



PAEDIATRICS

A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND

CHAPTER 18: COMMUNITY SERVICES FOR CHILDREN WITH ONGOING HEALTH NEEDS



Féidhmeannacht na Seirbhíse Sláinte
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**ROYAL
COLLEGE OF
PHYSICIANS
OF IRELAND**

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18.0 INTRODUCTION

The majority of children in Ireland are healthy and therefore do not need to use healthcare services regularly. However, some children have ongoing health needs and require access to healthcare services in the community. Historically, the development of these services for children in Ireland has been highly variable, dependant on geographical location of the child's home and locally available paediatric resources. In many parts of Ireland, and frequently in the larger urban areas, there is a dearth of both primary care paediatric and children's disability services. This results in an over-reliance on acute hospital care for many children who could have their needs best met by appropriate intervention in the community setting. Across Ireland, there remains huge variation in terms of equity of access to services for children both between community areas, and between teams and disciplines in the same community area.

There is strong evidence that an integrated health and social care system delivers better quality of care for patients (Hwanh et al., 2013; WHO, 2001), and thus leads to better outcomes. The Health Service Executive (HSE) Community Healthcare Organisations Report (DoH/HSE, 2014), which set out reconfiguration plans for community services, highlighted the fact that integrated care can make a real difference to the quality of care received by individuals. The report also acknowledged that it is difficult to turn the concept of integrated care into a cost-effective operational reality. The 2014 Community Healthcare Organisations (CHO) report identified clinical and service-level integration as one of its key requirements. Paediatric services in the community require urgent development, in order to enable the entire paediatric health system to flow in an integrated manner, as well as more efficiently and effectively. The consequence of insufficient development in community-based paediatric services to date, is an acute hospital system that is consistently overburdened, coupled with a community system that is unable to deliver high-quality, accessible healthcare to children with ongoing health needs. In the longer term, an integrated paediatric health service will deliver both quality and cost-effectiveness across both the acute and community sectors.

This chapter outlines how services for children in the community with ongoing health needs, and specifically primary care paediatric services, should be developed and delivered under a new model of care. It is essential that community paediatric services do not continue to evolve in a fragmented, disjointed manner in response to local need and locally available skills, but are developed in a standardised manner across Ireland, with the development of such services reflected and prioritised in service planning.

18.1 CURRENT SERVICE PROVISION

Services for children in the community are delivered across a number of divisions:

- Primary Care
- Social Care
- Mental Health
- Health and Wellbeing

The national primary care strategy envisaged that health services would be fully integrated and organised, with the primary care team at the centre delivering over 90% of the health needs of individuals (DoH, 2001). This has not yet been realised with regard to services for children. At community level, a number of teams deliver services to children across a number of divisions, and descriptions of most of these teams are set out below. There is still significant variation across regions in relation to the development of these teams.

Primary Care Team

These services are delivered by a multidisciplinary team (MDT) in a local community geographic area. Primary care delivers a 'cradle to grave' service in a community setting. For GPs, public health nurses and speech and language therapists, most of their day-to-day work with children is at local primary care team level.

Primary Care Paediatric Network-level Services

Primary Care Paediatric Network-level services are services for children aged 0-18 years, which are delivered across a number of primary care teams in a local primary care network. The service is seen as an extended role of the primary care team. Currently, network-level services are not organised within a formal paediatric team structure. Services for children are delivered predominantly by paediatric health and social care professionals (HSCPs) such as paediatric physiotherapists, paediatric occupational therapists, paediatric dietitians, psychologists, social workers who work at network level, as distinct from local primary care team level. Senior medical officers (SMOs)/area medical officers (AMOs) also provide services at network level; such services include developmental screening, second-tier referral clinics, school health services and vaccination programmes. In addition, other professionals provide services for children at and across networks; such services include dentistry, ophthalmology and audiology.

Children's Disability Network Teams

Children's Disability Network teams provide a service to children with a disability from age 0-18 years at primary care network level. These disability teams are currently being reconfigured in some areas and are newly established in other areas, in line with the Progressing Disability Services for Children and Young People (PDSCYP) programme (HSE, 2010). Under the PDSCYP programme a significant proportion of posts have recently been reconfigured to children's disability network teams. SMOs/AMOs and paediatricians also provide a service to these children's disability network teams. Neurodisability is covered in Chapter 33.

Child and Adolescent Mental Health Services (CAMHS)

CAMHS MDTs provide services to children and adolescents with specific mental health issues aged from 0-16 years. CAMHS deliver these services at primary care network level. Reform of CAMHS is currently underway under Vision for Change (DoH, 2006) which includes expanding the age profile to 18 years. CAMHS is covered in Chapter 13.

Services are fragmented, with no unified approach to service delivery across Ireland. There is a significant need for agreement on shared care of children with dual medical diagnoses who are attending primary care services and/or children's disability services services and/or CAMHS. Parents in particular have difficulty navigating the healthcare system, and may have some elements of their child's care delivered by a children's disability network team, whereas other elements of their child's care may be delivered by a local primary care team, CAMHS or acute hospital – but there is no synchronised approach to how services for children are delivered. The array of services for children in the community that are delivered by other divisions is evident from the brief teams/services descriptions outlined above. While these divisions are treated separately from a service planning and financial perspective, it is imperative when describing how services for children in the community should operate that meaningful integration across these divisions is implicit in the service description. It is only by developing, enhancing and incentivising integration of services for children across all divisions at community level – with primary care positioned at the centre – that we can enable true reform of our current healthcare system for children.

Referrals

A significant proportion of referrals to services for children in the community come from public health nurses (PHNs), SMOs/AMOs and general practitioners (GPs). PHNs, SMOs/AMOs and GPs are key professionals who continually identify children with health needs during developmental checks and immunisation appointments carried out in a community setting. Frequently, it is through the National Child Health Surveillance Programme that referrals to other professionals in the community are generated. Delayed milestones can be identified during this screening, which prompts early referral to individual HSCPs, e.g. speech and language therapists (for delayed communication skills) and physiotherapists (for motor delay). Among many other sources of referrals are paediatricians, HSCPs in acute hospitals and, in some instances, parents and schools.

Services at Primary Care Team and Primary Care Network Level

<p>Public health nurse (PHN)</p>	<p>Public health nurses (PHNs) work in a generalist role at local primary care team level. The role encompasses care for all groups including children and families. PHNs work within a defined geographical area, and provide a child health screening and surveillance programmes to all children under the age of five years. In addition, the PHN provides clinical nursing care to children, whereas those with complex needs are managed by a multidisciplinary team with a key worker, if necessary. All children in primary school are offered hearing and vision screening and immunisations, in line with the national immunisation schedule. The current job description for a PHN is outlined in the Department of Health and Children circular 41/2000, which states: <i>The PHN will focus on a district or an area meeting the curative and preventative nursing needs of the population within that area. The PHN will be expected to provide a broad-based integrated prevention, education and health promotion service and act a coordinator in the delivery of a range of services.</i></p>
<p>Speech and language therapist (SLT)</p>	<p>The speech and language therapist (SLT) works at primary care team level to assess, diagnose and treat children aged 0-18 years. Disorders seen include the following:</p> <ul style="list-style-type: none"> – Phonological delay/disorder – Articulation delay/disorder – Motor speech difficulties – Cleft palate – Receptive language delay/disorder – Expressive language delay/disorder – Specific speech and language impairment – Speech/language difficulties secondary to hearing loss – Stuttering – Voice disorders – Management and provision of specific evidenced-based treatment programmes – Consultation, education and training, and collaboration with carers, families, other health professionals <p>The majority of children attending primary care SLTs are referred to just this one HSCP discipline. However, a percentage of these children will have additional disabilities which will require referral to children’s disability network teams or CAMHS. SLTs work with children and their families, teachers and other professionals at universal, targeted and specialist levels in a range of settings in the community. It is well recognised that</p>

	<p>in children who have speech or language difficulties, multiple educational and social difficulties may be noted as they develop, e.g. in early expressive language-delayed children, between 41% and 75% of such children have reading problems at eight years of age (Law et al., 2000). This highlights the importance of early intervention for children with speech and language difficulties. SLTs also manage children with non-complex feeding, eating, drinking and swallowing (FEDS) disorders at primary care level.</p>
<p>Physiotherapists</p>	<p>Paediatric physiotherapists work at primary care network level. One of the primary roles of a paediatric physiotherapist is to assess and provide intervention to children with a range of developmental, sensory, motor, orthopaedic and musculoskeletal problems, which are identified by the PHN/SMO/AMO/GP during child health screening and surveillance, or during immunisation appointments. The majority of referrals to a physiotherapist require input solely from this HSCP discipline. A significant proportion of referrals relate to the presence of plagiocephaly and/or torticollis. Prevalence rates for plagiocephaly have risen fivefold since the introduction of the “Back to Sleep” campaign; in the literature, rates are estimated at between 22.1% and 46.6% of healthy infants aged 7-16 weeks. Prevalence of torticollis is estimated at 1:250 live births (Biolocercerkowski et al., 2008; Pacquereau, 2013). Another significant cohort of children who require paediatric physiotherapy are infants with motor delay. Motor delay may be isolated and may resolve with physiotherapy intervention, but is also frequently the first developmental delay to present itself in an infant who has an emerging disability. The early stages of an infant’s development from birth to 18-24 months are critical for the attainment of developmental milestones and the integration of reflexes into normal movement. Early intervention from a paediatric physiotherapist is crucial in order to ensure that appropriate intervention or onwards referral to a paediatrician and the appropriate multidisciplinary team can be organised where required.</p> <p>Other conditions requiring physiotherapy intervention include brachial plexus palsy; talipes; children with chronic disease, including rheumatological conditions and a range of other presentations affecting movement and function. Health promotion is also integral to the role of the physiotherapist. The role of physiotherapy in education and health promotion in encouraging, supporting and facilitating children’s inclusion in physical activities, healthy weight maintenance and healthy lifestyles that positively influences mental health is of significant value, and should be expanded. Normal childhood gait variations also account for a significant percentage of referrals to paediatric physiotherapists. Audits indicate that 50% of referrals to paediatric orthopaedics fall into this category, with in excess of 90% of presentations being benign.</p>
<p>Occupational therapist</p>	<p>Paediatric occupational therapists work with children at primary care network level who have difficulties with the practical and social skills necessary for their everyday life. Occupational therapists use their expertise to analyse a child’s skills, activities and occupations, and the context of these occupations. As a result of this analysis, appropriate intervention is offered, e.g. advice, treatment, individual or group work. The focus and delivery of intervention depends on the areas identified as most affecting occupational performance, e.g. sensory, motor, cognitive or psychosocial components, activity or environmental accommodations. Occupational therapists working with</p>

	<p>children 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:</p> <ul style="list-style-type: none"> – supporting specific skill development – environmental accommodations – activity modifications <p>Where limited resources are available to children, they are primarily targeted at high-priority occupational therapy-specific issues, e.g. urgent hospital discharges (equipment provision to support activities of daily living such as seating and mobility, bathing aids), meeting the changing needs of children with life-limiting conditions, or health and safety risks (moving and handling, postural needs).</p> <p>These services may be delivered in a clinic setting, at home, in school or in the community. In broad terms, primary care-level occupational therapists provide services for children who meet the following criteria:</p> <ul style="list-style-type: none"> • Non-complex or low level of complexity • Having an expected treatment pathway • Having an expected recovery pathway • Mild/moderate occupational performance challenges • Not meeting typical/expected functions of age group <p>With appropriate resources and skill levels, occupational therapists can address occupational performance issues within the child's natural settings; including supporting developmental difficulties that impact on occupational performance, rehabilitation, management of chronic conditions, and health promotion.</p>
<p>Psychologist</p>	<p>At primary care network level, psychologists treat a range of presentations that are of low-level complexity and may not meet the criteria for treatment by a psychology service in the child's disability network team or CAMHS team. Psychologists working with children and families are required to fulfil a wide range of roles, which include the following:</p> <ul style="list-style-type: none"> • Assessment and diagnosis of individual or system (family, service) problems • Treatment using psychologically-based techniques • Evaluation of the outcomes of clinical intervention • Consultation with other health professionals • Teaching/training of families, psychologists and other health professionals • Research, including service evaluation • Participation in the design and implementation of health promotion/prevention • Management of services both directly and through participation in supervisory board/committees • Supervision of both psychologists and other health professionals

<p>Dietitian</p>	<p>Dietitians work with children aged 0-18 years at primary care network level. Nutrition is recognised as being an essential component of the care of infants, children and adolescents. Children with inadequate nutritional levels may develop a range of problems including:</p> <ul style="list-style-type: none"> • Undernutrition, leading to failure to thrive and growth retardation • Dependence on enteral or parenteral nutrition • Management of gastrointestinal symptoms, e.g. reflux, constipation • Management of FEDS as part of the MDT • Overnutrition, leading to obesity and related disorders, and reduced mobility • Medication-nutrient interactions <p>The benefits of nutritional intervention are well documented, and significant developmental progress has been shown to accompany improved nutritional status. The early identification and referral of those who are at nutritional risk and require dietetic services is an integral component of the care of these children.</p>
<p>Social worker</p>	<p>Social workers work at primary care network level. Their focus is to support the delivery of health and personal social services at local level. This is separate from social work services provided by the Child and Family Agency (Tusla). Delivering such services involves supporting the service user to improve their own circumstances and health status. In this work, the values and related approaches that a primary care social worker uses include advocacy; promotion of independence; an individualised care plan and the promotion of dignity, respect, client choice and self-esteem (IASW, 2008). Social workers in primary care are agents of social change, offering a service to individuals, families, groups and communities that is:</p> <ul style="list-style-type: none"> – voluntary – cradle to grave – generic – open access (anyone, including a service user, can refer) <p>Some of the functions of the primary care social worker include:</p> <ul style="list-style-type: none"> • Holistic needs assessment • Consultation with other health and social care providers • Education and training in health and social care • Community development and capacity building • Concrete service provision • Support counselling and therapeutic services
<p>Community medical service</p>	<p>The Community Medical Service works at primary care network level and delivers a range of clinical, preventive medical, surveillance and screening services, as well as a range of specialised services to individuals and specific groups. These include children, adolescents, older persons, persons with disabilities and socially marginalised groups. The services are delivered at network level, and are underpinned by a population health approach. Community health medicine, like all other medical specialties, is evidence-based. Many of the services delivered are based on primary and secondary legislation.</p>

Staffing Levels

National paediatric staffing levels (combined primary care team and network-level paediatric staffing of all grades) have been estimated as follows:

	WTE	Vacancies
Public health nursing	1,456 (December 2014)	234
Speech and language therapy	289.5 (100% response rate, March 2015)	51.2
Physiotherapy	24.38 (100% response rate, February 2015)	5.3
Occupational therapy	72.0 (100% response rate, June 2015)	10.83
Dietetics	0* (100% response rate, February 2015)	
Social work	81 (March 2015) Note: these staff work across both adult and paediatric services	
Community medical officers (including Principal Medical Officers, Senior Medical Officers and Area Medical Officers)	118.44 (April 2014)	Two PMO posts unfilled at present. Several SMO posts left unfilled during recruitment moratorium.

* There are currently no dedicated paediatric dietetic posts in the community. In some cases, children who should be seen in the community are seen in an acute hospital setting. However, referrals from primary care teams for conditions such as weight management, faltering growth, constipation or anaemia may be seen by the dietetic service in the primary care network.

Drivers for Change

The current system of service delivery for children in the community is difficult to navigate for parents, referrers and service providers alike. Varying access criteria, or what are often interpreted as exclusion criteria, apply across Ireland. In particular, difficulties arise for children who do not have a clearly defined diagnosis. This has resulted in referrers having to adopt an uncoordinated approach to referral, referring to multiple services in multiple divisions simultaneously, in an effort to ensure that a child is provided with a service. Confusion in relation to referral destination leads to children being referred from service to service, where teams try to agree who is responsible for delivering various aspects of the child's health needs.

Referrers are united in their requests for the following clear information to meet the needs of their children and families – this is known as the five “Ws”. Any proposed model of care must make the answers to these questions as simple as possible by proposing a system that is easy to understand and to navigate:

What	What conditions and presentations are appropriate for referral?
When	When does a child with the above conditions and presentations require monitoring, and when do they require referral onwards?
Who	Who to refer to? Who is best placed to meet the child's needs and are concurrent referrals to different professionals/teams required?
Where	Where to direct the referral to? Where does that professional(s)/team work?
Which	Which referral form should be used? Which referral form is accepted by each professional/team?

The HSE Community Healthcare Organisations report (HSE, 2014) recommended that nine Community Healthcare Organisations (CHOs) be established at community level across Ireland, with the reorganisation of community services into 90 local primary care networks. The proposed model of care described below reflects these new structural changes. It is important to note therefore that when discussing a primary care network the report is referring to the proposed 90 local primary care networks, each of which will serve a population of approximately 50,000 people. The impact of this community services reorganisation is just beginning to be felt at community level.

In addition, the Progressing Disability Services for Children and Young People (PDSCYP) programme is currently at different stages of implementation nationally. The programme follows the report of the National Group on Multidisciplinary Disability Services for Children aged 5-18 years (HSE, 2009). The PDSCYP programme, which is being implemented across both primary care and children's disability services, outlines how children with a disability whose needs are defined as 'non-complex' will access future services from primary care, and will no longer access services from a specific disability team. This has significant implications for primary care. The National Coordinating Committee for Primary Care Paediatric Services was established by the HSE in 2011 to oversee the implementation of the PDSCYP recommendations at primary care level. The National Clinical Programme for Paediatrics and Neonatology also has formal links with this committee since March 2015.

The fourth driver of change is the review of the national child health screening and surveillance programme. It is imperative that once a child's health needs have been identified through the updated national screening programme that community services have the capability to meet the health needs of these children and families in a timely and clinically effective manner.

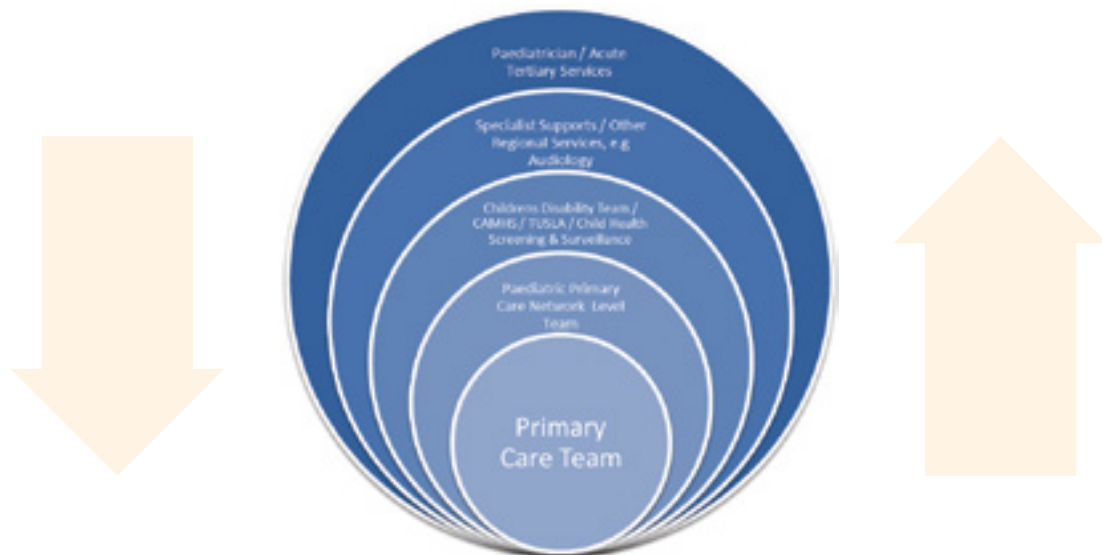
Finally, the Review of Paediatric and Neonatology Services and Framework for Future Development (NCPN, 2013) provided a platform for developing a national model of care for paediatrics and neonatology. The need to improve primary care services for children was identified in that review as one of the ten key pillars that would underpin future healthcare for children and young people in Ireland.

18.2 PROPOSED MODEL OF CARE

This model of care for children with ongoing health needs in the community aims to ensure that a standardised approach to service delivery is adopted throughout Ireland. Equitable, timely access to high-quality, safe and clinically effective healthcare for children is paramount. It is essential that each HSE area has sufficient breadth and depth of services for children and families to meet the needs of its local population. Clinicians working at each level must have the appropriate paediatric skill set to deliver this service. Referrers such as GPs/SMOs/

AMOs/PHNs and service providers must have clear information in relation to nationally agreed access criteria to services for children in the community, and clear information about where those referrals for various services should be directed.

Services for children in the community need to be appropriately linked from local primary care teams to primary care paediatric network teams, through to children's disability network teams, CAMHS and other providers; this is because many children present with co-morbidities and, as such, may access services from a range of providers at any given point in time. Services need to be developed, enhanced and consolidated, so that the needs of children can be met by the appropriate service 'right place, right time, right person'. This can only be achieved by establishing national standards for communication between agencies providing services to children. The primary team delivering services to each individual child and family must be identified, and communication must be centralised around this primary provider. This will help to ensure the best possible outcomes for the child and their family.



Relative relationships across and between community and acute services for children

At each level, there is a requirement for ongoing, robust communication with the primary service provider for the child and family, in order to ensure appropriate integration of services.

The following key principles should underpin a model of care for services for children in the community:

Child-centred and Family-centred Care

Child-centred and family-centred care places children and their families at the centre of everything the service does – by advocating for their needs; protecting their rights, respecting their values, preferences, and diversities; and actively involving them in the provision of care. Child and family-centred care promotes kindness, consideration and respect for the child and the family's dignity, privacy and autonomy. The needs and views of the child and their family should be paramount in the planning and delivery of paediatric services.

- Parents, caregivers and children should be provided with the information they require at all stages of their care journey, including information on access to services and diagnoses.
- There should be a strong emphasis on health promotion and prevention of chronic disease. Multidisciplinary targeted programmes should be expanded in partnership with the Health and Wellbeing Division, Healthy Ireland and local community groups.
- A collaborative approach to goal setting should be adopted, with a focus on the qualitative outcomes that matter most to the child and their family.
- Children and families should be enabled as 'co-producers of healthcare' in line with recommendations from the 2014 HSE Patient Charter (HSE, 2014).
- Children and families should have their ongoing health needs met by staff with appropriate paediatric clinical skills, who understand both the complexity of the child's healthcare needs and the healthcare system itself.
- Services for children and their families should be delivered as close to home as possible in an appropriately designed paediatric facility/space.
- Children with complex care needs cared for at home by parents require the support of staff with appropriate paediatric clinical skills. Relevant voluntary support organisations should be considered as integral to the care plan to ensure maximum support for parents.
- Child protection and welfare should be paramount in the minds of all healthcare providers.
- The need for increased support for parents and families at critical pressure points should be reviewed and subsequently addressed: for example, time of diagnosis, commencing pre-school and primary school, primary to secondary transition, and school leavers' transition needs should all be addressed. Communication pathways with the education sector need to be established along with joint professional development frameworks, and shared models of service delivery. There are many children whose health needs impact on access to the curriculum and socialisation in school, and whose needs would be better met in a school than in a clinical setting.
- Access to appropriate levels of respite services and home support to assist families with therapeutic programmes should be incorporated into national primary care and social care service plans. Nationally agreed access criteria for such supports are crucial, in order to ensure equity of access for children and families.
- Nationally agreed access criteria and standardised administration of the housing adaptation grant need to be developed in partnership with relevant government departments.
- National surveys of the views of children and families accessing the healthcare system should be conducted periodically, in order to enable continuous improvement of the child and family's experience of paediatric healthcare services.

Ease of Access

Simple access criteria need to be established:

- National access criteria have now been agreed by the PDSCYP programme and the Primary Care division; these criteria are not diagnostic based but are based on level of need. The PDSCYP and Primary Care National Policy on Access to Services for Children and Young People with Disabilities and Developmental Delay (draft HSE 2015) is due for publication in 2015, and will help define the needs of a child with a disability as either 'complex' or 'non-complex'. This will then assist clinicians determine whether a child with a disability will have their needs delivered by a primary care paediatric network team or by a children's disability network team.
- National referral pathways should be developed in order to provide clarity in relation to referral pathways to the appropriate children's services, i.e. primary care paediatric network team, children's disability network team, CAMHS and other specialist children's services, e.g. ophthalmology.

- National referral forms for primary care paediatric network teams and children’s disability network teams should be developed, so as to ensure consistency of information provided by referrers, and to assist prioritisation of referrals within teams. The National Policy on Access to Services for Children and Young People with disabilities and developmental delay” includes a suite of draft standardised referral forms which are intended for any child with a disability or developmental delay. This national policy is being developed collaboratively by the PDSCYP programme and Primary Care division for all children’s community services; and the national referral forms, clinical decision making form, referral pathways and other recommendations will greatly simplify the referral process and will also facilitate the inclusion of sufficient clinical information to appropriately manage all paediatric referrals.
- An integrated children’s services forum (ICSF) should be established in each network, in order to further drive integration across services in the community. One particularly useful function of this forum is to facilitate a multi-agency approach for children and families whose needs are difficult to ascertain, or whose needs are particularly complex, and who require services from a number of teams, divisions or agencies, e.g. Department of Health, Department of Education, Tusla. The PDSCYP also propose a forum for children with a disability, but it is recommended that this proposal should be expanded to all children whose needs are complex, and who may require a multi-agency approach; children with a disability are included as part of this recommendation.
- A communication strategy needs to be developed to ensure that primary referrers to services in the community (GPs/SMOs/AMOs, paediatricians, PHNs and HSCPs) are made fully aware of these new national processes. The five “Ws” should be considered as part of this communication.

Adequate resources are needed to ensure that high-quality, equitable services for children in the community are available nationwide:

- Primary care paediatric network teams must be established/organised for each network covering a population of approximately 50,000 people. As part of the workforce planning process, cognisance needs to be taken of the child population covered in each primary care network.
- National access criteria will help to ensure that referrals are directed appropriately in the first instance, thus avoiding unnecessary delays.
- Integrated care pathways should be developed for children accessing services across different healthcare sectors in the community, and across both community and acute hospital settings.
- Transition from paediatric to adult services should be structured.
- An appropriate complement of paediatric HSCPs at primary care network level is required in order to manage the range of clinical presentations referred via the child health screening and surveillance programme, PHNs and GPs; these services should be led by therapists at senior grade level.
- Paediatric HSCPs are also required to manage the future needs of children with a disability whose needs are defined as non-complex, and who will no longer have those needs met by children’s disability services – in line with the recommendations of the PDSCYP programme and the National Policy on Access to Services for Children and Young People with Disabilities and Developmental Delay. These services should be led by therapists at senior grade level; the services must be in place before full implementation of the PDSCYP programme can proceed.
- National standards should be established in relation to acceptable wait times, in order to ensure rapid access to paediatric services in the community within a nationally agreed timeframe. Annual national audit of performance against these standards will be essential, so as to identify pressure points and assist with devising solutions.

Early Detection and Diagnosis

The importance of robust child health surveillance and screening by GPs, PHNs and SMOs/AMOs in the community setting cannot be underestimated. The Child Health Screening and Surveillance (CHSS) programme provides systematic, evidence-based assessment of all pre-school and primary school children at specific nodal points of development. It provides for early identification of health needs and makes appropriate referrals to services that can meet such health needs.

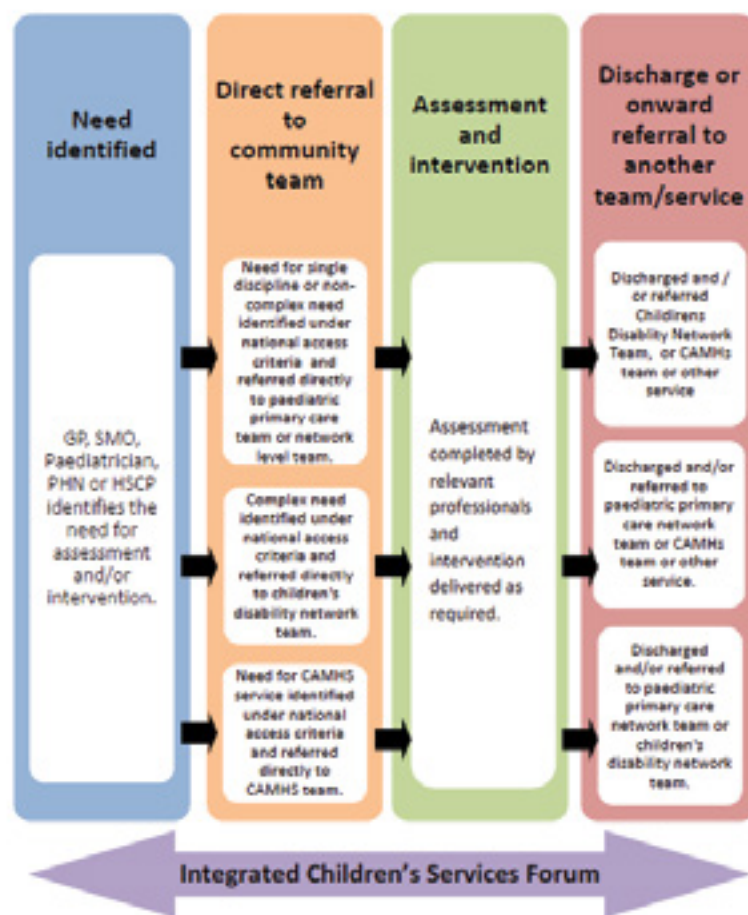
- All children should have timely access to national child health screening and surveillance programmes that will identify children with a range of health needs.
- National care pathways should be developed for children who have health needs identified via developmental screening, so as to ensure that referrals are directed to the appropriate service provider.
- HSCPs with paediatric clinical skills and expertise – and working across a number of primary care teams at primary care paediatric network level – should be available to assess and contribute to early diagnosis and identification of health needs, and to provide therapeutic intervention as required.
- Algorithms and information for referrers and parents for common clinical presentations to primary care should be developed by HSCPs, e.g. tummy time, gait deviations, stammer. Existing resources should be standardised nationally.
- Health promotion for children and families should be incorporated into all service contracts as a primary preventive measure to deal with issues such as childhood obesity.

High-quality Integrated Care

All children and families deserve high-quality paediatric care that is safe, clinically effective, person-centred, and delivered in a timely, efficient and equitable manner.

- All services for children should be delivered in line with international best practice standards.
- Shared information and communications technology (ICT) systems are required in order to facilitate integration within, and between, teams. Any ICT system implemented in the community needs to be integrated with hospital-based systems.
- Frequent communication between all service providers is essential; in particular, this should include communication between the child's GP, paediatrician or PHN. Arrangements to facilitate effective communication between MDTs who are working to deliver integrated care are essential. Where appropriate space exists, co-location would greatly facilitate this process. Sharing of necessary information to facilitate the safe transfer or sharing of care in a timely and appropriate manner, and in line with relevant data protection legislation, is key.
- National standards should be agreed regarding appropriate and consistent written communication between all agencies providing services to children. The primary team delivering services to each individual child and family must be identified, and communication should be centralised around this primary provider.
- All staff working with children must have appropriate paediatric clinical skills and experience. In the case of professions such as physiotherapy, occupational therapy and dietetics, paediatrics is a subspecialty requiring specific training and clinical expertise. Paediatric HSCPs work with children across a number of primary care teams at primary care paediatric network level, with an exclusively paediatric caseload that provides a sufficient critical mass of paediatric presentations to retain each professional's clinical competence.
- Robust clinical governance arrangements should be in place for each discipline in line with 'Clinical Governance - We are all responsible' Quality and Safety Clinical Governance Development Recommendations (HSE, 2013). Clinical governance for each professional working at community level must be provided by their relevant head of discipline, so as to ensure adherence to professional standards, monitoring of clinical effectiveness, and facilitation of appropriate continuous professional development (CPD).

- Competency frameworks should be devised for each profession working across the spectrum of community services for children, so as to ensure that each professional is clear about what is expected of them in fulfilling their roles, and that managers can support their staff by implementing the appropriate performance management cycle for each staff member.
- Annual national audit of access criteria should be completed, in order to ensure consistency of service delivery locally.
- Annual national audit of local adherence to integrated care pathways for children accessing services across acute and community settings should be completed, in order to ensure adherence to national standards and consistency in service delivery.
- Annual national audit of waiting time to access paediatric services at each level should be completed, in order to identify problems and assist in devising solutions.
- Team-based clinical research and outcome measurement should be supported, in order to drive clinical effectiveness.
- Team-based clinical risk management should be supported at CHO level.
- The Review of Paediatric and Neonatology Services and Framework for Future Development (NCPNP, 2013) recommended the establishment of paediatric clinical networks in the community, in order to ensure a cohesive approach to the management of healthcare for children. Furthermore, both hospital group and CHO paediatric clinical networks need to work closely together to appropriately manage the interface between both the acute and community sectors.



1. Need for Assessment and/or Intervention Identified

The need for assessment and/or intervention can be identified by a variety of sources. In an acute hospital setting, referrals may come from an acute maternity or paediatric ward/outpatient clinic. The need for assessment and/or intervention may also be identified by a HSCP in an acute hospital setting. In the community, the referral may come directly from a GP/PHN, SMO/AMO, or any health professional working with children. Some disciplines accept referrals directly from parents and schools. Referrals may also come from the local assessment of need officer.

The full breadth of a child's healthcare needs may not be immediately identifiable, but referrers should be able to identify if a child appears to have a need for one discipline or, alternatively, if a child's needs appear to be non-complex, based on using the National Policy on Access to Services for Children and Young People with Disabilities and Developmental Delay. This will assist the referrer in decision-making. The referrer may also simultaneously refer the child to their local paediatrician. The referrer needs clear information about the five "Ws" in order to direct the referral to the most appropriate service in the first instance. For simplicity, all referrals should be directed to the local primary care paediatric network-level team, unless it is immediately apparent that a child may have complex needs, based this policy.

2. Referral to Primary Care Paediatric Network Team: Non-complex Needs Identified

The need for single-discipline assessment, or assessment from one or more discipline for a child who presents with a low level of complexity, is identified. These children would have an expected assessment and intervention pathway, an expected recovery pathway and/or expected discharge plan. They may, for example, be not meeting typical or expected milestones for their age – as in the case of a child with a stammer who requires SLT; a nine-month-old child with gross motor delay who requires physiotherapy; a child with handwriting difficulties who requires occupational therapy, or a baby with failure to thrive who requires intervention by a dietitian. Children who fall into one of these categories should be referred to the primary care paediatric network team who can then decide if the referral can be managed by the local primary care team, e.g. SLT, or whether they require a response from paediatric HSCPs in the primary care paediatric network team.

The primary care paediatric network team should have access to dedicated multidisciplinary clinics for assessment and intervention. Referrals should be completed on a national standardised referral form, providing sufficient levels of information to assist in prioritising referrals. Assessment and intervention is provided where appropriate and the child is discharged back to the referrer when their health needs have been met. If the primary care paediatric network team feel that further assessment or intervention is required by a children's disability network team or CAMHS, then a referral is directed to the appropriate team on the relevant national standard referral form, and the child's case may be raised at the ICSF if required.

3. Referral to Children's Disability Network Team: Complex Needs Identified

Children who require interventions from multiple disciplines in order to meet their health needs are likely to have needs that are complex in nature, and, as such, a referral to the appropriate local children's disability network team is indicated. Complexity may be influenced by external and/or social factors impacting on the child; moderate to severe difficulties impacting on the child's participation in activities of daily living and by the child's interactions, and/or co-morbidity.

Children's disability network teams are divided into two categories:

- Early intervention team (EIT), and
- School-aged team (SAT)

Children whose needs have been identified as complex using the National Policy on Access to Services for Children and Young People with Disabilities and Developmental Delay will be seen by the local EIT or SAT. Clarity for referrers is required in each HSE area with respect to what local teams are in place (both statutory and voluntary). Teams should have contact details for referrers, so that they can discuss potential referrals if required. Referrals should be completed on the nationally agreed standard referral forms. Assessment and/or intervention is provided by the local EIT or SAT. If the children's disability network team identify that further assessment and or intervention is required by another specific team, e.g. CAMHS, or if they require access to specialist supports, e.g. spasticity management/FEDS, then a referral is directed to the relevant service on a nationally agreed standard referral form. It is important to note that many children at this level will require a shared care arrangement both across teams and agencies, while continuing to have many of their health needs met by the EIT or SAT. A small cohort of children with complex medical needs will have their health needs met across primary care and social care. These children should be discussed at the ICSF, in order to ensure that they are receiving the correct service at the right time in the most appropriate setting.

4. Referral Directed to CAMHS Team: Child or Adolescent with Mental Health Issues

Referrals should be accepted directly from GPs, paediatricians, the local primary care paediatric network team, psychologist or local children's disability network team, based on nationally agreed access criteria. Assessment and/or intervention is provided at this level, and the child will then be referred back to their primary care or disability team for ongoing management where appropriate. It is important to note that many children at this level will require a shared care arrangement both across teams and agencies, e.g. Tusla, CAMHS, while continuing to have many of their health needs met by the EIT or SAT.

5. Integrated Children's Services Forum (ICSF): Child with Complex, Incompletely Defined Needs Identified and/or Child Requiring a Synchronised Multi-agency Approach

An ICSF should be established at network level to drive integration of services. The ICSF would function as the clinical link for all community teams, and would also provide a link between multiple agencies delivering health and social care services. The ICSF would review a small cohort of complex referrals where the referral destination is unclear or where a multi-agency approach across health, education and, for example, Tusla, is required. An ICSF would improve integration of paediatric services between primary care, disability, CAMHS, and other teams providing services to children in a network, in particular during a period of reconfiguration of services. The need for an ICSF may diminish over time as referrers and service providers become clear in relation to nationally agreed referral pathways and access criteria. Progress on highly complex multi-agency cases requiring further assessment should be tracked and reported to the ICSF on a monthly basis. The ICSF would not be required for all cases; rather, it would be required solely for children who need to access health-care from a variety of teams in an integrated manner, or in cases where there is no clear picture as to where a child's needs will be best met. In order to be effective, the ICSF must establish a governance structure, work within clear terms of reference, and have the authority to make decisions in relation to referral destination.

18.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF THE MODEL OF CARE

Workforce Planning

In 2012, the Department of Health (DoH) committed to work with the HSE to implement an approach to workforce planning and development that includes recruiting and retaining the right mix of staff, training and upskilling the workforce, providing for professional and career development, and creating supportive and healthy workplaces. One of the DoH priorities for the period 2015–2017 is to build a sustainable workforce through the development of a National Integrated Strategic Framework for Workforce Planning (DoH, 2012).

The National Human Resources Directorate Workforce Planning, Analysis and Informatics Division is currently working on the development of the national framework. The NCPPN should link formally with the Workforce Planning, Analysis and Informatics Division to help inform the division of the clinical and non-clinical resource requirements needed in order to implement this model of care. Each profession must contribute to the required workforce planning, which should be coordinated by the HSE. Specific HSCP and nursing workforce recommendations for all paediatric teams should be developed in partnership with the relevant professional bodies, in order to help the HSE and the NCPPN to plan and develop paediatric services in the community.

Dietetics	A recent survey of primary care dietitians showed that paediatrics accounts for up to 50% of these dietitians' workload, despite the lack of dedicated paediatric community posts. The Irish Nutrition and Dietetic Institute (INDI) recommends that all primary care teams have access to a paediatric dietetic service at primary care network level, that all primary care teams, EITs, SATs and specialist teams should be trained in nutrition risk screening, and that access routes to local dietetic services are identified. The minimum requirement is one WTE senior dietitian per primary care paediatric network team, with 50% of this post allocated to children with disabilities. The early identification and referral of those who are at nutritional risk and who require dietetic services is an integral component of the care of these children.
Occupational therapy	Occupational therapy for children involves a specific skill set, and there is a need to have additional skilled, dedicated paediatric occupational therapists in place. Services for children should be organised and delivered at primary care paediatric network level. The minimum requirement is one WTE senior occupational therapist (with appropriate cover for leave provided) per primary care paediatric network team to lead the paediatric service; this occupational therapist should be supported by staff grades according as service activity demands. This staffing level is required to deal with the existing caseloads in the community and also to deal with children with a disability whose needs are defined as non-complex, and who will no longer have access to the children's disability network teams. In addition, one WTE clinical specialist paediatric occupational therapist is required for each CHO to lead quality improvement, training and research.
Physiotherapy	Paediatric physiotherapy is a specialised area of work and, as such, the Irish Society of Chartered Physiotherapy (ISCP) recommends that paediatric physiotherapy services in the community must be led by a paediatric physiotherapist at senior grade level. Paediatric physiotherapy services should be organised and delivered at primary care paediatric network level. The minimum requirement is one WTE senior physiotherapist

	to lead the paediatric service and one WTE dedicated staff grade physiotherapist (with appropriate cover for leave provided) per primary care paediatric network team. These physiotherapists should be supported by additional staff grades, according as service activity demands. In addition, one WTE clinical specialist paediatric physiotherapist is required for each CHO to lead quality improvement, training and research. This staffing level is required in order to deal with the existing caseloads of child health presentations, health promotion and also in order to care for children with disability whose needs are defined as non-complex and who will no longer have access to the children's disability network teams. If no local hospital respiratory outreach service is available, an additional clinical specialist to deal solely with paediatric respiratory physiotherapy in an outreach model across each CHO will be required.
Speech and language therapy	The minimum requirement is two WTE senior SLTs (with appropriate cover for leave provided) per primary care paediatric network team to lead the paediatric service; these SLTs would be supported by one WTE staff grade SLT per primary care team, according as service activity demands. This staffing level is required in order to deal with the existing caseloads of SLT staff, and also in order to care for children with a disability whose needs are defined as non-complex and who will no longer have access to the children's disability network teams. In addition, one WTE clinical specialist paediatric SLT is required for each CHO to lead quality improvement, training and research.
Social work	The recommendation from the Irish Association of Social Workers (IASW) is one principal social worker per CHO area; between five and six social work team leaders per CHO; and between three and five social workers to work with each social work team leader. These social workers would continue to work across both paediatric and adult services.
Public health nursing	It is recommended that one PHN should serve a population of 2,500 people. In reality, however, the PHN's catchment population may vary from 1: 2,500 to 1: 5,099 (HSE, 2002). The minimum requirement currently for the public health nursing service is that all vacant posts should be filled. This will ensure that PHNs are in a position to deliver services at primary care team level in accordance with the recommendations set out in the Community Healthcare Report (2014). The recently published Emergency Department Taskforce Report (HSE, 2015) recommends that a workforce planning exercise be undertaken for community nursing. This project will be led by the Department of Health, and is due to commence in 2016.
Community medical service	The future role of the SMO/AMO will be dependent on a number of processes which are currently ongoing, e.g. the outcome of the Child Health Review, and developments in immunisation programmes. The principal medical officers have established links with the Royal College of Physicians of Ireland Faculty of Paediatrics regarding the development of the SMO/AMO role in the provision of community paediatric services.

Infrastructure

Appropriate infrastructure, which enables children to access services in the community, should be delivered according to a nationally agreed specification. Primary care paediatric network teams and children's disability teams could potentially share dedicated paediatric space in some locations where suitable accommodation already exists. A national review of current accommodation for paediatric services at primary care network level should be undertaken, in order to establish what accommodation is required. An action plan to develop appropriate paediatric spaces should be developed, based on the findings in the national review.

Administrative Support

The critical nature of administrative support for healthcare professionals working with children and families in the community cannot be underestimated. Appropriate levels of administrative support for frontline paediatric clinical services are essential in order to minimise the loss of productivity resulting from clinicians performing administrative functions in addition to delivering therapeutic intervention. Administrative support staff are often the first point of contact for children and families and, as such, they are a key communication link. Administrative support staff assist with scheduling and issuing appointments, in particular, appointments requiring multiple team members; they also assist in managing waiting lists. Primary care paediatric network teams require dedicated administrative support. Appropriate cover for leave also needs to be considered when assigning administrative support to the primary care paediatric network team.

Information and Communications Technology (ICT)

Appropriate information and communications technology (ICT) support is required for the safe and confidential transfer of data and information across the health services. ICT and secure email access should be available for all community staff members; such access is essential in order for different components of the health system to communicate effectively. Primary care services in all areas should have access to the integrated patient management system (iPMS) to track paediatric admissions to acute hospitals for children with disabilities or for children who have complex medical needs in the short term. In the medium to long term, a common ICT system needs to be developed for all community services; this would integrate with existing acute hospital ICT systems as well as the proposed paperless ICT systems in the new children's hospital.

The benefits of this would be twofold. They would:

1. Facilitate and encourage effective communication and sharing of information across teams and services, which would in turn drive the integration of services.
2. Capture clinical activity and other relevant service-related data for future planning and auditing of performance against key performance indicators.

Additional development of the pilot of Healthlink, a confidential system for emailing GPs, should be further explored and implemented.

Education and Training

In the case of physiotherapy, dietetics and occupational therapy, paediatrics is a subspecialty area, requiring both specific additional paediatric training and clinical expertise. Appropriate, dedicated time for all staff to complete continued professional development is essential. Training needs should be identified as part of the performance management cycle. All staff working with children must have appropriate paediatric clinical skills and experience, and must work within their scope of practice. All staff members should have access to professional support that is delivered in a variety of ways, including attendance at relevant paediatric courses, peer support, preceptorship and shadowing other clinicians. Competency frameworks should be devised for each profession working across the spectrum of community services for children. Sharing of skills between team members is highly recommended both formally through in-services, and informally through joint working. Study leave should be facilitated for all staff in a standardised manner across all community areas. Updated, evidenced continuing professional development (CPD) is also a requirement for professional registration.

18.4 STANDARDS FOR PROGRAMME METRICS AND EVALUATION

- Proportion of integrated primary care paediatric network teams with recommended staffing levels in place.
- National standard for access to paediatric services set at 12 weeks. There should be an annual audit of waiting time for both initial assessment and subsequent intervention irrespective of whether a child accesses a primary care paediatric network team or a children's disability network team.
- National access criteria for children's disability network teams and primary care paediatric network teams should be agreed and implemented nationally in line with the National Policy on Access to Services for Children and Young People with Disabilities and Developmental Delay. Audits of compliance with the national access policy should be completed annually.
- National integrated care pathways should be developed for children accessing services across healthcare divisions in the community. Annual audits should be completed in order to assess performance against the standard.
- National integrated care pathways should be developed for children accessing services across both community and acute hospital settings, with an annual audit completed in order to assess performance against the standard.
- National integrated care pathways should be developed for structured transition from paediatric to adult services, with an annual audit completed in order to assess performance against the standard.
- National standards regarding appropriate written and consistent communication between all agencies providing services to children should be agreed, with communication centralised around each child and family's primary service provider. Annual audits should be completed, in order to assess performance against the standard.
- Outcome measures need to be developed, in order to assure the quality and effectiveness of interventions.

18.5 KEY RECOMMENDATIONS

- Primary care paediatric network teams must be established/organised for each network covering a population of approximately 50,000 people. This will involve reconfiguration of existing staff in primary care working with children.
- Complete a mapping exercise across community services in order to establish the MDT staffing levels providing services to children and families.
- Increase paediatric HSCP staffing levels in primary care teams and primary care paediatric network teams, in order to provide safe, accessible and effective services.
- Increase senior paediatric HSCP staffing levels in primary care paediatric network teams, in order to provide appropriate leadership and clinical governance, and also in order to lead safe, high-quality, clinically effective service provision.
- Develop a nationally approved competency framework for healthcare professionals working with children in the community to ensure that there is appropriate paediatric skills and competencies to standardise healthcare provision.
- Enhance integration within and between teams, services and settings, so as to ensure a child-centred and family-centred service.
- A common ICT system needs to be developed for all community services; this would integrate with existing acute hospital ICT systems.
- Develop appropriate outcome-based key performance indicators, in order to monitor the effectiveness of interventions.

18.6 ABBREVIATIONS AND ACRONYMS

AMO	Area Medical Officer
CAMHS	Child and Adolescent Mental Health Services
CHO	Community Healthcare Organisation
CPD	continuing professional development
DoH	Department of Health
EIT	early intervention team
FEDS	feeding, eating, drinking and swallowing
GP	general practitioner
HSCP	health and social care professional
HSE	Health Service Executive
IASW	Irish Association of Social Workers
ICSF	Integrated Children's Services Forum
ICT	information and communications technology
INDI	Irish Nutrition and Dietetic Institute
IPMS	Integrated patient management system
ISCP	Irish Society of Chartered Physiotherapists
MDT	multidisciplinary team
NCPPN	National Clinical Programme for Paediatrics and Neonatology
OT	occupational therapist
PDSCYP	Progressing Disability Services for Children and Young People
PHN	public health nurse
PMO	Principal Medical Officer
SAT	school-aged team
SLT	speech and language therapist
SMO	Senior Medical Officer
WTE	whole-time equivalent

18.7 REFERENCES

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