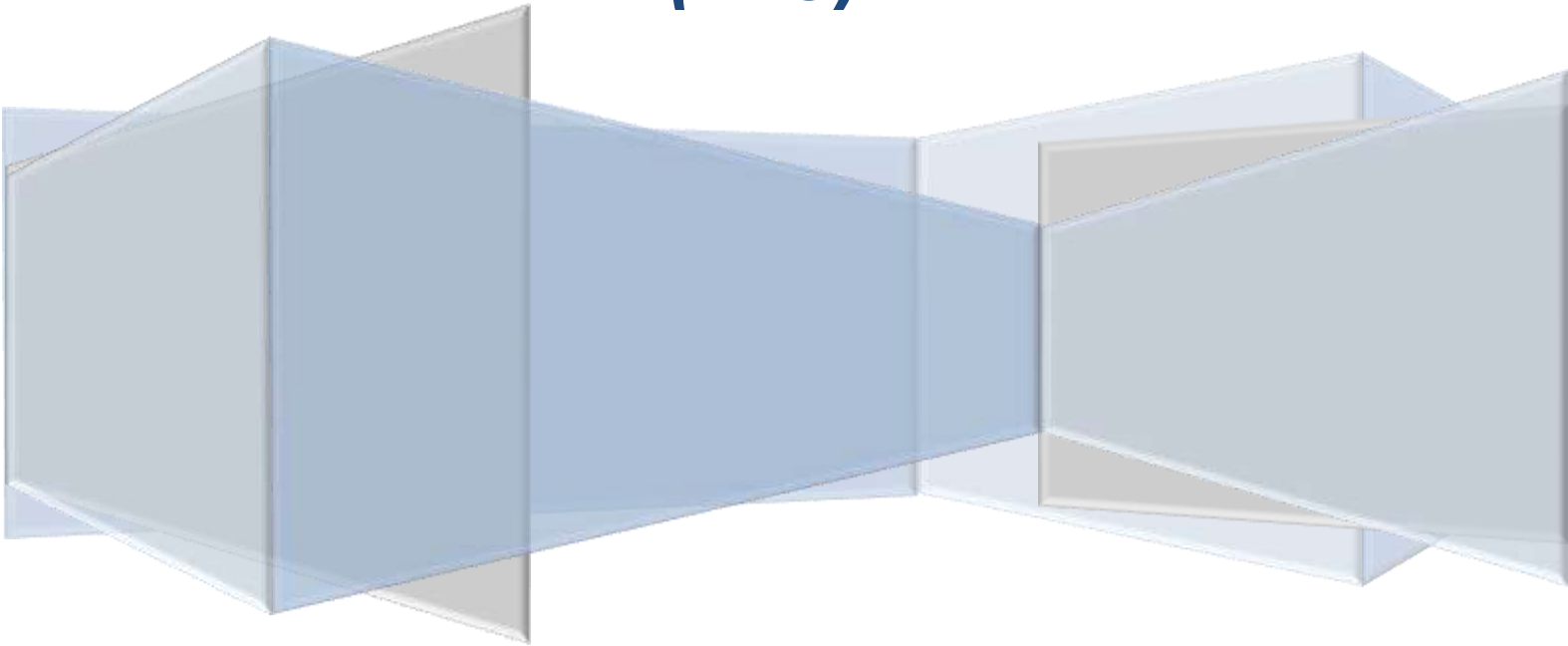




Progressing Disability Services for Children and Young People Programme (PDS)



February 2020

Progressing Disability Services for Children and Young People Programme (PDS)

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Note: for all PDS related policies, protocols, guidance documents referenced within this document, please see www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/

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1. Children's Disability Services

Children's disability services are health services for children and young people¹ up to 18 years² of age with a disability or developmental delay. The majority of these services are provided by voluntary agencies, funded by the HSE and others are provided directly by the HSE. Services usually include nursing, occupational therapy, physiotherapy, psychology, speech and language therapy and social work amongst others.

2. Why do Children's Disability Services need to change?

Services developed in an ad hoc way across the country based on local needs. Many organisations provide services for children with a particular disability only. This means that in one area, there may be excellent services for some children with a particular diagnosis and little or no service for children with a different diagnosis. Children with the same diagnosis may have very different needs. For example, a child with 'mild autism' may need very little, albeit critical, health service supports whilst another child with 'severe autism' may have significant health service needs, requiring full support of a team of professionals working closely together with them and their family. Children's Disability Services are changing from diagnosis based to needs based so that all children with a disability or developmental delay have access to the right service based on their need.

3. What is PDS about?

Progressing Disability Services for Children and Young People Programme (PDS) is a significant change programme for the provision of therapeutic services for children from birth to 18 years of age. It is being rolled out nationally by the HSE in partnership with its funded voluntary organisations. PDS will

- Provide a clear pathway and fairer access to services for all children with a disability.
- Make the best use of available resources for the benefit of children and their families

¹ Throughout this document, reference to 'children' includes those aged from birth to eighteen years of age.

² Some may access children's disability services up to 19 years of age in line with finishing post primary school

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- Ensure effective teams working in partnership with families and with education staff to support children with a disability to reach their full potential.

PDS requires pooling together all resources, including staff, facilities and equipment, from the different voluntary agencies and the HSE providing specialist children's disability services, in order to set up **Children's Disability Network Teams (CDNTs)**. A CDNT comprises a team of health and social care professionals who will provide services for a specific geographical area. Once all teams are in place, there will be full national cover.

4. How will these changes benefit children with a disability?

A child's access to services will be based on his/her needs, i.e. a diagnosis will not be required. Instead of a service providing for children with one type of disability only, resulting in some children unable to access a service, each CDNT will provide for all children with complex need arising from their disability who live in that area. Children with non-complex needs will receive services at Primary Care level. A small number of children with very complex needs will need a level of expertise which may not solely be met by Primary Care services or the Children Disability Network Team. Specialist services will be developed to support and work with the CDNT and Primary Care services to meet the needs of this group of children.

5. Why would a child need these services?

When children are diagnosed with a disability or there are concerns that his/her development may be delayed, it is important that parents are supported to provide the extra care their child needs to reach their full potential. For example, a child may need medical or therapy interventions for their health and development. Parents may need new knowledge and skills to encourage their child's communication or movement, or positive behaviour support strategies and practical supports to help the family.

6. How will a child access these services?

When the CDNTs are in place, parents/legal guardians, healthcare professionals including general practitioners, hospitals, assessment officers and case managers, and education staff can refer a child aged from birth to 18 years for services.

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Referrers will submit a completed national *Children's Services Referral Form*, including signed parental consent, and an age specific *Additional Information Form* to the local Primary Care Service or Children's Disability Network Team. These two forms will allow services to accept and prioritise referrals fairly and consistently – a key objective of PDS. Referrers should attach any relevant existing reports.

The team will review this information to determine the most appropriate service(s) for the child at this time. If another service is more appropriate, the team receiving the referral will advise the parent(s) e.g. a child with profound hearing loss and cochlear implants referred to a CDNT but who only requires SLT is more appropriate for primary care services. With the parent(s) consent, the team will then discuss the referral with the appropriate service. On agreement with that service, the team will transfer the referral and all relevant documentation to the more appropriate service and inform the referrer/parent. Parents will receive a confirmation note from the service accepting the referral with an estimate of when they can expect to have a first contact.

Where the referring information does not clearly indicate the most appropriate service for a child, the service receiving the referral will contact the referrer for more information and where necessary, discuss the referral with other appropriate services to agree the most appropriate service for the child at this time. In some cases, where agreement cannot be reached on the most appropriate service or on joint working of two services with the child, the referral documents and information gathered will be forwarded to the **Integrated Children's Services Forum (ICSF)**. This is a local meeting of relevant services and healthcare disciplines, and, where necessary, hospital service, Tusla, Education and others. The ICSF will agree the most appropriate service to meet the child's needs at this time. This may include a shared care plan across a number of services agreed in the ICSF depending on the child's needs. See *HSE Primary Care, Disability & Child and Adolescent Health Joint Working Protocol* and *National Policy for Access to Services for Children and Young People with a disability & Developmental Delay 2019* and the *HSE Primary Care, Disabilities and Child and Adolescent Health Joint Working Protocol (2017)*. For more details, please see

<https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents>

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7. Principles of PDS

These twelve principles are the foundation for the type of service that CDNTs will provide. They were developed by the National Children's Programme Oversight Group, based on evidence and consultation with staff and parents.

1. Accessibility	7. Equity of Access
2. Accountability	8. Evaluation of outcomes
3. Bio-psychosocial model	9. Family centred practice
4. Clinical governance & evidence based practice	10. Inclusion
5. Cultural competence	11. Interdisciplinary team
6. Early detection & referral	12. Staff are valued and respected

Table 1: Principles of PDS

See Policy *Framework for Service Delivery of Children's Disability Network Teams*:

www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/

8. How does PDS link with current national policy on providing supports for children and their families?

Community Healthcare Organisations – Report and Recommendations of the Integrated Service Area Review Group (2014) puts Primary Care at the centre of community health services with better integration and access to specialised services in Disabilities, Mental Health and Health and Wellbeing. Community Healthcare Networks are being implemented across the country to deliver this change and will reshape how we deliver community health care services. A Community Healthcare Network will deliver Primary Health Care Services across an average population of 50,000 and consist of 4-6 primary care teams including General Practice (GPs) working collaboratively to ensure better coordinated care for people using services. <https://www.hse.ie/eng/services/list/2/primarycare/community-healthcare-networks/>.

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All CDNTs will align geographically with the 96 Community Healthcare Networks, enabling staff in both services to work better together, in order to ensure the best outcomes for each child with a disability and their families using our services.

Sláintecare Report (2017) is a cross government agreement on a 10 year programme for Irish health and social care services. Two clear objectives of this report are to

- Provide the majority of care at or as close to home as possible
- Create an integrated system of care with healthcare professionals working closely together.

CDNTs will provide services based on the child's home address in line with Sláinte Care. Implementation of the **National Access Policy** (see 9.1) will drive Disability and Primary Care staff to work more closely from the time a referral is received, in order to ensure a clear pathway to the right service for each child and their family without further delay. The **HSE's Primary Care, Disability, Child and Adolescent Health Joint Working Protocol** (2017) (9.2) will also require staff across the three health service areas to work more closely, to enable children with a disability to access the services they need.

9. How will we ensure that the three PDS objectives are achieved?

The PDS objectives are to

- i. Provide a clear pathway and fairer access to services for children with a disability and their family, based on their need, not diagnosis, where they live or go to school
- ii. Make the best use of resources for the benefit of children and their families
- iii. Work in partnership with families and education staff to support children with a disability to reach their full potential.

9.1 National Policy for Access to Services for Children and Young People with a Disability and Developmental Delay

This policy, shortened to the National Access Policy (NAP), will be implemented across all CDNTs and Primary Care. It provides a clear pathway to the most appropriate health service for children with a disability or developmental delay and their families.

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Some children have health needs such as a mild delay in the development of their speech which can be met by their local primary care service. This service typically includes public health nurses, GP, community speech and language therapists, occupational therapists, physiotherapists, psychologists amongst others. Other children may have more significant difficulties called 'complex needs' requiring services of a team working closely together i.e. the Children's Disability Network Team (see 13.4 re interdisciplinary working).

Services will be provided by the team covering the child's home address. Where significant numbers of children with complex needs (see 3.4 of the policy) attend a special school outside of the catchment areas of the CDNT, local arrangements may be agreed that allow these children to access the team nearest that special school. This arrangement should be clearly defined and must take full cognisance of the principles of service delivery for CDNTs. In this case, it does not mean that this service provision would necessarily be school based, or that services for these children will be prioritised over services for children attending mainstream school. Each CHO must have a process in place to consider any exceptional individual circumstances that may require a child to access an alternative CDNT to that determined by their home address.

As stated previously, where the referral information does not clearly indicate the pathway to the most appropriate service(s), the service receiving the referral will contact the referrer for more information and where necessary, discuss the referral with other services to agree the most appropriate service for the child at this time. In some cases, where agreement cannot be reached on the most appropriate services or on the need for joint working of two services with the child, the referral and additional information gathered will be forwarded to the Integrated Children's Service Forum for review by representatives of the relevant services e.g.

Disabilities, Primary Care, CAMHS, to agree the right service and lead provider. See the NAP at www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/

9.2 Primary Care, Disability, Child and Adolescent Health Joint Working Protocol (2017)

This Protocol aims to ensure HSE Community Services and voluntary organisations work together effectively and efficiently to support children with a disability and their families to access the service(s) they need in a timely manner within available resources. It provides clarity on:

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- Roles and responsibilities of each of the three services
- A more seamless and timely referral pathway to the right service at the right time
- How services work together on joint assessment and intervention where needed
- Keeping families fully engaged throughout the process
- Referring a case to the Integrated Children's Service Forum (ICSF) and purpose of the ICSF.

9.3 Joint Protocol for Interagency Collaboration between the HSE and Tusla – Child and Family Agency to Promote the Best Interests of Children and Families (2017)

This protocol, known as the HSE Tusla Joint Protocol, sets out clearly the responsibilities for staff of both organisations in working together to support children with a disability and /or mental health condition in state care and also in planning for their transition on reaching adulthood from state care to alternative appropriate supports. This may include joint assessment and/or intervention, and joint clinical meetings

Where a concern is raised by HSE Primary Care, CAMHS or Disabilities/ HSE funded agencies or Tusla, the protocol provides a stepped pathway and structures to resolve the concern at the earliest stage possible. This begins with a discussion at local level between the two services involved where most issues are addressed. Where that is not possible, the concern is escalated to the Local HSE/Tusla Joint Working Group to resolve and in rare exceptions where it is not resolved here, escalated to the HSE Chief Officer and Tusla Service Director to reach an agreement. The Local Area Joint Working Group is also tasked with joint transition planning for young people with a disability or mental health condition from state care to appropriate alternative supports at 18 years of age and also, for those with a child protection plan in place who would be deemed a vulnerable adult on turning 18. See the Protocol at www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/

This interagency forum provides an opportunity for educating frontline staff on work systems of both organisations e.g. Tusla's Signs of Safety, Thresholds and Meitheal, HSE Disabilities needs led policy and programmes, and specialist areas e.g. ASD. It also can explore opportunities to integrate with local Children and Young People Service Committees.

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9.4 Outcomes for Children & their Families, An Outcomes Focused Performance

Management & Accountability System for Children's Disability Network Teams (2013)

Implementation of the OCFF will change how we deliver services. It requires a fundamental shift for staff from how they were trained to work with service users and families where they deliver 'expert' interventions to the child and family to an authentic child and family centred model where the parents/carers and their children are empowered to set and achieve their own goals, (often different to those of staff) supported by the team. For example, families, including their child or young person (depending on age and maturity), are supported through an Individual Family Service Plan process to identify what their primary goals are and how the team will support the child and family to achieve their goals. This also involves a large shift for families. Ultimately, the benefit of this seismic shift will be families who are empowered to support their children in belonging and participating actively in their community alongside their peers, in line with the UN Convention on the Rights of Children and the UN Convention on the Rights of People with a Disability.

An OCFF working group is progressing roll out of the framework, including development of a suite of process and outcome indicators for trial in the Mid-West Community Healthcare. Ultimately, CDNTs will move from reporting on single discipline outputs e.g. number of interventions delivered to outcomes achieved by children and families as a measurement of team performance and efficacy.

9.5 Framework for Collaborative Working between Education and Health Professionals (2013)

This framework was developed by a group comprising a parent representative, health and education representatives on consultation with parents/carers, health and education staff. Its purpose is to identify and address gaps between health and education in provision of services with a focus on joined up planning and working together to support children and young people in and through key transition phases in their lives e.g. from preschool to primary school, primary to post primary school etc. A National Education and Health Collaborative Forum is in place to oversee the implementation of the framework's recommendations. They include setting up local Education and Health Fora including parent representatives, an online national directory of services and supporting local fora to use the integrated guidelines on

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Transitions Planning template in the framework to develop their own local pathways for key stages of transitions.

10. Who is responsible for ensuring all of this is rolled out across the country?

Each of the nine HSE's Community Health Organisations (CHOs) is led by a Chief Officer with responsibility for implementation of all national policies within their area. Each Chief Officer has a CHO lead for PDS roll out and a number of local implementation groups (LIGs), each covering a geographical area within the CHO. LIGs include representatives of the HSE and voluntary agencies providing local children's disability and primary care services, and parents. LIGs are tasked with planning and reconfiguring children's disability services into CDNTs under the PDS Programme.

Children's Disability Network Managers (CDNM) will provide leadership for the CDNTs and be accountable and responsible for the delivery of high quality, safe, integrated children's disability services to the population of the Community Healthcare network (see 13.3). CDNMs will be key players in planning and leading the implementation of the final CDNTs with their LIGs and CHO PDS Leads.

A National Children's Disability Network Manager Forum will be responsible for ensuring models of service developed and implemented are evidence based, sustainable in the long term and most critically, child and family centred in line with PDS principles.

The Head of Operations – Disabilities and his team will continue to provide direction, support and oversight of PDS implementation, driving a consistent approach to implementation of PDS.

11. How are parents and families involved?

In addition to the parent voice on the National Children's Programme Oversight Group and parent representatives on Local Implementation Groups (LIGs), some areas have a parent forum in line with National PDS Guidance on Family Forums from where representatives are nominated onto LIGs. There will be further opportunities for engagement on local Education and Health Fora (see 9.5). Parents/carers are also encouraged to feed in directly to their local services, all of whom will be engaged in PDS roll out.

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12. When will PDS be fully rolled out across the country?

Fifty six CDNTs are in place, providing services for children aged from birth to 18 years or from birth to 6 and 6 to 18. The remaining teams are to be set up in 2020 to achieve national cover. Figure 1 shows areas in green where all teams are set up, orange where early intervention teams are in place and red areas in pre-reconfiguration planning. Note, the latter continue to provide disability services for children up to 18 years of age with a disability.

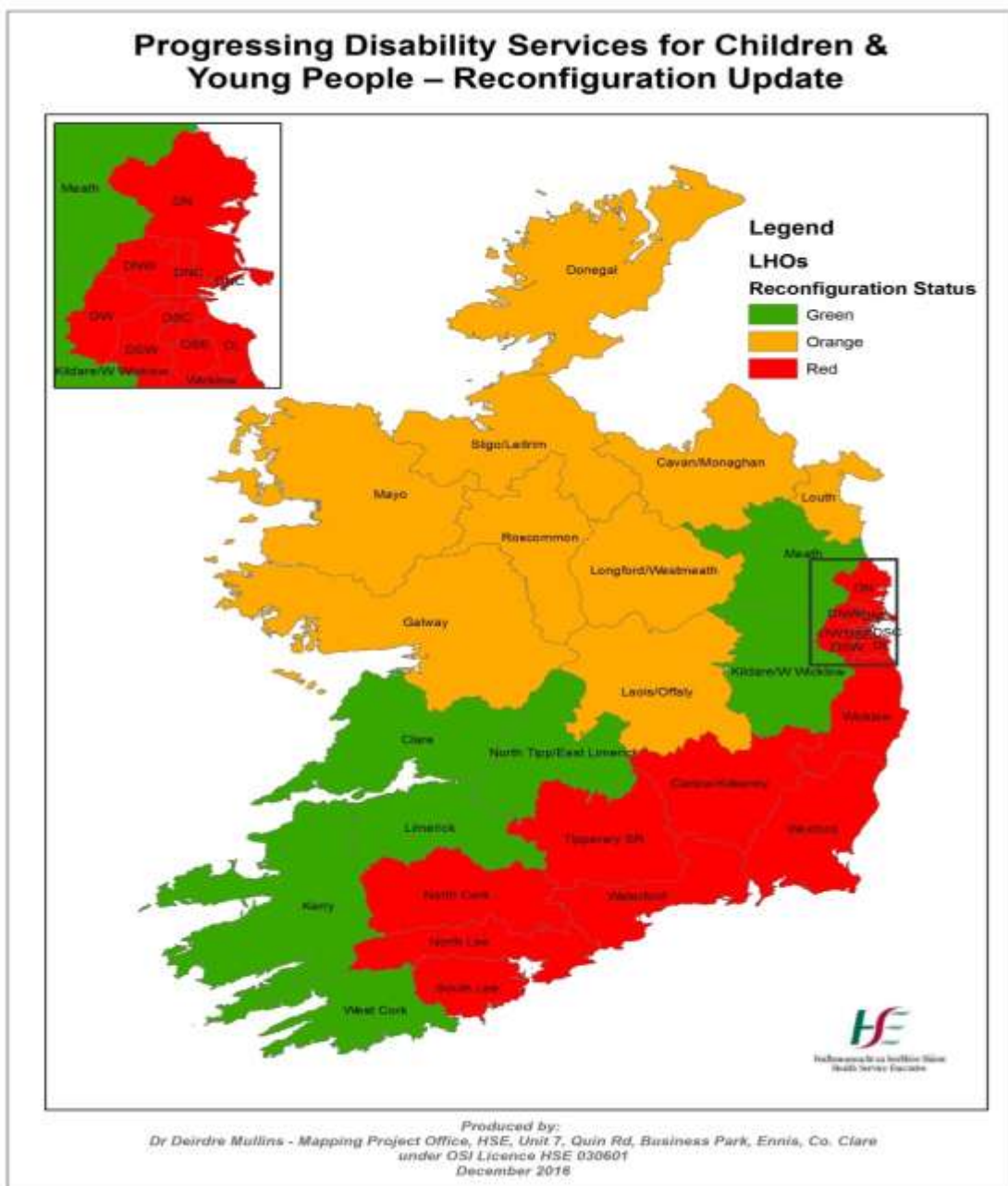


Figure 1: Status of PDS Implementation – Children’s Disability Network Teams Established

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13. The Next Twelve Months – PDS Implementation

13.1 CHO and LIG PDS Implementation Plans

PDS Implementation Plans are currently being reviewed and updated by the CHO PDS leads with their LIGs, and supported by the National Children's Team, in preparation for the Children's Disability Network Managers coming into post. Once they are in place, target start dates will be set for remaining teams and approved by the relevant CHO Governance Group.

13.2 Expressions of Preference for CDNTs

CHOs are progressing their Expressions of Preference processes for assigning staff to CDNTs in line with the National Guidance on Expressions of Preference Procedure. This is designed to help LIGs with their process of assigning staff currently working in children's disability services (statutory and voluntary) to new CDNTs within their CHO through seeking their preferences and making decisions on the best possible skill mix to meet the needs of children and their families. The process agreed in each area will reflect the requirements of that area.

13.3 Assigning Children's Disability Network Managers (CDNM)

13.3.1 Recruitment of CDNMs

Filling of the CDNM posts from the CHO CDNM panels and appointment of the ring-fenced CDNMs to post is a priority for HSE National Disabilities in 2020 as the key enabler to setting up the final CDNTs under PDS. A robust process is in place to ensure this is achieved in a timely, coordinated and transparent way.

13.3.2 Employment of CDNMs

CDNMs will be employed by the HSE or a Section 38 funded agency. Each team will be managed by a Lead Agency. Where the Lead Agency is a Section 39 organisation, the CDNM will be seconded to that organisation from the HSE or Section 38 organisation. The Section 39 Lead Agency will agree the employer for each CDNM with local CHO management. Where the HSE is the agreed employer of a CDNM to be seconded to a Section 39 Lead Agency, the Head of Social Care will ensure that appropriate secondment arrangements and necessary

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documentation are in place. As CDNMs become vacant, the same recruitment and employment processes will apply.

13.3.3 CDNMs Responsibilities

The CDNM is the accountable and responsible person for ensuring the delivery of high quality, safe, integrated children's disability services to the population within their designated network(s). The CDNM is the line manager for all staff members of the Children's Disability Network Teams in their designated network(s). He/she will provide clinical assurance regarding professional supervision of each clinician working in their teams.

The CDNM may provide professional supervision for senior clinicians of the same discipline within their network. In addition, the CDNM may agree to provide cross network supervision for senior clinicians of the same discipline in agreement with the relevant CDNM. Where this is not possible, the CDNM will liaise with the appropriate Therapy Manager/Head of Discipline/Professional Discipline Lead to access appropriate supervision. Senior clinicians in the CDNT will provide professional supervision for staff grade colleagues in their network. Where there is a requirement for senior clinicians to provide cross network supervision, this will be agreed by the relevant CDNMs.

13.4 Developing Family Centred Practice across all CDNTs

It is essential that existing and new CDNTs are supported to develop authentic family centred practice models in line with PDS principles in order to achieve its core objectives. Interdisciplinary working is critical to family centred practice in CDNTs and this will be new for many staff moving from a multidisciplinary service where each discipline (e.g. Occupational Therapy, Physiotherapy) works separately with the child and family. An interdisciplinary team is a number of professionals of different disciplines working with the child and family, sharing information, decision-making and goal-setting. They have common procedures and policies and frequent opportunities for communication, and work collaboratively to meet the identified needs of the child with a joint service plan. This model of practice enables each child and family to experience and access a holistic, unified continuum of service delivery where a family centred planning approach is central to the process.

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The National Operations – Disabilities Team is supporting CDNTs in developing the required competencies to implement Family Centred Practice services through the following initiatives:

13.4.1 Second National PDS Conference – Family Centred Practice

The second PDS Conference was held in Mary Immaculate College, Limerick in December 2019, attended by 1100 people in person or via Webinar. The theme was Family Centred Practice and its objective was to support the on-going development of CDNT staff competencies to meet the needs of all children with complex needs as a result of their disability. The entirely home grown conference provided an opportunity to share innovative, family centred models of service from across the country developed by staff with parents and/or based on parents/family feedback. Several parents and grandparents presented on the day and workshops included recordings of young people benefitting from this change in service focus to what they and their families need. Feedback from staff and family members was very positive.

13.4.2 National Team Development Programme - PDS

This programme was developed, based on evidence and significant feedback from staff in existing CDNTs on development needs of newly forming teams (see www.hse.ie/childdisability for National Team Development Report).

Aims of the programme are to

- drive a consistent foundation and understanding of the PDS family centred model for all managers and staff of existing and newly forming CDNTs
- Support CDNTs and their teams with the seismic change required to move to this way of working
- Establish the National CDNT Forum to continue the drive for consistency of practice and sustainability nationally.

Most CDNTs will be made up of staff from different organisations with different cultures and ways of working. The National Team Development Programme will support all CDNTs to

- Develop a common understanding of authentic child and family centric services
- Identify and address their early development needs.

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- Develop a 'new way of working' from the outset i.e. moving to an interdisciplinary, child and family centred service model. Evidence shows that practice is more difficult to change when teams have already formed.
- Create a consistent understanding of team working and performance, clarity of purpose, roles and self-evaluation.
- Develop one team culture, essential to the sustainability of multiagency teams and the PDS model in the long-term.

The National Team Development Programme Working Group identified the

- Core deliverables of the CDNT and competencies required to achieve the deliverables
- Training required by teams and individuals to develop the required competencies
- Resources available within the HSE and HSE funded Voluntary Agencies and where required, external sources
- Methods of training deliverance
- A process for quality assuring the recommended training resources

The programme comprises the **Managers Development Programme** to equip them with a solid foundation on requirements to rolling out authentic and sustainable family centred practice models across their teams in line with PDS and the **Staff Development Programme**, delivered in turn by CDNMs for their staff on CDNTs or moving to new CDNTs.

Children's Disability Network Managers Development Programme will run for 5 days over 5 consecutive weeks and will be mandatory for all CDNMs. It includes

- **Day 1:** PDS Programme, including interdisciplinary working & budget management
- **Day 2:** Family Centred Practice: Theory, learning from Midwest Pilot & workshops
- **Day 3:** Change Management Workshop / PDS Implementation Plans workshop
- **Day 4:** Resilience/Capacity building & Communications – Gerry Farrell
- **Day 5:** National Access Policy Implementation

A **6th CDNМ development day** will take place in June 2021 based on evaluation of the programme to date and further areas of development identified by the National CDNT Forum.

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It is estimated that the majority of CDNMs will be in post by end of June. The National Children's Team is supporting CHO PDS Leads to review, update and progress PDS Implementation Plans with their LIGs in preparation for this. CDNMs will play a critical part in progressing this work over July and August in advance of the CDN Development Programme in September. PDS Implementation Plans must include target dates for setting up all remaining CDNTs. Each CDN will require a clear understanding of their immediate stakeholders (staff, young people and carers) state of readiness for moving into their new CDNT, the status of actions in their PDS Implementation Plan and what works they need to progress to achieve the final stages of implementation. The National PDS Implementation Plan template is being expanded to include key Family Centred Practice actions for staff planning new CDNTs to build into their way of working from the start. This preparation work is critical in advance of the CDN Development Programme to maximum their benefit from the programme.

The CDN Development Programme will run twice, accommodating half of the CDNMs in each group with a spread of ring-fenced CDNMs across both groups to share PDS experience. For group one, the CDN Programme is tentatively set to run on 5 consecutive Wednesdays commencing Sept 9th with group two running on Thursdays commencing Sept 24th.

On completion of the first 5 days, CDNMs will be tasked with delivering the **Children's Disability Network Team (CDNT) Development Programme** for their staff:

- **Day 1:** PDS Induction
- **Day 2:** Family Centred Practice Workshop will be run at both CHO and LIG level

Timing of the National CDNT Development Programme for staff will be determined by the CDNMs, dependant on local factors and supported by the National Children's Team and Team Development Working Group. It is very important that staff currently in the planning stage of setting up their CDNTs are released to participate in the National Team Development Programme with their CDN in advance of their team's start date, to ensure a common basic understanding of the model and team working from the beginning.

Please note: this Programme is in addition to employer mandatory induction for all staff.

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13.4.3 CDNMs Resources

CDNMs will be provided with the following resources to support them in rolling out the CDNT Development Programme with their staff/incoming staff

- ✓ A comprehensive CDNMs Resource Pack (online and hard copy)
- ✓ An extensive Team Development Programme Training Portfolio including free and fee based resources
- ✓ Standardised Strengths Needs Analysis template for CDNT staff/staff to be
- ✓ CDNMs Development Programme presentations and recordings.

13.5 National CDNMs Forum

This forum will be set up as part of the National Team Development Programme. Its purpose is to continue the national drive for consistent and sustainable implementation of the PDS model. This group will lead the implementation of the *Outcomes for Children and their Families Framework* and provide a central place for shared practice developments, resolution of challenges and development of national policies where required.

13.6 Children's Services Change Programme - Communication Plan

In order to cascade all of this information and further developments to the key partners in this change programme, most especially parents and staff, a national communication plan will be implemented in tandem with the appointment of Children's Disability Network Managers. The plan includes regular PDS Newsletters, capturing the progress of PDS implementation and promoting good change management practices and service developments across the country.

13.7 National Children's Disability Information Management System (NCDIMS)

With approval by the Office of Chief Information Officer (OoCIO) and Digital Government Oversight Unit (DGOU), the Mid-West Community Healthcare trialled an upgraded version of Children's Disability Information Management System (MIS) that supported a nationally agreed work process for CDNTs. It included improved functionality on using Individual Family Services Plans to inform all service provision and a suite of management and performance-related metrics to help CDNMs in understanding and addressing how their teams are functioning.

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The OoCIO and DGOU then approved a 'permission to tender' business case for further development of the MIS, including a new Assessment Officer System, for roll out to all CDNTs as the NCDIMS. A Procurement Evaluation Group is now preparing a submission to Procurement for tenders. This has been informed by many sources including feedback from the Data Protection Office on a submitted Data Protection Impact Assessment, from HSE funded voluntary organisations on what functionality they would like in the NCDIMS and their data migration requirements, from CHOs, Assessment Officers, Liaison Officers and the HSE Legal Services Team, and learning from the Mid-West Community Healthcare trial of the enhanced MIS and their Family Centred Practice project. The NCDIMS will link to the National Ability Supports System and provide other data to CDNMs, CHOs and the National Office on how teams are functioning. The NCDIMS is estimated to be available to all CDNTs by Q4 2020.

14. Other resources for parents to help their child

A child's parents/carers are the most important people in his or her development. There are many ways which they can give their child additional support if he or she has a disability or developmental delay. Once linked with a Children's Disability Network Team or Primary Care services, these services will help parents/carers with this. In the meantime, the following websites have very useful information.

www.aim.gov.ie outlining a model of supports designed to ensure that children with disabilities can access the Early Childhood Care and Education (ECCE) Programme

www.citizensinformation.ie Caring for a child with a disability – services and entitlements

www.hse.ie A to Z of conditions with links to specific websites for your child's condition

www.inclusionireland.ie Connect Family Network – for information on a wide range of services

www.informingfamilies.ie for families and for professionals about the early days around the time of diagnosis of disability or concerns

www.mychild.ie on health services and support, your guide to pregnancy, baby and toddler health, trusted information from experts

www.specialneedsparents.ie Lists of national and local support groups, sports and activities.

Appendix 1 PDS Implementation Structures

