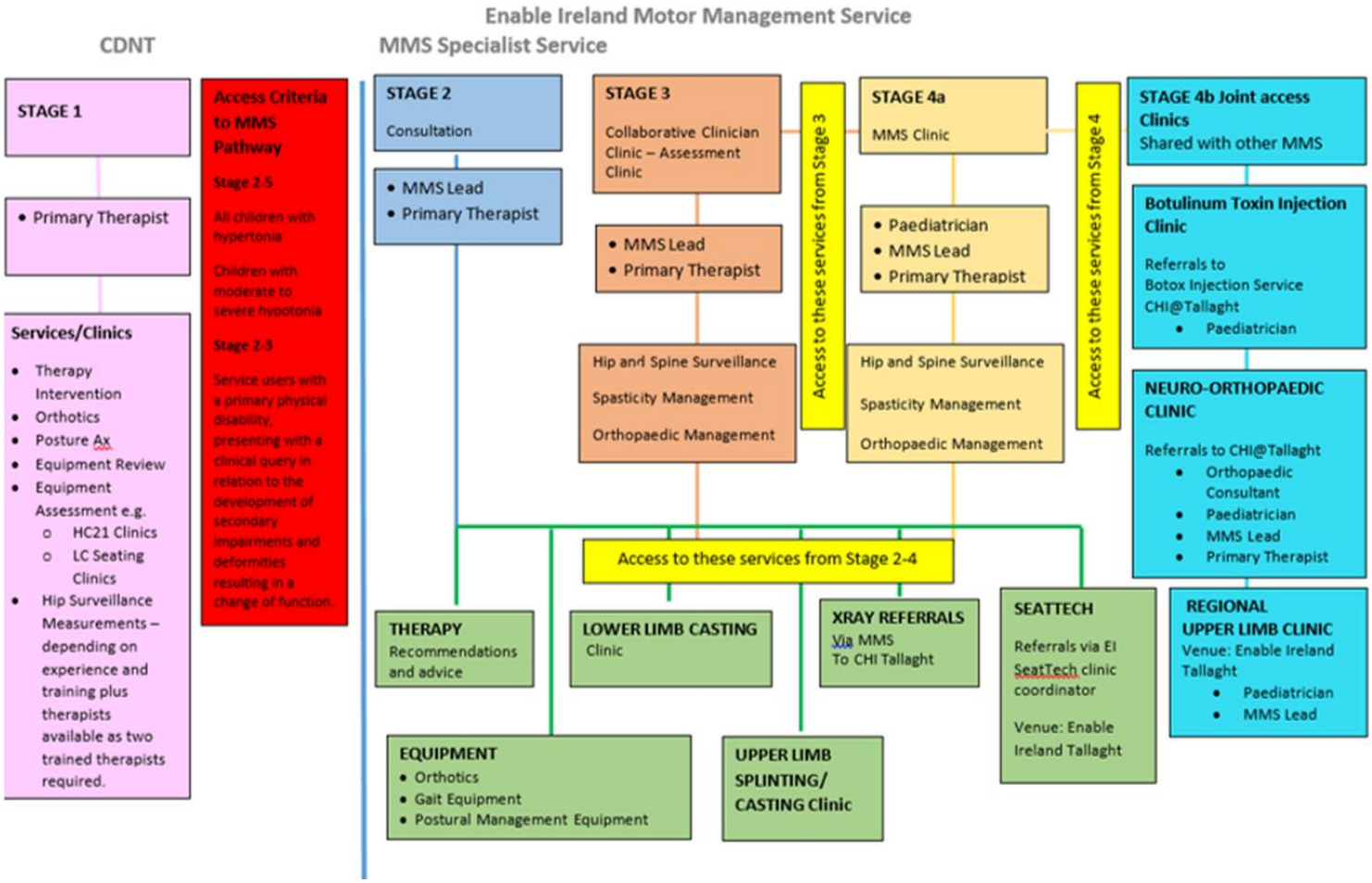
Appendix 2 – Specific Paediatric Competencies related to Motor Management Services

As a regional specialised service, this requires a paediatrician with special interest in neurodisability with particular interest in physical disability. This includes expertise in diagnostics where required, and experience in general and focal spasticity management including the administration of botulinum toxin, to ensure each regional service can complete treatment cycles independently of more distant services. The paediatrician should have knowledge of the general principles of orthopaedic surveillance and input, and have experience of specialist tone management interventions (ITB, SDR) - this is necessary to support the appropriate advice to parents in conjunction with therapists.

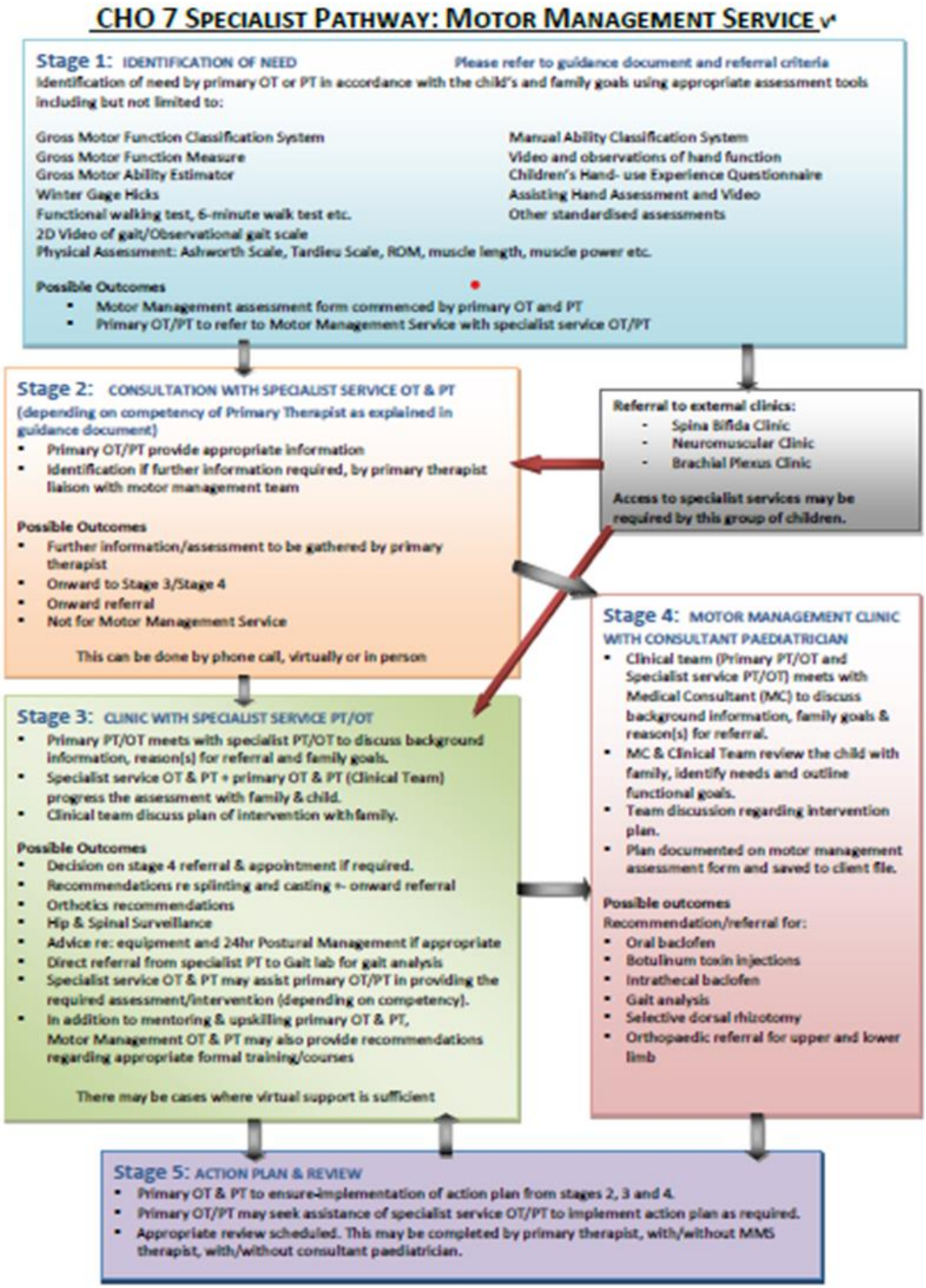
Appendix 3 – Sample Motor Management Pathway in CHO 4



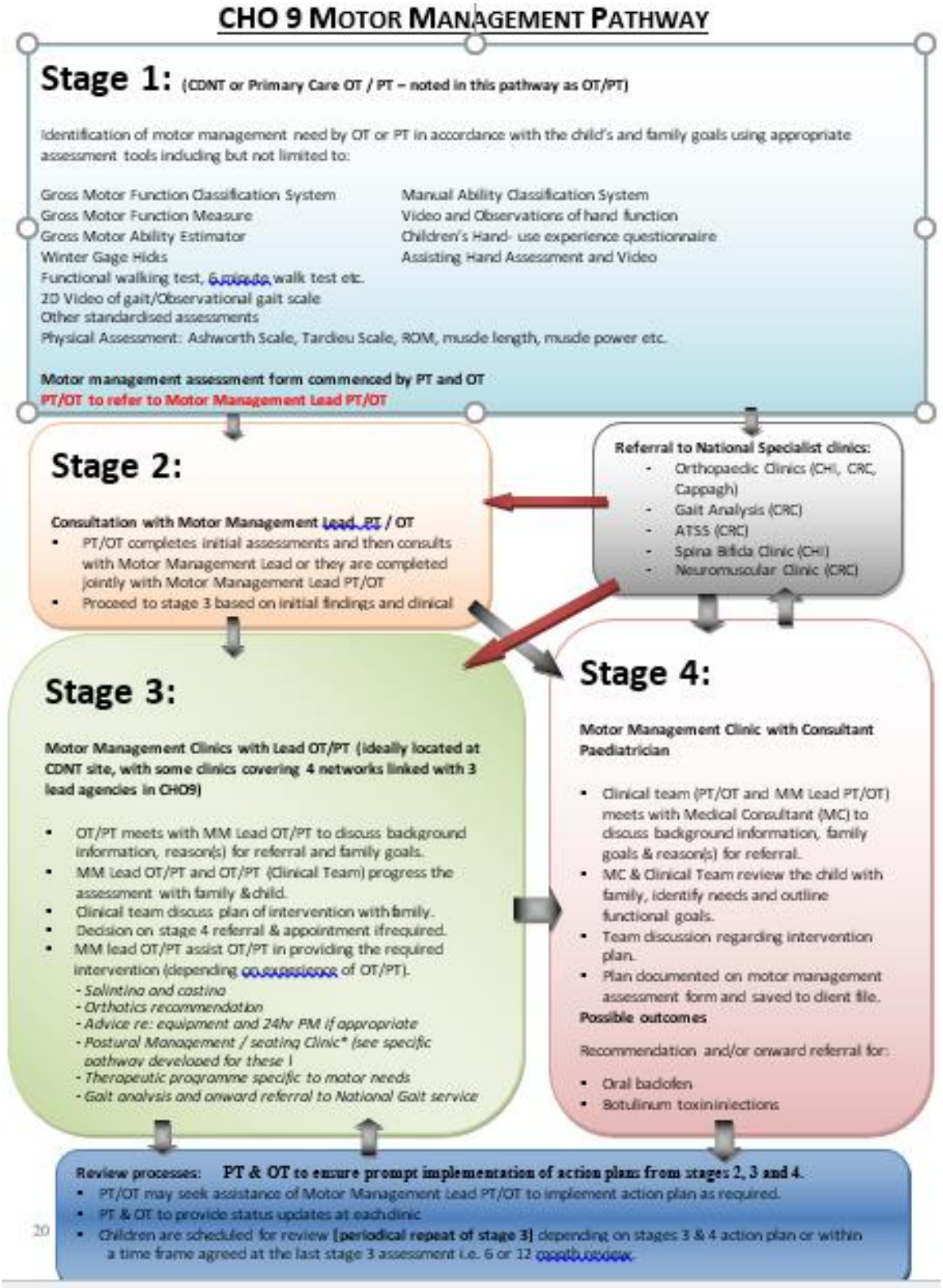
Appendix 4 – Sample Motor Management Pathways in CHO 7



Appendix 5 – Sample Draft Motor Management Pathway in CHO 7



Appendix 6 – Sample Draft Motor Management Pathway in CHO 9



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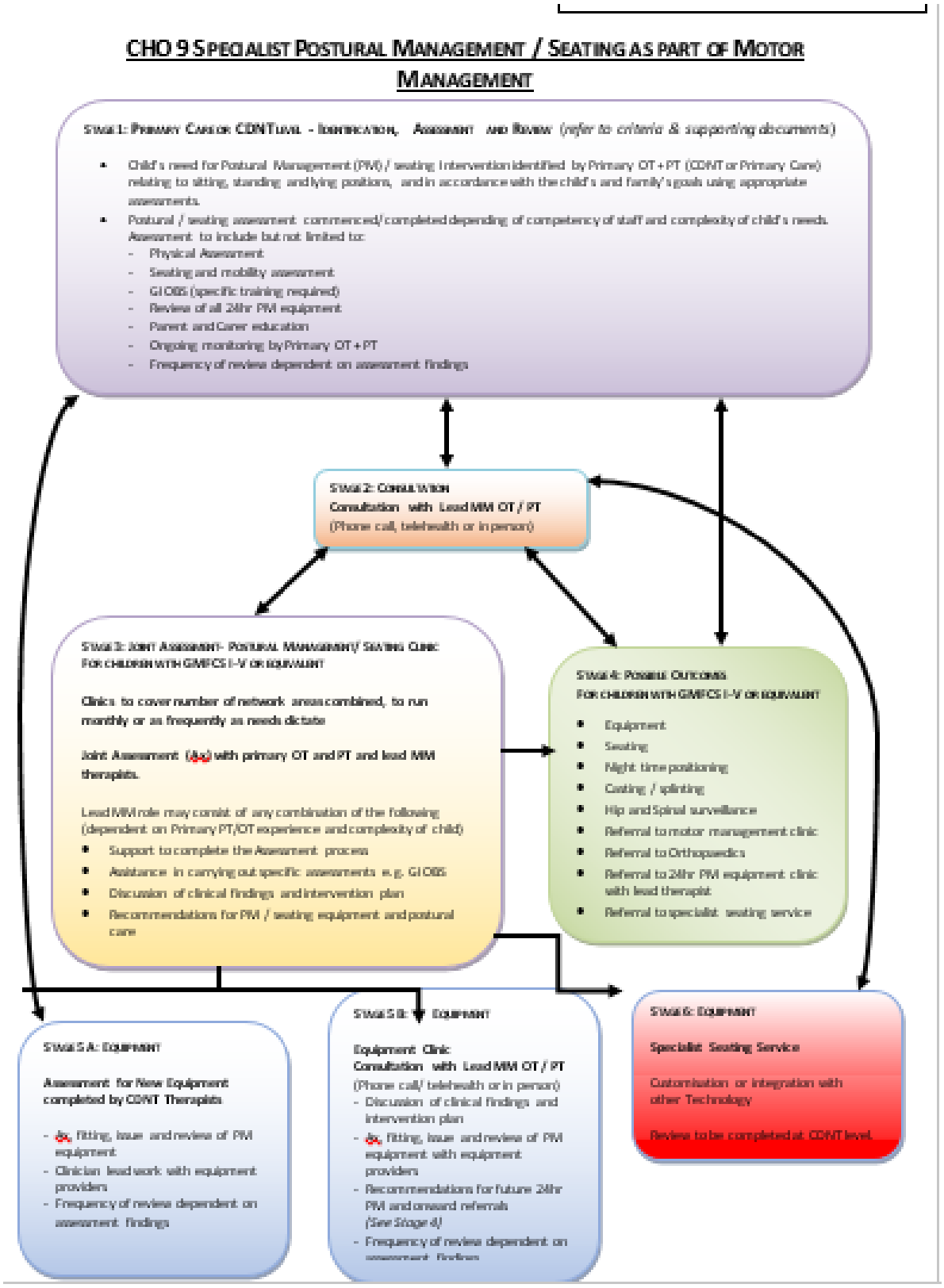
CHO 9 Specialist Postural Management / Seating as part of Motor Management
Stage 1: Primary Care or CDNT Level - Identification, Assessment and Review (refer to criteria & supporting documents)
Child's need for Postural Management (PM) / seating intervention identified by Primary OT + PT (CDNT or Primary Care) relating to sitting, standing and lying positions, and in accordance with the child's and family's goals using appropriate assessments.
Postural / seating assessment commenced/ completed depending of competency of staff and complexity of child's needs. Assessment to include but not limited to:
- Physical Assessment
- Seating and mobility assessment
- GMFCS (specific training required)
- Review of all 24hr PM equipment
- Parent and Carer education
- Ongoing monitoring by Primary OT + PT
- Frequency of review dependent on assessment findings
Stage 2: Consultation
Consultation with Lead MM OT / PT
(Phone call, telehealth or in person)
Stage 3: Joint Assessment- Postural Management/ Seating Clinic
For children with GMFCS I-V or equivalent
Clinics to cover number of network areas combined, to run monthly or as frequently as needs dictate
Joint Assessment (&) with primary OT and PT and lead MM therapists.
Lead MM role may consist of any combination of the following (dependent on Primary PT/OT experience and complexity of child)
Support to complete the Assessment process
Assistance in carrying out specific assessments e.g. GMFCS
Discussion of clinical findings and intervention plan
Recommendations for PM / seating equipment and postural care
Stage 4: Possible Outcomes
For children with GMFCS I-V or equivalent
Equipment
Seating
Night time positioning
Casting / splinting
Hip and Spinal surveillance
Referral to motor management clinic
Referral to Orthopaedics
Referral to 24hr PM equipment clinic with lead therapist
Referral to specialist seating service
Stage 5 A: Equipment
Assessment for New Equipment completed by CDNT Therapists
- &, fitting, issue and review of PM equipment
- Clinician lead work with equipment providers
- Frequency of review dependent on assessment findings
Stage 5 B: Equipment
Equipment Clinic
Consultation with Lead MM OT / PT
(Phone call/ telehealth or in person)
- Discussion of clinical findings and intervention plan
- &, fitting, issue and review of PM equipment with equipment providers
- Recommendations for future 24hr PM and onward referrals (See Stage 4)
- Frequency of review dependent on
Stage 6: Equipment
Specialist Seating Service
Customisation or integration with other Technology
Review to be completed at CDNT level.

Appendix 7 -Specialised Services and Supports Task Group Members

Membership	Representation
Mac MacLachlan (Chairperson)	Clinical Lead, National Clinical programme for People with Disability (NCPPD)
Mike Walsh	Programme Manager, NCPPD
Lorraine Dempsey	Parent and Lived Experience
Fionna Brennan	Child Health Ireland
Edel Quinn	CHO Heads of Service Disability
Briege Byrne	Progressing Disability Services Project Managers
Ann McGreal	Children's Disability Network Team Managers
Maeve Raeside	National Primary Care Operations
Tony McCusker, Laura Molloy (initially)	National Mental Health Operations
Ann Bourke, Angela O'Neill	National Disability Operations
Denise McDonald*, Siobhan Gallagher	Medical Subcommittee to NCPPD* and Consultant Paediatricians
Therese O'Loughlin, Riona Morris (initially)	Umbrella Bodies Disability
Gillian O'Dwyer	Heads of Discipline, HSCP
Renjith Joseph	Physiotherapy Subcommittee to NCPPD Disability Advisory Group (DAG)
Karen Henderson	Speech and Language Therapy Subcommittee to NCPPD DAG
Mary McGrath	Occupational Therapy Subcommittee to NCPPD DAG
Karen Cowan	Dietetics Subcommittee to NCPPD DAG
Liam O'Callaghan	Nursing Subcommittee to NCPPD DAG
Kate Falvey	Psychology Subcommittee to NCPPD DAG
Rose Bradley	Social Work Subcommittee to NCPPD DAG

Appendix 8 – Motor Management Working group Membership

Membership	Representation
Mike Walsh (Chairperson)	Programme Manager NCPPD
Gillian O'Dwyer	Head of Discipline, Co-ordinator of Physical Disability Support Pathway, Enable Ireland, Cork
Amanda O'Sullivan	Senior Physiotherapist, Mid Kildare Children's Disability Network Team, Enable Ireland Motor Management Service
Denise McDonald	Consultant Paediatrician, CHI. Mid Kildare Motor Management Service.
Rory O'Sullivan	Head of Specialist Services, CRC
Therese Seymour	Senior Occupational Therapist, Motor Management Lead Enable Ireland, Dublin
Ann Bourke	National Disability Specialist, National Disability Operations