



PAEDIATRICS

**A NATIONAL MODEL
OF CARE FOR PAEDIATRIC
HEALTHCARE SERVICES
IN IRELAND
CHAPTER 33:
NEURODISABILITY**



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**ROYAL
COLLEGE OF
PHYSICIANS
OF IRELAND**

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33.0 INTRODUCTION

The aim of this paediatric neurodisability model of care chapter is to establish the best standard of care for children and young people with disability. However, it is being written at a time of considerable change in disability service delivery due to the work associated with the Progressing Disability Services for Children and Young People (PDSCYP) Programme (HSE, 2010).

While this chapter proposes a model of care that mirrors the planned service framework as envisaged by the PDSCYP programme, these changes have not yet been realised across the country. The term neurodisability describes the paediatric subspecialty that treats children with disability. Therefore, the chapter is given this title. The terms neurodisability and disability are used interchangeably throughout the chapter.

Paediatric neurodisability is an important specialty that needs appropriate recognition and service development. It is the paediatric subspecialty managing a diverse number of conditions where there is impairment of the brain and or neuromuscular system. A specific diagnosis is not always identified. These conditions may be congenital or acquired, static or progressive, have a neurological, genetic or metabolic aetiology, and some may be life-limiting. There may be multiple associated functional limitations with a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour. It is estimated that 4% of children have complex on-going disability needs for health supports, with a further 10% having occasional needs for health intervention (HSE, 2009), this equates to 48,000 children with complex disability and 161,000 children with disability nationally.

As many children with disability have complex and continuing needs, they are frequent users of the health service at all levels. It is important to improve the health outcomes for children and young people who have a neurodisability in an early, appropriate and cost-effective manner. In line with the International Classification of Functioning, Disability and Health (ICF), the goals of management are activity and participation of the child and quality of life (World Health Organization 2001). Children, young people and their families' health outcomes are maximised through the provision of a multidisciplinary neurodisability service. Multidisciplinary teams (MDTs) in Ireland have varying levels of access to both paediatricians and health and social care professionals (HSCPs), depending on geographical location. It is important that local teams and specialist teams have appropriate levels of access to paediatricians and HSCPs in order to provide a high-quality, efficient and clinically effective service for children and young people with neurodisability.

The evolution of childhood disability services, both in terms of need and outcome has been well described, particularly in the UK, where services are well established (British Association for Community Health, 1999; 2012). More low birth weight infants are surviving. Some have definite cerebral palsy, but many are now recognised to have less clear but still significant impairments in the realms of learning, fine motor control, emotional and behavioural well-being. An increasing proportion of children with cerebral palsy experience a greater severity of impairment than previously, leading to an increasing number of children who have severe multiple disability, e.g. total body cerebral palsy, severe learning difficulties, cortical visual impairment and epilepsy. Children affected by a range of incurable and progressive conditions are living longer due to advances in medical technologies. They require comprehensive and labour-intensive multi-agency packages of support at home and at school to enable them to participate more fully in family activities and society generally. As these situations are enormously challenging for families, high standards of interagency working is necessary. There is a need to improve not just services for children with disability, but also services for adults with disability. Currently there is very little medical service for adults with disability. This service needs to be developed to allow for a seamless transition from paediatric services.

Table 33.1 illustrates the range of conditions requiring input, many of which may present with dual or multiple impairments.

Physical disability	Intellectual disability (ID)	Sensory impairments	Other
<p>Cerebral palsy</p> <ul style="list-style-type: none"> • Incidence is 2-3/1,000. • Diagnosis and screening for visual, hearing and cognitive impairments and behavioural issues. • Motor management, including treatment of spasticity and other movement disorders. • Surveillance for orthopaedic deformities (hip migration and scoliosis). • Medical: nutrition, bone health, epilepsy, saliva control, behavioural and emotional issues. A proportion of children with CP have exceptional healthcare needs.^a • The role of the paediatrician is to provide medical management with network teams, with some paediatricians providing specialist input with specialist teams, e.g. in the case of aspects of feeding and more complex spasticity management. 	<p>Cognitive impairment</p> <ul style="list-style-type: none"> • Incidence is 2-3%. • It has been defined as cognitive and adaptive skills of >2 standard deviation below the mean, i.e. an IQ of 70 or lower. In children <5 years of age, the term global developmental delay is used. • Given the multiple aetiologies, all children with global developmental delay or ID should have a paediatric assessment. • Medical co-morbidities such as cerebral palsy, autism, epilepsy, visual and hearing impairment, mental health and behavioural difficulties require on-going paediatric review. 	<p>Hearing impairment</p> <ul style="list-style-type: none"> • Prevalence of congenital permanent childhood hearing impairment is 1.39/1,000.^g • Best practice dictates that a child with hearing impairment has an aetiological work-up performed by a paediatrician, including neurodevelopmental history, physical examination and targeted investigations.^h • The universal neonatal screening programme requires significant paediatric support to ensure appropriate aetiological investigation and assessment for medical co-morbidities. 	<p>Specific conditions requiring medical surveillance</p> <ul style="list-style-type: none"> • There are neurodevelopmental disorders with recognised co-morbidities, e.g. trisomy 21, neurofibromatosis type 1.^{i,j} • Clinical paediatric review should occur in line with surveillance guidelines.

Physical disability	Intellectual disability (ID)	Sensory impairments	Other
<p>Spina bifida</p> <ul style="list-style-type: none"> • Incidence is 1/2,000.^b • There is an intensive neonatal period at the specialist centre: spinal surgery, insertion of shunt with baseline assessment and screening. • Throughout childhood particular attention is paid to growth, nutrition, bone health, postural management and urological surveillance. • Children with Spina Bifida should have access to a multidisciplinary team including paediatric neurosurgery and paediatric urology. 	<p>Autism spectrum disorder (ASD)</p> <ul style="list-style-type: none"> • Prevalence is 1%.^e • Assessment and diagnosis is with MDT. • Paediatric evaluation advised for all children with autism spectrum disorder (ASD), including consideration of investigations and medical co-morbidities. • Medical follow-up may be required for management of nutrition, sleep, etc. 	<p>Visual impairment (VI)</p> <ul style="list-style-type: none"> • Reported UK prevalence is 1.4/1,000 children (likely underestimate). • Paediatric assessment and investigation, as the majority of children with significant VI have additional disability. • Management of co-morbidities such as sleep and behavioural disorders. • Functional visual assessment should be integral to paediatric neurodisability assessment, as all children with neurodisability have a high rate of VI, particularly cortical VI. 	<p>Acquired brain injury (ABI)</p> <ul style="list-style-type: none"> • Incidence is 2/1,000. • The impact of ABI in childhood can have far-reaching consequences from a physical and cognitive perspective. • Medical management of complications is necessary. Initial neuro-rehabilitation occurs at tertiary level in the more severe cases, a small proportion of which receive rehabilitation at the National Rehabilitation Hospital. • Follow-up paediatric disability input is necessary.

Physical disability	Intellectual disability (ID)	Sensory impairments	Other
<p>Neuromuscular disease</p> <ul style="list-style-type: none"> • Prevalence is approximately 200 children in Ireland, including muscular dystrophies (most commonly Duchenne [DMD]), spinal muscular atrophy (SMA), Friedrich's ataxia and rarer degenerative conditions. • These conditions are progressive, and multiple organ systems may be affected. • TREAT-NMD has established guidelines for best practice management of neuromuscular disorders, including a comprehensive clinical programme involving multiple medical specialists and allied health professionals. • Specific guidelines are published for DMD and SMA.^{c,d} • Care should be provided 6-12 monthly at specialist level. 	<p>Specific learning disability</p> <ul style="list-style-type: none"> • Specific learning difficulties are common, estimated to affect up to 15% of children. • These include those impairments associated with developmental coordination disorder (or dyspraxia), specific speech and language impairment, dyslexia and inattention and/or hyperactivity (ADHD). • There are specific guidelines available in relation to diagnosis and intervention in developmental coordination disorder.^f • The role of the paediatrician is in providing a neuro-developmental assessment as required, excluding an underlying neurological disorder and screening for co-morbidities. • These paediatric assessments are most often single-visit assessments. 		<p>Palliative care</p> <ul style="list-style-type: none"> • Prevalence is 3.2/1,000.^k • ACT and RCPCCH have defined four categories of paediatric palliative care.^l It is estimated that approximately 50% of children with life-limiting conditions have palliative care needs at any given time. • Symptom control and support in medical decision-making are key components of children's palliative care. • Approximately two-thirds of children with life-limiting conditions have a disability, and receive paediatric care from the paediatrician at network level; many of these paediatricians have developed expertise in children's palliative care.

Table 33.1: range of conditions requiring neurodisability input

a NHS Scotland, 2015; b Governey et al., 2014; c Bushby et al., 2010; d Wang et al., 2007; e Lai and Lombardo, 2014; f Blank et al., 2012; g Washington State Department of Health, 2012; h BAAP and BAPA, 2008; i Down Syndrome Medical Interest Group, 2015; j Hersh, 2008; k Fraser, 2012, Ling 2015; l ACT, 2007

Roles of Multidisciplinary Team Members in the Provision of Services to Children with Neurodisability

The MDT aims to enable the child to be as physically, psychologically and socially independent as possible. In addition to working with the child, the team supports the family in the comprehensive care and development of the child or adolescent through support of health, educational, leisure and vocational needs. Team members work jointly or through liaison, and while the collaboration is time-consuming and labour-intensive, it is a worthwhile and effective model of care. The multidisciplinary team should include a paediatrician, nurse, physiotherapist, occupational therapist, speech and language therapist, psychologist, social worker, dietician, family support worker, childcare worker, early childhood education staff, and administrative staff. Child and adolescent mental health services (CAMHS) should be available to support children and families where there are co-morbidities or mental health issues that require such specific expertise, in a shared care model. The specific roles of a number of professionals in the disability team are detailed below.

Allied health and social care professionals with additional training and expertise in neurodisability will be required for Specialist disability teams to provide consultative support to the Network Disability Teams. This model of support is outlined in the document entitled “Guidance on Specialist Supports” (HSE, PDSCYP July 2015).

Consultant Paediatrician

The remit of a consultant paediatrician in neurodisability encompasses the initial assessment, diagnosis, and on-going management of children with potential and established learning and/or physical disabilities and co-morbidities. It includes addressing growth and nutrition, safe feeding, gastrointestinal issues, bone health, management of motor disability, epilepsy, pain, incontinence caused by neurogenic bladder and bowel, chronic respiratory problems and sleep. Some common conditions, such as Down syndrome and neurofibromatosis, have specific guidelines for medical surveillance that should be followed. Young adults with childhood-onset disability often experience functional deterioration, pain or fatigue, and an inactive lifestyle, with associated increased medical need. Primary prevention of potential health issues is therefore important, and includes orthopaedic surveillance and health promotion. The paediatrician has an active role in the holistic palliative care of the child or young person with a life-limiting condition. Alongside other health, education and social care professionals, the paediatrician has an important safeguarding role, as children and young people with disability have an increased vulnerability to abuse.

Paediatricians with a special interest in neurodisability are critical members of the multi-disciplinary team. Co-morbidities are screened for and detected in a timely manner. Preventative health care is implemented. An example of this is hip surveillance decreasing extent of orthopaedic surgery and preventing chronic pain. Through a holistic overview paediatricians coordinate care and optimise efficiencies. Unnecessary assessments and duplication of services are avoided. Acute admissions and tertiary referrals are decreased.

Paediatric neurodisability is different from other paediatric subspecialties in many respects:

- The number of children with disability needing paediatric input is in excess of the numbers of children requiring any other paediatric subspecialty.
- Clinical input is labour-intensive, owing to the complex nature of many conditions and the need for multidisciplinary working.

- Paediatricians working in neurodisability in Ireland maintain general paediatric expertise and therefore are in a position to provide a comprehensive health review. Most posts are appointed with a 0.5:0.5 whole-time equivalent (WTE) ratio; general paediatrics:community child health (CCH)/neurodisability. However, this dual commitment to general paediatrics, acute paediatrics, neonatology and child protection work is onerous (with excessive pressures from the acute services) and it significantly impedes delivery and development of neurodisability services.

Clinical Nurse Specialist in Neurodisability

To date the benefits of this role have not been recognised. The disability nurse (or CNS in neurodisability) is a key professional on the team who specifically manages the child's health needs, and through co-ordination and advocacy supports the parent in navigating the system, thereby relieving the care burden. Communication between local and specialist services is a large part of this role. The continuity of input throughout childhood in the children with multiple healthcare needs is hugely beneficial. The role is cost-effective in terms of decreasing inefficiencies and duplication and preventing unnecessary hospital admissions.

Physiotherapist

The physiotherapist provides assessment and on-going intervention for children with neurodisability and their families, addressing the physical needs of each individual child, which impacts on their level of function. The overarching aim of physiotherapy is to enable each child to reach their maximum potential in relation to their movement and mobility, in order that they can achieve their activity capacity. The long term goal of physiotherapy intervention for children and families is to promote maximum participation and quality of life in their everyday activities. Common physiotherapy interventions include neurodevelopmental therapy, strengthening, assisted mobilisation, hydrotherapy, sensory integration, 24 hour postural management, equipment management, balance and gait re-education, fitness and endurance intervention. Children with neurodisability may also require respiratory physiotherapy due to the complexity of their condition.

Occupational Therapist

The occupational therapist working with children with neurodisability will aim to enable the child to be as physically, psychologically and socially independent as possible. Occupational Therapists working with children use their expertise to analyse a child's skills, activities and occupations and the context of those occupations. The focus and delivery of intervention will depend on which areas are determined to be most affecting occupational performance (e.g. sensory, motor, cognitive or psychosocial components, activity or environmental accommodations).

Occupational therapists identify the supports and barriers to participation in meaningful activities (self-care, school and play/leisure) and daily routines. Interventions to enhance children's participation include; supporting specific skill development, environmental accommodations, activity modification and 24-hour postural management.

Speech and Language Therapist (SLT)

The role of the SLT is to assess, diagnose and treat children with communication or Feeding, Eating Drinking Swallowing (FEDS) difficulties. The aim of communication intervention is to develop and optimise the child's communication skills to ensure improved education, participation and function in life. FEDS intervention aims to maximise normal oral intake wherever possible, while minimising the risk of aspiration. The role of the SLT is broader than working directly with the child; an essential element of intervention is working with and educating parents and carers, other members of the team and stakeholders beyond the team to optimise communication with the child.

Psychologist

The psychologist assesses the child's abilities and identifies the appropriate strategies to optimise progress. The process involves on-going assessment; intervention with regard to social, emotional or behavioural issues; development of educational programmes; planning for transitions to pre-school or primary school; counselling; parent and staff training. The psychologist plays an important role in supporting families when adjusting to having a child with disability, and supporting children and young people in understanding and living with disability.

Dietician

Nutrition is recognised as being an essential component of the care of infants, children, and adults with disabilities and special healthcare needs. The prevalence of feeding difficulties and compromised nutritional status is higher in this population than in the population as a whole. These include undernutrition and overnutrition, inefficient or unsafe oral feeding, dependence on enteral or parenteral nutrition and gastrointestinal symptoms, e.g. reflux and constipation. The benefits of nutritional intervention are well documented, and significant developmental progress has been shown to accompany improved nutritional status.

Social Worker

The purpose of social work input is to help the family access all possible practical and emotional supports, and to keep the family functioning as a unit. Social workers have a key role in assisting families and carers to find solutions and maintain resilience in the face of complex day-to-day challenges. The role includes supporting access to respite services, in order to assist with care planning and psychosocial supports.

Administrative Staff

A central administrative support as a point of contact for children and families, teachers and other healthcare professionals is essential for all children's network disability teams. This team member has an essential role in communication and in minimising the cost to productivity when clinical staff has to perform administrative functions in addition to delivering therapeutic interventions.

33.1 CURRENT SERVICE PROVISION

Disability services in Ireland stand out as an area of health that has been chronically under-resourced. It is essential to expedite plans to significantly expand services. These services have evolved without national planning, in an uncoordinated, ad hoc manner, varying in different geographical regions, thus resulting in some areas being without specific disability teams. In the past, services have been divided into those for children with physical disability and those for children with learning disability. They have often been only accessible to children with a specific difficulty or diagnosis, leaving some children and their families with little or no access to services. Teams in Ireland developed varying access criteria that, coupled with historically low staffing levels in many areas, have resulted in limited and insufficient access for children and families to the high-quality disability services required. There have been significant deficits in some services where there has been no access to a paediatrician. Specialist services have developed in some areas, these include clinics for the upper limb, brachial plexus injuries, FEDS clinics, 3D gait analysis, specialised orthopaedics, spasticity management, assistive technology clinics, specialised seating clinics, augmentative and alternative communication clinics, outreach clinics, spina bifida and neuromuscular clinics, among others. These clinics provide essential expertise, but have not been developed strategically to provide equitable access to all local service providers.

Disability services are currently being reconfigured through the Progressing Disability Services for Children and Young People (PDSCYP) programme (HSE, 2015). The programme was initiated in 2010 in response to recommendations in the Report of the Reference Group on Multidisciplinary Services for Children Aged 5-18 Years (HSE, 2009) and includes a reconfiguration of early intervention services for children aged less than five years. This approach is based on providing local services for all children with disability, access to which will be based on geographical location rather than specific impairment. The vision of the PDSCYP programme, supported by the national Clinical Programme, is that each and every child or young person with a disability is supported to achieve their full potential.

The PDSCYP programme follows the Report of the Reference Group on Multidisciplinary Services for Children aged 5-18 years published in 2009. Recommendations of this report include:

- A clearly understood referral pathway for all children requiring assessment and intervention and the establishment of a referral forum to coordinate referrals to appropriate services in each local health office (LHO) area.
- Children should receive treatment and interventions as close to home as possible.
- School age interdisciplinary teams (referred to as 'Children's Disability Network Teams') should be established in each Primary Care Network.
- Children with more complex needs should be referred if needed to more specialist teams either within their region or outside their region.
- HSCPs with paediatric training and expertise are required to work with children.
- The Children's Disability Network Team should work in one premise (the Child Development Centre) and should be able to address the needs of children with intellectual disability, physical disability, sensory disability and autism spectrum disorder.
- One WTE consultant paediatrician with an interest in community child health should be available in each LHO area.
- Subspecialty teams are required to provide training, consultation and in some cases direct intervention for children, to respond to the exceptional complexity or specialist nature of their needs.

The programme is implementing an integrated service model that will allow children, whatever the nature of their disability, to be seen as locally to their home and school as possible:

1. At primary care level when their needs can be met there (non-complex). Non-complex needs refer to one or more impairments giving rise to functional difficulties which result in mild restrictions in participation in normal daily living. It may also refer to children with moderate functional difficulties which are likely to be mitigated by unidisciplinary or primary care team level supports.
2. At Children's Disability Network level for children with more complex needs. Complex needs refers to one or more impairments which contribute to a range of functional skill deficits and give rise to significant activity limitations or at least moderate restrictions in participation in normal daily living activities and interactions. The child with complex needs and their family will require additional supports in terms of key working, interdisciplinary management and or medical supports to mitigate secondary impairments and their challenges in terms of environmental and personal factors.
3. At specialist services level where a high level of expertise is necessary to support primary care services and disability network teams (HSE 2013).

The implementation of PDSCYP, while welcome, presents a particular challenge to describing current service provision, as it has not been implemented uniformly across the country, and areas are therefore at different stages

of development. The establishment of local or network teams under PDSCYP is in the planning stage in some areas, while it has been established in others.

In June 2015, the PDSCYP group published 'Guidance on Specialist Supports' acknowledging that local teams will at times require access to specialist support and that each Community Healthcare Organisation (population of approximately 500,000 people) should determine how specialist support services will be developed in their area.

In some areas there are dietitians, occupational therapists, physiotherapists, psychologists and speech and language therapists with specialist skills in neurodisability who have the expertise to work in regional specialist services as outlined in the 'Guidance on Specialist Supports'.

Ultimately, the aim is to have Paediatric Primary Care Network level teams and Children's Disability Network Teams in all areas for children aged from birth to 18 years. In many cases this will involve the reconfiguration of staff in existing services into paediatric primary care network teams and children's disability network teams through a multi-agency partnership agreement.

Notwithstanding the potential benefits of PDSCYP, there are a number of barriers to providing for sufficient services for children with disability:

- At present, there is no national policy with respect to prioritisation of referrals – some network disability teams prioritise children on clinical need, whereas some prioritise in order of referral date.
- Despite the PDSCYP aspiration that paediatric support should be provided to all network teams, there has to date been no plan to adequately resource paediatrics to meet this role. There are significant gaps in many localities where a paediatrician has never been appointed. As a consequence of limited and inequitable access to paediatricians, the healthcare needs of children are not currently being met. To ensure equitable access to care, all children's disability network teams should have access to a paediatrician. At current consultant levels, this is unfortunately not feasible.
- Disability clinics remote from the hospital have no links to hospital radiology and diagnostics. This poses a clinical risk for paediatricians managing patients on a number of sites.
- There is no formal training scheme in Ireland for paediatricians in neurodisability although it is available in the UK.
- Due to acute hospital commitments, non-consultant hospital doctors (NCHDs) often do not get an opportunity to regularly attend neurodisability clinics.
- Despite the increased mental health needs of children with disability, they do not have ready access to CAMHS services. Nationally, there is a significant shortage of child psychiatrists who treat children with intellectual disability.
- Access of children with physical disability to orthopaedic surgeons with paediatric expertise is grossly inadequate. Waiting times for clinical review are excessive and, where surgical intervention is planned, there is further lengthy waiting time for surgery.
- There is very limited service providing visual assessment for children with complex neurodisability.
- There is limited access to respite, which impacts significantly on the quality of life of the child and their family.
- There are some minority groups for whom engagement with disability services presents a particular challenge.
- Services for adults with disability are limited and exceptionally limited in the case of those with complex disability. Adults with disability are a potentially vulnerable group, as they are often unable to advocate for themselves.

- There are significant delays between assessment for, and provision of, equipment due to delays in funding in the community.
- There is a very limited service for the appropriate assessment, investigation and management of children with permanent congenital hearing loss diagnosed by the national neonatal hearing screening service.

33.1.1 Current Staffing

Paediatricians

There are 11.25 WTE consultant paediatricians (the majority in designated community paediatric posts) that work in neurodisability, and 3.35WTE consultant paediatricians in designated neurodisability posts (as of May 2014). This is less than 25% of what is recommended.

HSE area	Hospital	Population 2011 Census	Consultant in neurodisability	Consultant in community child health
Dublin Mid Leinster	Our Lady's Children's Hospital, Crumlin; Tallaght; Portlaoise; Mullingar	1,319,754	0.75 0 0 0	0 1.0 0.5 0.5
Dublin North East	Temple Street Children's University Hospital; Central Remedial Clinic (CRC); Drogheda; Cavan	1,019,658	1.0 1.6 0 0	0 0 1.0 0.5
South	Kilkenny; Wexford; Waterford; Clonmel; Cork; Tralee;	1,162,112	0 0 0 0 0 0	0.5 0.5 0 0.5 1.25 0.5
West	Limerick; Galway; Ballinasloe; Castlebar; Sligo; Letterkenny	1,086,728	0 0 0 0 0 0	0.5 1.0 0.5 0.5 1.0 1.0
Total		4,588,252	3.35	11.25

Table 33.2: Numbers of community child health and neurodisability consultants per population in previous HSE areas

Health and Social Care Professionals

HSCPs provide services to children with disabilities across a variety of teams in Ireland. HSCP services are fragmented and are unable to adopt a true child and family-centred approach to service delivery. This, coupled with exceedingly long HSCP waiting lists, is extremely challenging for both parents and HSCPs providing services.

Recommendations for HSCP staffing levels in children’s disability network teams are as follows: For speech and language therapy, occupational therapy and physiotherapy, a ratio of 1.5 WTE: 100 children with a disability, whose needs are defined as complex, is the minimum requirement. For Social work and Psychology a ratio of 1WTE: 100 children is recommended. For dietetics 0.5 WTE is recommended for each children’s disability network team. For teams who also deliver specialist support, a ratio of 1 WTE: 150 is recommended for the relevant HSCPs. There are severely inadequate HSCP staffing levels in all regions in Ireland.

Children’s Disability Network Team current Staffing Levels

In 2014, a national mapping exercise across statutory and voluntary providers of services to children with disabilities was undertaken by the Progressing Disability Services for Children and Young People programme (PDSCYP). Table 33.3 gives a national total for nursing and HSCPs in 2014, which has been shared with the national Clinical Programme for Paediatrics and Neonatology (NCPPN) by the PDSCYP programme.

Discipline	2014 Totals*
Speech and language therapy	270.00 WTE
Occupational therapy	261.22 WTE
Physiotherapy	184.18 WTE
Psychology	186.45 WTE
Social work	101.80 WTE
Dietetics	4.88 WTE (2012 PDSCYP figures)
Children’s disability nursing	156.84 WTE

Table 33.3 Children’s Disability Network Team Staffing Levels

*These figures include all vacant posts, both permanent vacancies and maternity leave, which comprise a significant number - maternity leave alone is approximately 10% of the overall WTE.

33.2 PROPOSED MODEL OF CARE

The proposed model of care is in the context of the current disability strategy (PDSCYP, HSE 2010), including the recently published PDSCYP document, Guidance on Specialist Supports (HSE 2015) and the national Clinical Programme for Paediatrics and Neonatology (NCPPN, 2015). PDSCYP and NCPPN share the concepts of equity of access to care and services being provided as close to home as possible. The NCPPN has also linked with the national Coordinating Committee for Primary Care Paediatric Services to ensure that services for children with ‘non-complex’ disability accessing their future services at paediatric primary care network level are appropriately planned and organised.

The following components are necessary for a neurodisability service and are consistent with the core principles as outlined by the Community Child Health subgroup of the Royal College of Physicians of Ireland (RCPI).

Local disability services

- Primary care and disability network teams should employ the bio-psychosocial model to address the health, education and social needs of the child and family.
- There should be integrated care pathways to signpost professionals and parents to enable ease of access and equity of care.

- There should be a robust screening system at the point of referral, which will identify both clinical and parental priorities for intervention.
- Assessment, surveillance and treatment must be in line with international best practice.
- There must be an emphasis on outcome, where functional and therapeutic goals are agreed between clinicians and parents and regularly reviewed.
- Multi-disciplinary teams should have ready access to specialist services that have been equitably and strategically planned. These services will support the MDT's and provide specialist management as required.
- Seamless transition to adult services is essential. Appropriate planning for transition to adult services is critical to ensure that adolescents and young adults with neurodisability continue to engage with health services following transition.
- There must be robust clinical governance.
- It is essential that there is a commitment to training and continuing professional development of all MDT members including paediatric trainees and consultant paediatricians.

Specialist Disability Services

There are a small number of children with complex needs who require highly specialist clinical and therapeutic expertise. A Children's Disability Network Team would not have the critical number of children requiring this service to develop or maintain this level of expertise. To ensure excellence and equity of access to this expertise, the specialist knowledge and skills currently available in children's disability services should continue to be accessible. Without access to this expertise children and their families will incur serious risk to outcomes in their function and participation as the Children's Disability Network Team alone will not be able to cater fully for their needs.

There should be specialist services working in partnership with the local team to support increasing levels of complexity. These services require highly skilled personnel from different disciplines and a critical mass to maintain specific expertise.

Examples of services that should be available and easily accessible for all regardless of where the child lives:

- Spasticity management
 - o Orthotics, casting, botulinum toxin
 - o Complex spasticity
 - o Orthopaedic surveillance
 - o Gait analysis
- FEDS (feeding, eating, drinking, swallowing) clinics for more complex feeding issues
- Seating services.
- Augmentative and alternative communication; assistive technology.
- Multi-disciplinary clinics for conditions including spina bifida and neuromuscular conditions.
- Rehabilitation following traumatic or non-traumatic acquired brain injury (ABI) and acquired spinal cord injury (ASI), including post-surgery.
- Evaluation of children with complex neurodevelopmental disorders, including complex ASD diagnosis.
- Functional vision assessment for children with primary visual impairment and for those with complex neurodisability.
- Services for children with hearing loss
 - o Audiology services
 - o Aetiological investigations of permanent congenital hearing loss

Services should only be at national level where the specific multi-disciplinary expertise required is only available at a national centre, e.g. selective dorsal rhizotomy.

Paediatric Services

Paediatricians working in neurodisability should have hospital links either by a commitment to general paediatrics or access to diagnostics and peer support. There should, however, be a strategic move away from currently onerous job descriptions, and recognition that consultants working across urgent and planned care services should have appropriate allocation of time towards administration, service development and clinical governance duties. Future resources and contracts should support the opportunity for development of clinical leads in particular aspects of service delivery in each region, thus achieving clinical excellence in all aspects of medical care. There is a need to expand the number of consultants in paediatric neurodisability across Ireland on a per capita basis, with expansion to 42WTE recommended by the Faculty of Paediatrics, RCPI. There should be consideration to configure future neurodisability posts to increase the portion of the posts committed to neurodisability work, to enable additional provision of specialist expertise to multidisciplinary teams providing specialist care across the country.

Subspecialty Services

Child and Adolescent Mental Health Services (CAMHS)

Children with disability have significant mental health needs, including psychiatric co-morbidities (e.g. anxiety, ADHD, OCD in children on the autism spectrum), mood disturbance and challenges of living with disability/chronic illness. Multidisciplinary teams managing children with a range of disabilities and developmental delay need ready access to child psychiatry (ideally co-located with network teams), in particular to psychiatry for children with an intellectual disability, to provide specialist support and advice in this often very challenging population. National shared care protocols need to be devised and implemented in order to ensure that all children requiring a shared care approach between disability teams and CAMHS have equitable access to this approach in Ireland.

Paediatric Orthopaedics

Regional access to paediatric orthopaedics will be essential to specialist motor management services. While paediatric orthopaedic surgery is confined to tertiary and large regional hospitals, support to regional clinics will be critical to the success of orthopaedic surveillance programmes.

Paediatric Neurology

Regional access to a paediatric neurologist is necessary. While paediatricians in neurodisability are competent in the management of childhood epilepsy, consultation with a paediatric neurologist or paediatrician with a special interest in paediatric neurology is essential in the management of complex epilepsy. It is also essential in establishing diagnosis in certain children, including some of those with significant developmental impairment, neuromuscular or neurodegenerative disease.

Paediatric Ophthalmology

Visual impairment and strabismus are common in children with disability (preterm children, children with Down syndrome), and visual function needs to be confirmed in children with developmental challenges in order to maximise potential. Input from a paediatric ophthalmologist is critical to the diagnosis of certain conditions, e.g. those associated with retinopathy, obesity and intellectual disability. Ready access to paediatric ophthalmology is critical for children with neurodisability and should be available at local or community level. Paediatric ophthalmology support to specialist functional visual assessment clinics is also essential, and demands increased ophthalmology resources at regional/national level.

Clinical Genetics and Metabolic Medicine

Many children with disability have rare genetic diseases that may require assessment by a clinical geneticist and follow-up for genetic counselling. This service is currently provided by the Department of Medical Genetics in Crumlin including their outreach service. Much of this work is also undertaken by the paediatrician, with close clinical and laboratory support. Due to on-going advances in genetic diagnosis in epilepsy, autism and learning disability, liaison with the clinical genetics service will increase. Many children with disability have an inborn error of metabolism and are jointly managed with the national metabolic service.

Paediatric Otorhinolaryngology (ENT) and Audiology

Hearing impairment, whether congenital or acquired, requires coordinated management between Audiology, Paediatrics and ENT surgery. Access to ENT surgery, including Cochlear Implantation services in Dublin, is essential and clear guidelines to manage permanent congenital hearing loss in particular, need to be developed and resourced.

Other subspecialties requiring regular links include neurosurgery, urology, respiratory, cardiology, gastroenterology, endocrinology, dentistry and palliative care.

Primary Care Services

General Practitioners (GPs)

Apart from the role of the GP in recognising developmental disorders, there is an essential health care role. GPs should be supported in their involvement with children and families, to avoid an overdependence on hospital services and to strengthen the role of the GP in the management of life limiting conditions in the home.

Community Health Doctors

Consideration should be given to establishing a more formalised role for senior medical officers (SMOs)/community health doctors within local teams. The creation of such a role would necessitate further extension of training to include specific aspects of developmental assessment and complex medical care.

Public Health Nurses (PHNs)

The role of the public health nurse (PHN) is critical in developmental and child health surveillance, and also facilitates access to other services.

Social Care and Educational Services

Child and Family Agency (Tusla)

Education services – schools and special educational needs officers

Respite services

Carer support services

Information Technology (IT) Services

- Hospital clinical reports, laboratory results, radiology films and reports should be available electronically in community services. Electronic patient records (EPRs) will allow for seamless interagency and interdisciplinary working. Many disability services are developing these at present, and the new children's hospital will incorporate EPR.
- There is a need for the development of national databases for people with disability that include diagnosis. Both the national Intellectual Disability Database and the national Physical and Sensory Database provide information on needs, but not on diagnosis. With respect to metrics and evaluation, it is impossible to do this without good databases.

- A neurodisability webpage should be developed, with guidance for all paediatricians working in disability, providing clinical protocols, referral pathways and up-to-date relevant information.
- Linked information technology (IT) systems for laboratory reporting and radiology viewing need to be developed at all sites.

33.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

The following is required to implement this model of care:

33.3.1 Service development

- Integrated best evidence care pathways for all aspects of childhood disability should be established and additional resources made available for appropriate consultant, HSCP and nursing staffing to implement these care pathways.
- Referral guidelines for all disability services nationally should be developed where these do not exist, and improved as needed.
- The ethos of providing maximum levels of care as close to the child and family as possible as outlined in the PDSCYP programme should be implemented as much as possible, including providing specialist services for children with complex disability in areas of Ireland where there is sufficient critical mass, available expertise and capacity to provide such services.
- Standardised prioritisation systems must be in place in order for children to have equitable access to services.
- Careful planning of additional multi-disciplinary health and social care support, nursing support and consultant paediatric neurodisability support to the implementation of the PDSCYP programme is required, to support equitable access of this support to paediatric primary care, children's disability network and specialist disability teams in Ireland.
- There should be appropriate focus on the healthcare needs of children with disability through funding of additional consultant paediatric neurodisability, paediatric orthopaedic, paediatric neurology, health and social care professional and specialist nursing posts.
- Services should be developed and expanded where specific deficits exist, e.g. specialist functional visual assessment for children with disability and assessment and management of permanent congenital hearing loss and acquired hearing loss.
- Services for assessment and post-diagnostic intervention and support for children with Autism Spectrum Disorder and learning disability need to be further developed and expanded.
- There should be further development and investment in currently available internationally established surveillance and treatment protocols, e.g. hip surveillance, spine surveillance, limb deformity and other complications of physical disability.
- There is a requirement to develop transition services and adult services for children with disability.
- The process of prescribing, funding and providing equipment needs to be reviewed in order to enable timely provision that benefits the child and avoids unnecessary delays.
- Neurodisability teams require improved access to currently under-resourced child psychiatry services (in particular, psychiatry for children with learning disability), which ideally should be co-located with multidisciplinary disability teams.
- Respite services should be expanded to cater for children with all forms of childhood disability who need them.
- Secure IT systems are necessary in order to facilitate sharing of clinical information between hospital and community services, and future ICT systems should be capable of integrating with one another.
- The PDSCYP strategy should be reviewed following a period of implementation.

33.3.2 Staffing

- Paediatricians should be resourced to support network disability and specialist disability teams where they exist around Ireland. Neurodisability paediatric specialists working with specialist disability teams should have specific proportion of their WTE allocated to specific specialist services.
- The Faculty of Paediatrics, RCPI, submitted a workforce planning document to the HSE National Doctors Training and Planning department in February 2014. This recommended a total of 42 WTE consultant paediatricians in neurodisability nationally, equating to 84 paediatricians based on a 0.5 WTE: 0.5 WTE split with acute / general paediatrics. A 0.7:0.3 neurodisability: general ratio should be considered at least for a proportion of future posts, particularly those where more specialist services are provided. The required expansion would be an additional 30 WTE for Paediatric Neurodisability, or 60 WTE if each post had a 0.5WTE commitment to General Paediatrics.
- Expansion in HSCP posts is necessary, as outlined earlier.
- Recommendations for HSCP staffing levels in children's disability network teams are as follows: For speech and language therapy, occupational therapy and physiotherapy, a ratio of 1.5 WTE: 100 children with a disability, whose needs are defined as complex, is the minimum requirement. For Social work and Psychology a ratio of 1WTE: 100 children is recommended. For dietetics 0.5 WTE is recommended for each children's disability network team. The numbers of consultant paediatric orthopaedic surgeons need to be expanded.
- The clinical nurse specialist role is essential, needs to be expanded and staffed appropriately both at network and specialty level.
- The appointment of therapy assistants should be considered, in order to relieve HSCP staff of some duties.
- Appropriate levels of administrative support for frontline paediatric clinical services are essential.

33.3.3 Training

- HSCPs who are currently reconfiguring under the PDSCYP programme require specific/protected time for training and supervision, in order to allow all staff to up skill in relation to new areas or practice.
- It is essential to develop and prioritise specific training rotations and curricula for junior doctor trainees in Paediatrics who wish to specialise in paediatric neurodisability.

33.3.4 Education

- Commitment to training and continued professional development of all clinicians should be upheld.

33.3.5 Governance

- A robust clinical governance system should be in place for all clinicians.

33.4 PROGRAMME METRICS AND EVALUATION

Audit of the neurodisability service is difficult without complete and accurate local or national databases, and consideration therefore needs to be given to upgrading and expanding such national disability databases / registers, such as the National Intellectual Disability Database (NIDD) and National Physical and Sensory Database (NPSE) in Ireland. It would also be appropriate to establish databases / registers for specific conditions, such as Cerebral Palsy, Spina Bifida, Down Syndrome, Autism Spectrum Disorder. Improvements in health outcomes have occurred in countries where databases for these disorders exist, and this should be achievable and aspired to in Ireland.

Examples of useful performance indicators in neurodisability are as follows:

Service Delivery Targets

- Waiting time to the appropriate service measured for each child newly referred.
- National standard for access to paediatric HSCP services is set at 12 weeks, irrespective of whether a child requires access to a paediatric primary care network team, a children's disability network team or specialist service.

Clinical Outcomes

- Hip and spine surveillance
- Documentation of nutritional status, growth and bone health
- Consideration of visual function
- Urological surveillance in spina bifida
- Aetiological work-up of severe hearing impairment
- Investigation of learning disability
- Screening for complications of brain injury
- Discussion of end-of-life issues
- Adherence to established condition-specific guidelines

Qualitative Outcomes

- Qualitative research undertaken in relation to children and families
- MDT individualised care plan in place for each child

33.5 KEY RECOMMENDATIONS

Children with disability represent the largest group of children with chronic disease in the country. With a national complex disability prevalence of 4 %, there are approximately 45,325 children aged 0-19 years in need of specialised care. The key recommendations of the neurodisability chapter of this model of care are:

- Ensure equitable local access for children with a disability.
- Ensure on-going access for children and their families with complex neurodisability to existing high quality specialist services.
- Increase paediatric neurodisability consultant posts to the required 42 WTE to meet the healthcare needs of children with disability across network and specialist services (RCPI Medical Workforce Planning, February 2014).
- The clinical nurse specialist role is essential, needs to be expanded and staffed appropriately both at network and specialty level.
- Increase children's disability network team HSCP staffing levels in order to provide safe, accessible and effective services.
- Develop standardised integrated care pathways and prioritisation systems to ensure equity of access for all children with a disability and their families.
- Develop secure IT systems to facilitate information-sharing between hospital and community services.
- Develop specific training rotations for junior doctor trainees in paediatrics who wish to specialise in neurodisability.
- Support and encourage the involvement of children with a disability and their families in the planning and delivery of their neurodisability services.

33.6 ABBREVIATIONS AND ACRONYMS

ABI	acquired brain injury
ACT	Association for Children's Palliative Care
ADHD	attention deficit hyperactivity disorder
AMO	Area Medical Officer
ASD	autism spectrum disorder
ASI	acquired spinal cord injury
CAMHS	Child and Adolescent Mental Health Services
CCH	community child health
CNS	clinical nurse specialist
CRC	Central Remedial Clinic
CP	cerebral palsy
DMD	Duchenne muscular dystrophy
EPR	electronic patient record
FEDS	feeding, eating, drinking and swallowing
HSCP	health and social care professional
ICF	International Classification of Functioning, Disability and Health
ID	intellectual disability
LHO	Local Health Office
MDT	multidisciplinary team
NCHD	non-consultant hospital doctor
NCMG	Centre for Medical Genetics in Crumlin
NCPNP	National Clinical Programme for Paediatrics and Neonatology
NRH	National Rehabilitation Hospital
OCD	obsessive-compulsive disorder
PDSCYP	Progressing Disability Services for Children and Young People
PHN	public health nurse
RCPCH	Royal College of Paediatrics and Child Health
RCPI	Royal College of Physicians of Ireland
SLT	speech and language therapist
SMO	Senior Medical Officer
VI	visual impairment
WTE	whole time equivalent

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