POLICY FRAMEWORK FOR SERVICE DELIVERY OF CHILDREN'S DISABILITY NETWORK TEAMS

REVISED MAY 2022

List of contents

Introduction

This Policy Framework for Service Delivery outlines the processes involved in the delivery of Children's Disability Network Team (CDNT) Services. It is not an exhaustive list of all policies required for teams, but signposts to national policies and provides guidance for teams in developing and reviewing their PPPGs.

The full text of PDS and CDNT policies referenced in this document can be found on the Progressing Disability Services pages on:
https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/

Abbreviations

AIM	-	Access and Inclusion Model of pre-school supports
AON	-	Assessment of Need under the Disability Act 2005
CAMHS	-	Child & Adolescent Mental Health Service
CDN	-	Children's Disability Network
CDNT	-	Children's Disability Network Team
CDNM	-	Children's Disability Network Manager
CHN	-	Community Healthcare Network
CHO	-	Community Healthcare Organisation
CPD	-	Continuing Professional Development
FOI	-	Freedom of Information
GDPR	-	General Data Protection Regulation
GP	-	General Practitioner
HOD	-	Head of Discipline
ICF	-	WHO International Classification of Functioning, Disability & Health
ICSF	-	Integrated Children's Services Forum
IFSP	-	Individual Family Supports Plan
OT	-	Occupational Therapist /Occupational Therapy
PC	-	Primary Care
PDS	-	Progressing Disability Services for Children & Young People
PHN	-	Public Health Nurse
PT	-	Physiotherapist /Physiotherapy
SOP	-	Standard Operating Procedures
SLT	-	Speech and Language Therapist/Speech and Language Therapy
SW	-	Social Worker/Social Work

Context

Children's Disability Network Teams are developed under the Progressing Disability Services for Children and Young People Programme (PDS) in order to:

➢ Provide a clear pathway and fair access to services for each child with a disability and their family based on their need, regardless of their diagnosis, where they live or go to school.

➢ Make the best use of available resources for the benefit of children and their families

➢ Work in partnership with families and with education staff to support children with a disability to reach their full potential.

Reconfiguration

There are 91 Children's Disability Networks (CDN), aligned with 96 Community Healthcare Networks (CHNs). Following reconfiguration, each CDN will have an inter-disciplinary team of health and social care professionals. The Children's Disability Network Team (CDNT) will provide services and supports for all children aged from birth to 18 years living in the Network, who have complex needs (for definition see National Policy on Access to Services for Children with Disability or Developmental Delay 2019)

Children's Disability Network Team Services operate within the legislative context for health services in Ireland and follow the direction of national strategy and policy.

All policies for service delivery should be developed in the first instance with the primary goal of achieving best possible outcomes for children and their families. Policies should be within the framework of current legislation and national policies. These include:

- UN Convention on the Rights of Persons with Disabilities (UNCRPD)
- National Disability Strategy 2004
- Education for Persons with Special Education Needs (EPSEN) Act 2004
- Disability Act 2005
- Better Outcomes, Brighter Futures: Report of the National Policy Framework for Children & Young People 2014-2020. Department of Children and Youth Affairs. 2014
- Children First Act 2015
- Slaintecare

Model of Service for Children's Disability Network Teams

Under the programme Progressing Disability Services for Children and Young People, Children's Disability Network Teams (CDNTs) of health and social care professionals are established in each of the nine CHOs within defined geographic areas, aligned with Community Healthcare Networks. CDNTs are the providers of services for children and young people aged from birth to 18 years with complex needs.
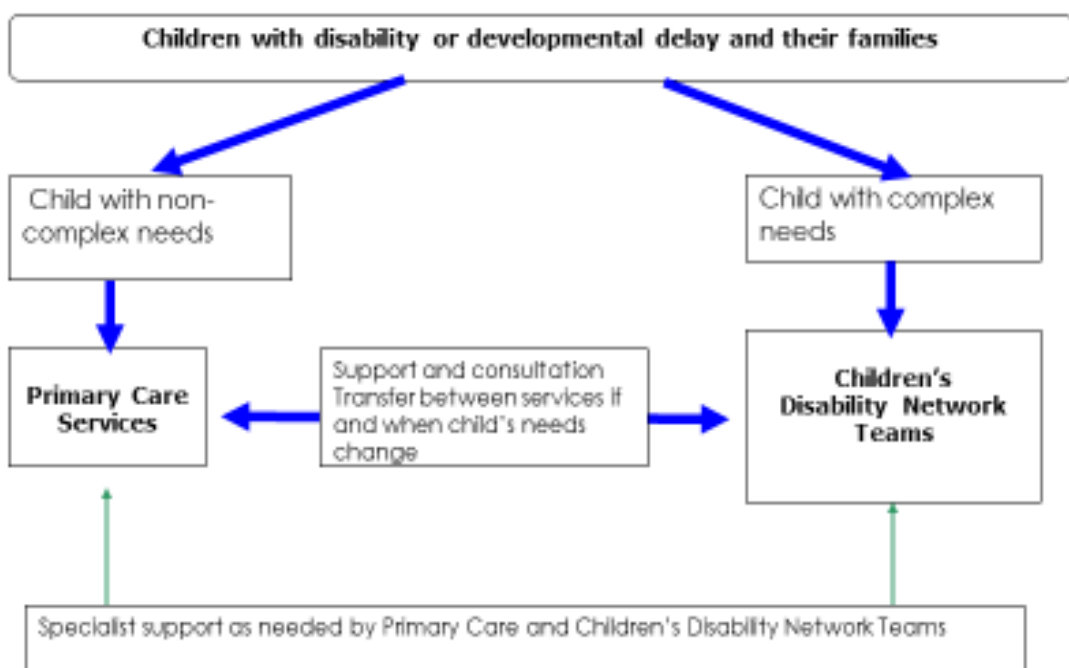
Principles and Values

The following twelve principles and values underpin the model of service delivery for CDNTs. These principles have been identified and developed through an iterative process based on national and international evidence, consideration by the PDS national and local implementation groups, and consultation with stakeholders.

Accessibility

Environment: All services and supports are provided in an accessible physical environment. Ability to travel, access to public transport and the geographical location of the family should be taken into account.

*Information***:** Families know how to access information, from whom or where it can be obtained. Information is presented in a clear and concise manner, jargon-free and in a language that is easily understood. Information is available in a variety of accessible formats and languages as required.

Accountability and governance

Governance is the framework of rules, practices and policies by which an organisation can ensure accountability, fairness and transparency in their relationships with their stakeholders. Accountability is embedded in the culture of the team and is the responsibility of all involved in service delivery. It is achieved through:

o Governance structures
o Written policies and procedures

- o Monitoring
- o Audit
- o Outcome measurement
- o Compliance with legislation and national policy

Bio-psychosocial model

The bio-psychosocial model is a broad view that attributes outcome to the intricate, variable interaction of biological factors (genetic, biochemical, etc), psychological factors (mood, personality, behaviour, etc.), and social factors (cultural, familial, socioeconomic, medical, etc.). Services are delivered holistically, focusing on all aspects of a child and young person's and family's life, particularly in the context of the community and society. The model promotes the idea that society and the environment must recognise and accommodate individual needs, based on dignity and respect, supporting and facilitating children and families to access and be included in their community and society. This involves working in partnership with families and the wider community.

Clinical governance and evidence informed practice

Services are planned and delivered under a system of clinical governance and evidence informed practice. The application of research is part of an evidence based approach to decision making.

The application of an evidence informed approach involves ensuring that services keep up to date with on-going research that informs new practices or techniques and the inclusion of agreed clinical guidelines, policies and protocol with inbuilt audit and review dates. Through clinical governance and supervision teams demonstrate that they deliver an evidence based practice.

Cultural competence

Sensitivity to cultural differences is entwined in the systems of service delivery which are compatible with family values and goals. Each family's unique cultural differences and diversity are recognised. The uniqueness will inform the partnership in service delivery with the family.

Early identification of needs

Identifying the needs of children as early as possible can help achieve optimal outcomes. Disability services have a key role in assisting those who come in contact with children and families to recognise risk factors and make appropriate referrals. There is a clear pathway to services which is easily understood by parents and other referrers.

Equity of access

Access to the CDNT is based on the child's needs. The National Policy on Access to Services for Children with Disability or Developmental Delay 2019 provides the framework for services to consider a child's needs and the most appropriate service to meet those needs. Eligibility criteria and procedures for accessing services is transparent and user friendly.

Evaluation of Outcomes

Outcomes are measured through the Individual Family Supports Plan. This process includes agreeing goals according to the child's and family's priorities, determining the family strategies and team supports which will be used to work towards the goal and measuring achievement of the goal within a timeline.

The implementation of the Outcomes for Children and their Families Framework (OCFF) will bring in accountability and reporting to measure what benefits the child and family have experienced as a result of services and supports provided, in other words the added value. When the national CDNT Information Management System is fully operational all CDNTs will measure their performance under the OCFF.

Family Centred Practice

Family centred practice ensures that supports provided are determined from family priorities. It requires that there is family involvement in the identification and measurement of achievements. It recognises that each family has its own role, values, structures, beliefs and coping styles. It is important to appropriately assess the varieties of stressors that can adversely affect family patterns of interaction and utilise that information to strengthen families. This may require the identification of social supports, resource supports, information and services. See report **Progressing towards Outcomes-focussed Family-centred Practice**

Inclusion

Children's Disability Network Teams support the inclusion of children in their community and facilitate the maximum development of each child's independence and participation. This includes offering programmes that support the development of skills for daily living, participation in pre-school and school as appropriate and information for families on local activities, social, sporting and cultural opportunities.

Interdisciplinary Team Approach

An interdisciplinary team is a number of professionals from different disciplines who work with the child and family, sharing information, decision-making and goal-setting. They have

common procedures and policies and frequent opportunities for communication. They work collaboratively to meet the identified needs of the child with a joint Individual Family Support Plan, and meet the child's goals collectively or individually as appropriate. The interdisciplinary team approach is supported by national and international best practice[1]. This model of practice aims to enable 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.

Staff are Valued and Respected

Effective services for children with a disability and their parents are grounded both in the knowledge and skills of frontline staff and in the relationships formed between staff and families. The efforts of staff to provide the best possible service must be acknowledged, valued and supported, promoting a culture of respect amongst staff and between families and staff.

People Strategy Priorities[2]

- Leaders at all levels, working together towards a shared purpose, creating a caring and compassionate culture, nurturing talent and inspiring innovation and excellence throughout the system.
- A meaningful and safe work culture exists where the organisation enables healthy behaviours among staff, supporting them to take responsibility for their own health and wellbeing, and where staff feel valued, are emotionally engaged and deliver services they are proud of.
- A culture that prioritises learning and development to ensure we have the capability and capacity at individual and team levels to confidently deliver person-centred care, problem solve and innovate.

Service audit

The Self Audit Tool for CDNTs has criteria to be met under the twelve principles and is completed annually by the whole team to support ongoing consistency of the model of service delivery. It is a tool for CDNTs to acknowledge their achievements, assess and monitor quality, promote continuous improvement and identify and prioritise development opportunities.

Link: **Self-audit tool for Children's Disability Network Teams**

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[1] Ten principles of good interdisciplinary team work. Susan A Nancarrow, Andrew Booth, Steven Ariss, Tony Smith, Pam Enderby and Alison Roots. Human Resources for Health. 2013

[2] Health Services People Strategy. HSE. 2019-2024

Governance

CHO Governance of Children's Disability Network Services January 2021 provides a nationally standardized governance structure for children's disability network services across the CHOs.

- CHO Children's Disability Networks Governance Group
- CDNM Operational Management Group
- CHO Clinical Advisory Group
- Children's Disability Network Manager
- Family Forum (one per network)
- Family Representatives Group (one per CHO)

Link: **Community Healthcare Organisation Governance of Children's Disability Network Service**
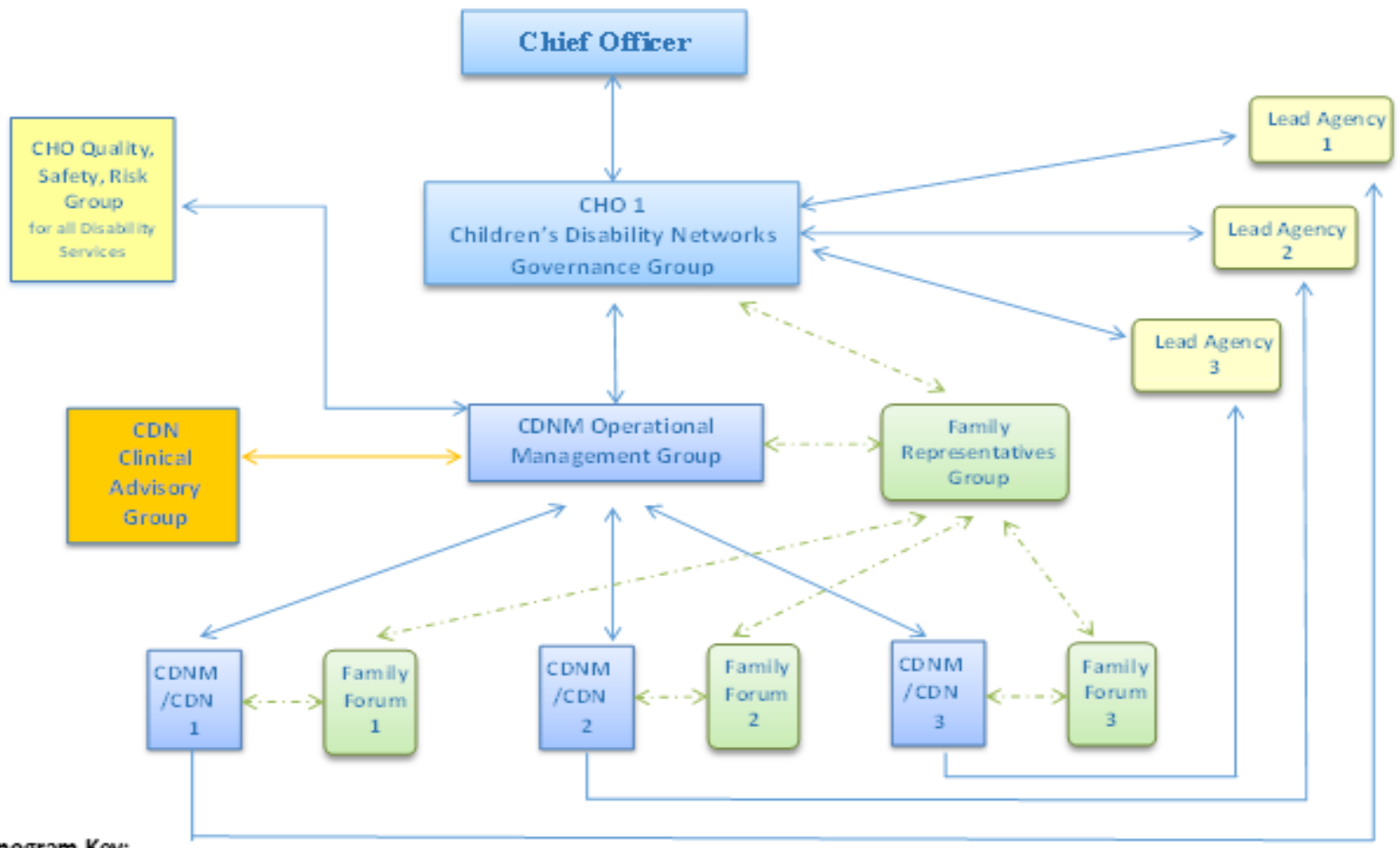
Lead Agency Model

The Lead Agency Model is the agreed structure for the service delivery of children's disability services. Each lead agency has responsibility for the provision of services for children 0-18 with complex disability in the Children's Disability Network Team(s) (CDNT) assigned to that agency. The lead agency may be a HSE funded non-statutory organisation or a HSE Community Healthcare Organisation.

Link: **National Policy on the Lead Agency Model 2019**

Interagency Agreement

The majority of CDNTs comprise staff of more than 1 organisation, e.g. HSE and HSE funded non statutory agencies. The purpose of the Interagency Agreement (IA) is to set out the terms and conditions under which the consortium of employers will operate the provision of CDNT services. It provides clarity on roles and responsibilities of Lead Agencies, Consortium Members (employers of non Lead Agency staff) and their staff in a CDNT, in order to enable the delivery of safe, effective services through an integrated management structure.

Next page: Diagram of Governance Structures taken from CHO Governance of Children's Disability Network Services 2021

Chief Officer

CHO Quality, Safety, Risk Group
for all Disability Services

Lead Agency 1

CHO 1
Children's Disability Networks Governance Group

Lead Agency 2

Lead Agency 3

CDN Clinical Advisory Group

CDNM Operational Management Group

Family Representatives Group

CDNM /CDN 1

Family Forum 1

CDNM /CDN 2

Family Forum 2

CDNM /CDN 3

Family Forum 3

Organogram Key:

‹- - - - - -› = Family partnership and participation

‹——————› = CHO Operational relationships

Clinical Governance and Supervision

Clinical governance refers to the systems, structures, processes and standards through which health and social care teams, and others, contribute to and are accountable for the quality, safety and experience of service users in the delivery of services. Multiple individuals have important roles and responsibilities within an overall system of clinical governance; while there are lines of individual clinical responsibility, good clinical governance emerges from the practice of interlocking and integrated working throughout the system.[3]

- Each individual, as part of a team, knows the purpose and function of leadership and accountability for good clinical and social care;
- Each individual, as part of a team, knows their responsibility, level of authority and who they are accountable to;
- Each individual, as part of a team, understands how the principles of clinical governance can be applied in their diverse practice;
- A culture of trust, openness, respect and caring is evident among managers, clinicians, staff and patients;
- Each individual, as part of a team, consistently demonstrates a commitment to the principles of clinical governance in decision making; and
- Clinical governance is embedded within the overall corporate governance arrangement for the statutory and voluntary health and personal social services in realising improved outcomes for patients.

  Ref: HSE (2012) Quality and patient Safety: Clinical Governance Information Leaflet[4]

Link: **Community Healthcare Organisation Governance of Children's Disability Network Service** pages 7 - 9

Supervision is a workforce development strategy that can contribute to higher quality service outcomes, improve practitioner skills and inform and consolidate training and development. See Interim Guidance on Clinical and Professional Supervision for CDNTs.

Link: **Interim Guidance on Clinical and Professional Supervision for Children's Disability Network Teams (PDF, size 911KB,18 pages)**

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[3] Interim Guidance on Clinical and Professional Supervision for Children's Disability Network Teams. 2021

[4] CHO Governance of Children's Disability Network Services.2021

Team Strengths Needs Analysis[5]

The CDNM should complete a Strengths and Needs Analysis with the team against the required competencies on a regular basis to identify any critical gaps and, where they arise, the training required to address this.

A Strengths and Needs Analysis will enable CDNMs to direct finite resources into areas where they will contribute the most to bridging critical competency gaps and to CDNT development and performance to support them in implementation of the PDS framework, a key component in ensuring the delivery of a quality services.

Training should not be viewed in isolation by individual staff but as a key element in the overall implementation of the PDS framework by the team. The CDNM and the team in deciding on training requirements and how many team members should complete any particular training, must consider:

- The current needs of children and families in their Network, including considerations of demography, geography and current service demands
- Staffing and disciplines currently on the team
- Existing staff competencies and whether they are sufficient to meet the current needs

A comprehensive Team Development Portfolio has been developed as a resource for CDNMs and their teams which clearly lays components of induction, ongoing team development and clinical training, linked back to specific competencies, core deliverables and principles of PDS. It identifies where they are available within health services, online on HSELand and external providers.

The named external training courses should not be regarded as a list of required training but as alternatives for managers and the team to consider when a gap is identified within the team.

The training and clinical categories section is concerned with specific areas of competency which can be supported by sharing of knowledge within the team, across teams within the network, by mentoring and by external training courses. Each of the 17 sections names a particular area of expertise and support for children and their families, and a variety of related training opportunities to address this area.

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[5] National Team Development Programme Children's Disability Network Teams 2019

Team Structures and Responsibilities

Staff and teams are clear about roles, relationships and responsibilities and are supported to channel their energy and maximise individual and team performance to add value and impact for service users.[6]

Interdisciplinary Team

A Children's Disability Network Team works to an interdisciplinary team model. An interdisciplinary team is a number of professionals from different disciplines who work with the child and family, sharing information, decision-making and goal-setting. They have common procedures and policies and frequent opportunities for communication. They work collaboratively to meet the identified needs of the child with a joint service plan, and see the child separately or together as appropriate.[7]

Responsibilities of the Children's Disability Network Manager

The Children's Disability Network Manager (CDNM) is responsible to the Lead Agency for the development of Children's Disability Services within a designated area. The CDNM is the accountable and responsible person for ensuring the delivery of high quality, safe, integrated children's disability services to the population of the Children's Disability Network[8]. This will be provided in accordance with legislative and service delivery frameworks and requirements, within the resources allocated.

Using the key principles of the Progressing Disability Services for Children and Young People programme as a model of service which is based on family centred practice and interdisciplinary team working, the CDNM will have full responsibility and accountability for managing resources within the Children's Disability Network.

The CDNM will provide day to day operational line management for children's disability staff and provide clinical assurance regarding the professional supervision of each team member.

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[6] Health Services People Strategy 2019-2024

[7] Report of the Reference Group on Multi-disciplinary Disability Services for Children aged 5 to 18 years. 2009

[8] Children's Disability Network Manager Job Specification & Terms and Conditions. HSE. 2018 **Children's Disability Network Manager Job Specification**

Responsibilities of team members

- To work within the Model of Service Delivery and Principles
- To make a positive contribution to inter-disciplinary team working
- To ensure that family members are partners of the team around their child
- To work collaboratively with other services and agencies involved with the children and families and share information with parents' consent as appropriate.
- To deliver evidence informed practice
- To promote a learning culture within the team, sharing evidence informed practice with colleagues and others
- To maintain their registration with CORU or professional registration body
- To maintain their competencies through CPD
- To participate in professional/clinical supervision
- To contribute to the identification of learning and or training needs, both individual professional and team needs
- To advise management in relation to the delivery of services and on additional supports families might need
- To monitor and evaluate their own standard of service delivery and report on this to their manager
- To clearly define their roles in relation to clinical and non-clinical core team functions

Lead agencies and employers have responsibility to ensure clarity for all team members regarding their respective roles (see National Policy on the Lead Agency Model 2.3)

Policies, Procedures, Protocols and Guidelines for CDNTs

Policies which apply to the operation of CDNTs are:

- National
- CHO Governance Group
- Lead agency
- Employer

> *There should be a documented process for formulating, approving and reviewing local policies and procedures. All policies and procedures should record dates of development, date of approval, who it was approved by and proposed review date.*

> *Written policies and procedures must be available and accessible to all stakeholders and policies and procedures must be clearly communicated through the induction process*

	POLICY	Resources online
National statutory & mandatory policies	Children First	www.hse/childrenfirst.ie
	Health and Safety	https://healthservice.hse.ie/staff/benefits-services/health-and-safety/
	Fire Safety	https://www.hsa.ie/eng/Topics/Fire/
	Safeguarding Vulnerable Adults	https://www.hse.ie/eng/about/who/socialcare/safeguardingvulnerableadults/
	Data Protection and GDPR Data Protection Acts 1988 -2003 Freedom of Information Acts 1997-2003	https://www.dataprotection.ie/en/who-we-are/data-protection-legislation https://foi.gov.ie/ https://www.hse.ie/eng/about/who/qualityandpatientsafety/safepatientcare/healthrecordsmgt/
	Consent, guardianship and assisted decision making	https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/ https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/guidehealthsocialcareprofdoc.html https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/assisteddecisionmaking/ www.treoir.ie/information-guardianship.php

	Assessment of need Disability Act 2005 Part 2	http://www.irishstatutebook.ie/eli/2005/act/14/enacted/en/html
National CDNT policies issued by HSE Head of Operations	CHO Governance of Children's Disability Networks. 2021 National Policy on the Lead Agency Policy 2019 National Policy on Access to Services for Children and Young People with Disability or Developmental Delay V2 2019 National Policy on Prioritisation of Referrals to CDNTs 2016 National Policy on Discharge and Transfer from CDNTs 2017 National policy for CDNTs regarding children accessing private, independent, complementary and alternative therapies 2021 National policy on family engagement and attendance 2021 Standard Operating Procedure for Assessment of Need	All found at: https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/ Contact your local Assessment Officer
Priority policies and procedures agreed by the CHO Governance Group for all CDNTs in the CHO, or issued for an individual CDNT by the Lead Agency This is not an exhaustive list. Other policies will be agreed as required.	1. Pathways for the recording, reporting and management of child protection and welfare concerns, in line with Children First and Safeguarding Vulnerable Adults, so that all staff have clear guidelines of the reporting process and procedure. 2. Processes to ensure compliance with GDPR, record, and data management procedures including reporting, management and recording for data breaches.	

	3. Consent agreements from parents/carers for interventions from the team for their child, including sharing of information with colleagues on the team and the wider health service, pre/schools, management of digital information, student involvement and other relevant activities that may be appropriate to the particular service. This should also include information on the limitations to confidentiality e.g. child protection and welfare issues. 4. Pathways for the recording, reporting and management of comments, compliments and complaints 5. Procedures for support, supervision and performance management of staff 6. Process and pathway for reporting, management and recording of incidents 7. Processes for supporting the implementation of the national Open Disclosure Policy 8. Processes for supporting the implementation of Informing Families Policy. E-learning module 9. The management of behaviours that challenge and the implementation of related polices including restrictive practices.	https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/opendisclosure/ www.informingfamilies.ie http://www.informingfamilies.ie/information-for-professionals/elearning-module.284.html

National Guidance for CDNTs	Framework for Collaborative Working Between Education and Health 2013	All found at: https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/
	Outcomes for Children and Their Families 2013	
	Guidance on Specialist Supports 2016	
	Report of National Advisory Group on Specialist Supports for Deaf Children 2017	
	Progressing towards Outcomes-focussed Family-centred Practice 2020	
	Telepractice: a practical guide for CDNTs 2020	
	National Guidance for CDNTs on IFSPs 2021	
	Interim Guidance on Clinical and Professional Supervision for CDNTs 2021	

Guide to Lead Agency and Employer policies

No.	Category	Relevant policies	Policy to be used	Rationale
		1) FINANCE		
1	**Finance**	Examples include: Accounts Procedure, Employee Travel & Expenses, fundraising, procurement etc	Lead Agency	As per Service Arrangement Section 4.4 / 4.4g

		2) HEALTH AND SAFETY		
2	Health & Safety	Example include :Health and safety statement , Accident/ Incident Reporting, Infection control, Blended working, Lone working , risk management etc	Lead Agency	Health & Safety Policies apply as per Service Arrangement, Interagency Agreement (IA) Section 6.3 & CDNM Job Spec
		3) HUMAN RESOURCES		
3 .1	Human Resources - codes of conduct	Examples include: Dignity & Respect, informal counselling, Disciplinary, Grievance (IA, section 6) etc	Employers Policy -	As per IA
3.2	Human Resources - Leave	Examples include: annual , sick , parental , maternity , carers and compassionate leave, part time working etc	Employer Note: must be approved by Lead agency CDNM in line with employer policy. Procedure will be required locally	As per IA 6.9, 6.1b
3.3	Human Resources - Employee Development & Support	Examples include: Supervision and support, training and development, performance management (IA, section 6.1), managing probation, stress management, smoke free workplace, health and well being etc	Lead Agency Policy Note: Where performance issues are not resolved, it is escalated to Employer per 3.1 above and IA, section 6.	As per IA Section 4.4(iv), 6.1b, 6.3 6.8 6.9, Appendix 9
3.4	Human Resources Recruitment & Selection	Examples include: Recruitment & Selection, Garda Vetting, Obtaining References etc,	Lead Agency	As per IA section 4.5
3.5	Human Resources Student & Volunteers	Examples include: Third level Student Placement, Volunteer Policy, Graduate Therapy, Secondary School Transition Year Student Placement,	Lead Agency	As per IA section 6.10
3.6	Human Resources Working Arrangements	Examples include: Managing unexpected closures, Code of conduct and behavior, Flexible working etc	Lead Agency	As per IA

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3.7	**Human Resources - Complaints**	Examples include: Complaints, protected disclosure.	Lead Agency	Complaints Policies apply as per Service Arrangement
		4) QUALITY & PATIENT SAFETY (9 QPS)		
4	**Quality Patient Safety**	Example: Open Disclosure	Lead Agency Policy	As per IA section 4.4
		4) INFORMATION MANAGEMENT & IT		
5	**Information Management & Security**	Examples may include: Data protection, it security, mobile phone, social media , information management and record keeping	Lead Agency Policy	Service Arrangement & IA, section 14, 4.2 & 4.3 and Dasta Sharing Agreement (DSA)
		5) SERVICES		
6.1	**Service Delivery - National**	Examples include: PDS service related policies e.g. National Access Policy , CDNT Policy Framework, which includes all nationally standardised CDNT policies, IFSP process and pathway	National PDS Policy	As per IA and DSA
6.2	**Service Delivery Regional**	Examples include: Specific service related policies across a CHO area, e.g. referral pathways, initial assessment etc	Regional Policy (CHO area)	As agreed and signed off by the CDN Governance Group
6.3	**Service Delivery Local Team**	Examples include: Specific to team eg Children First, intimate care, transport, medical devices , clinical governance, medication management, use of restraint, research and ethics	Lead Agency Policy	As per IA, section 6.2, 6.8, 6.10

Key CDNT processes

Referral

Access to CDNT services is determined in accordance with the *National Policy on Access to Services for Children and Young People with Disability or Developmental Delay 2019*.

Link: **National Policy on Access to Health Services for Children with Disability or Developmental Delay 2019**

Integrated Children's Services Forum

The purpose of the Integrated Children's Services Forum (ICSF), led by Disability Services, Primary Care and CAMHS, is to ensure a coordinated and flexible approach to the delivery of services to children and their families. Other services, such as Tusla and Education, will be invited to attend meetings of the ICSF as required to discuss an individual child's needs.
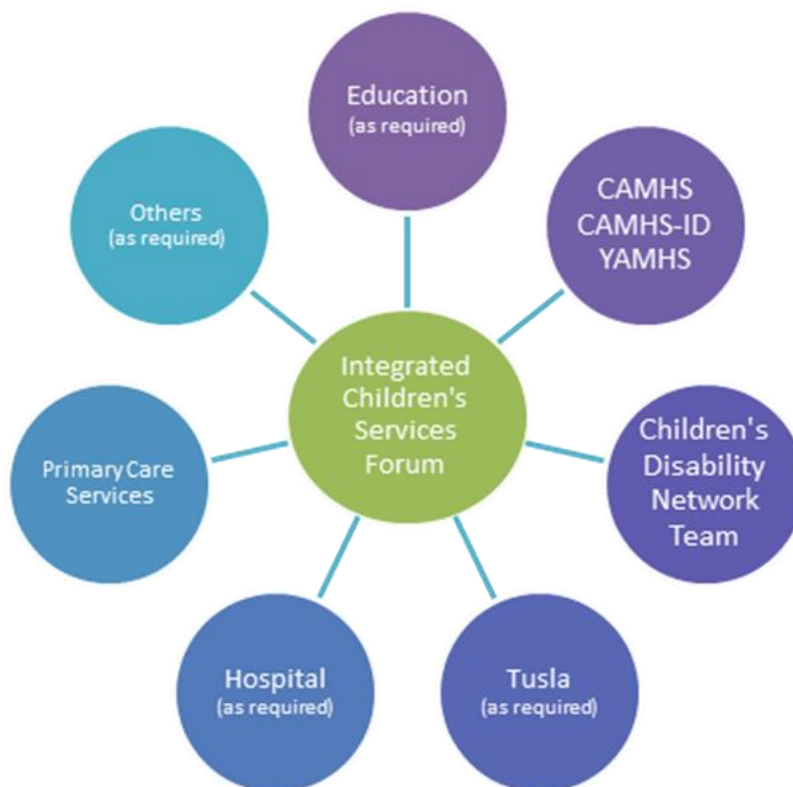
The ICSF will:

☐ Develop a shared understanding of the child's presenting needs

☐ Assist the process of meeting the service requirements of children /families based on their needs rather than based on current service arrangements /thresholds.

☐ Make recommendations for shared care provision i.e. joint working across services where pathways or level of service is not clear. Act as a clinical decision making forum to ensure seamless access to and between agencies and services, using standardized criteria.

☐ Act as a decision making forum for referrals of children where pathways or level of service is not clear

☐ Make the best use of available resources to meet the needs of children and their families

☐ Provide an opportunity to highlight young people who will be in need of services post 18 years of age.

The functions and operation of the ICSF are described in the National Policy on Access to Services for Children with Disability or Developmental Delay 2019 and the Joint Working Protocol between Primary Care, Disability and CAMHS 2017.

Link: **National Policy on Access to Health Services for Children with Disability or Developmental Delay 2019**
HSE Joint Working Protocol between Primary Care, Disability and child and Adolescent Mental Health Services September 2017

Prioritisation

Prioritisation of referrals is determined in accordance with the *National Policy on Prioritisation of Referrals to CDNTs 2016*.

Link: **National Policy on Prioritisation of Referrals to Children's Disability Network Teams 2016**

Waiting for services

There must be a written policy and procedure for recording and managing any waiting times for access to the service. (See National Policy on Prioritisation of Referrals to Children's Disability Network Teams 2016 – link above)

Each CDNT must have a protocol for the management of waiting times to access the service in relation to: -

♦ Responsibility for contact with the family every 6 months to review needs
♦ Response to an urgent need that the team have been informed about or that has been identified by a member of the team including procedure for informing relevant staff member(s)
♦ Information for families on the waiting list procedure, the determination of urgent needs, the child's place on the waiting list according to date of referral, and that they will be contacted regularly while their child is on the waiting list
♦ Managing the waiting timeframe through the best use of the available resources.

Supports should be provided for families while their child is waiting for services in line with the model for intervention:

1. Information about the service
   ➢ Written leaflets
   ➢ Introductory meetings
   ➢ Recorded sessions to access online

2. Access to universal supports being provided by the team e.g. behaviour management; post diagnosis support; preparing for school; sleep; toileting. The purpose and function of these supports will be clearly explained to families when they are offered. Families will be given the option to attend or not according to whether the topic is appropriate for their child's needs.

3. Lists of useful online resources by topic (e.g. videos on specific aspects of child development, activities for children) that families can access, as they consider appropriate for their child's individual needs.

Initial meeting with child and family

The aim of the initial contact meeting is to begin to develop the IFSP including discussing priorities, some initial goals and provide some initial strategies as well as allocating a key worker/support coordinator.

- o   Provide an orientation to the service.
- o   Profile parental priorities for their child / family.
- o   Achieve a better understanding of a child's needs via assessing them through, for example, informal observation; play-based assessment; administration of screening assessment tools / formal or informal assessment tools; discussion with the child;
- o   Based on parental priorities and child disability team observations, develop agreed initial goals and an IFSP within 6 weeks of initial contact.
- o   Provide guidance on interventions specific to the agreed initial goals that parents can use immediately.
- o   Assign a key worker/service co-ordinator to the family
- o   Facilitate development of initial goals and IFSP within six weeks
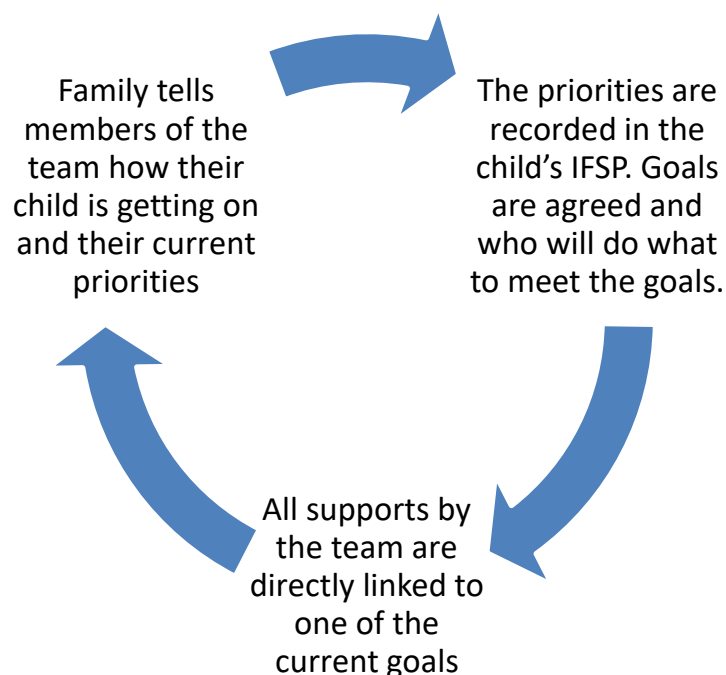
Individual Family Support Plan and Goal Attainment

To ensure that families and the team work together in the best possible way they need to agree and share a plan. Each child and family has different needs so they must have their own individual plan.

The team finds out about the important issues or priorities from the family's view. The family knows their child best and the team has expertise and experience with children who have disabilities. Together the family and the team work out how they are going to achieve the goals. Putting together a plan of what to do, how to do it, and who does it, is a key part of the team and family working together. It ensures the team is focusing on what will make a difference for this child and their family.

An IFSP does not require formal assessments in advance nor does it need to be a formal meeting. It can be developed with the family by their key contact at home, on a video call or when they meet for an appointment. It is a live document, amended as priorities change. So it should never be regarded as 'finished' or only to be revisited annually.

All supports by the team are linked to one of the child's goals and this is made clear to the family when giving them an appointment, whether by letter, email or verbally. The IFSP and active goals are referred to in all interactions with the family to ensure they are current and still what the family wants to prioritise. If the family's priorities change so should the IFSP, and existing goals which have not been achieved may be set aside.

Family tells members of the team how their child is getting on and their current priorities

The priorities are recorded in the child's IFSP. Goals are agreed and who will do what to meet the goals.

All supports by the team are directly linked to one of the current goals

The National Guidance on IFSPs includes the process of developing an IFSP and quality audit, the national IFSP template, guides for children and young people and their families to help with thinking about their priorities and an information leaflet about IFSPs for families.

National Guidance for Children's Disability Network Teams on Individual Family Support Plans. Revised June 2021

Model of CDNT supports

CDNTs offer different supports depending on the child's needs and what is currently most important for the family. Sessions by a therapist one to one with the child may be the best option, but not always. Sometimes the child joining a group with other children has better results. Parents may find a workshop gives them all the information they need for a particular issue. The supports offered can vary over time, as the needs of the child and their family change, and may be provided in differing combinations.
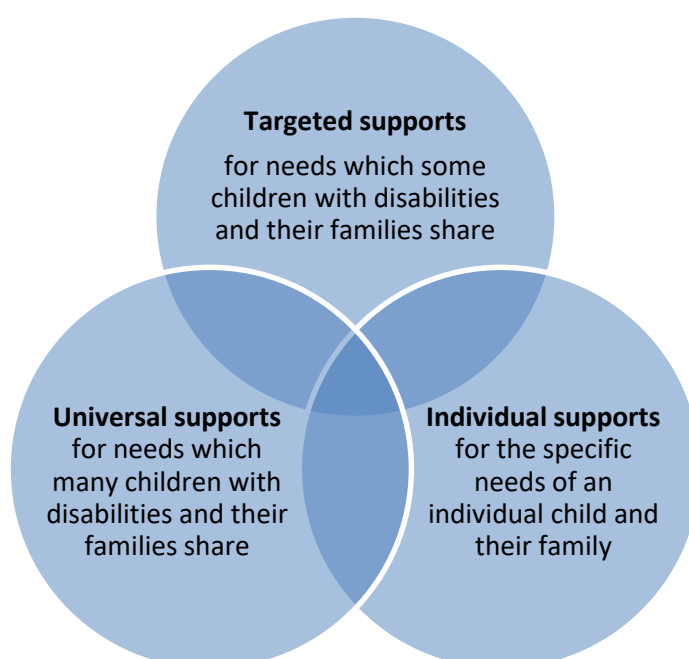
Universal Supports - for needs which many children with disabilities and their families share

These include information sessions, talks and workshops for families.

Examples

· How to help your child sleep through the night

· Toilet training with children who have extra needs

· Supporting your child to develop their language and communication

· How to prepare your child for the move from primary to secondary school

Targeted Supports - for needs which some children with disabilities and their families share

These are for children who have similar needs. The programmes used are well-recognised internationally. Bringing together parents who have common and shared challenges can be very powerful. It gives them an opportunity to meet each other and share ideas and experiences. Bringing children together in groups can be much more fun for them and they learn from each other.

Examples

Hanen Programmes - See www.hanen.org
· It Takes Two to Talk – for children with language delay
· More than Words and Talkability - for children with autism or social communication disorder

Triple P and Triple P Stepping Stones– See www.triplep.net
Triple P Positive Parenting Programs have been widely researched over 40 years. They are used successfully in 30 countries around the world. Triple P Stepping Stones is for families of children with additional needs.

Individual Supports - for specific needs of an individual child

These are interventions and supports to address a child's or their family's individual needs.

Examples
Movement
Children who have difficulties with their movement and posture are assessed by therapists. The family and therapists agree a plan of action which could include treatment or equipment. A few children may need a specialised service such as a review by an orthopaedic surgeon.

Feeding, eating, drinking and swallowing
There may be lots of different reasons why this is an issue for a child. It may need a full assessment including expertise from several professionals. Following assessment the family and the team agree a plan of action.

Transfer and Discharge

Discharge of children from services or closure after a period of intervention, and transfer of services is determined in accordance with the *National Policy on Discharge/Closure and Transfer from CDNTs Revised October 2017*.

Link: **National Policy on Discharge and Transfer from Children's Disability Network Teams 2017**

Assessment of Need

All teams are required to provide Assessments of Need in line with the legislative timeframes described in the Disability Act.

Joint working with other services

Protocols ensure continuity of care, good communication, sharing of relevant information, seamless movement across services and avoid duplication.

A protocol should outline:

1. The aims and principles underpinning the protocol
2. A description of the role of the service/team, the services it delivers and criteria for access
3. A procedure for consultation and/or joint working which may include regular consultative or review meetings, shared case work or information sharing
4. Procedures for referral across teams
5. Process, pathway and responsibility for resolving issues that may arise
6. Process for ensuring compliance with protocol
7. Responsibility and timeframe for a review of the protocol[9]

There are three key national joint working protocols:

Joint Working Protocol Primary Care, Disability and Child and Adolescent Mental Health Services. 2017
Ensuring seamless provision for children whose needs cross these three services, including collaborative working and shared care pathways.

Link: **HSE Joint Working Protocol between Primary Care, Disability and child and Adolescent Mental Health Services September 2017**

Joint Working Protocol for Interagency Collaboration between the Health Service Executive and Tusla – the Child and Family Agency to Promote the Best Interests of Children and Families. 2020
The roles and duties of the HSE and Tusla the Child and Family Agency, regarding children & young people with a disability.

Link: **HSE/Tusla Joint Working Protocol December 2020**

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[9] Guidelines for local implementation groups on developing a governance structure and policies for children's disability services. HSE. 2012

Joint Working Protocol between the HSE and HSE funded service providers, Better Start Early Years Specialists and the Department of Children and Youth Affairs for the provision of health service supports to children with a disability under AIM. 2020

The provision of health service supports for children with a disability attending pre-school under the Access and Inclusion Model.

Link**: Joint Working Protocol between Health, Better Start Early Years Specialists and Department of Children and Youth Affairs (DCYA)**

Where national protocols do not exist local protocols may be developed. Any local protocols should be informed by consultation with the National Disability Operations and the National Clinical Programme for People with Disability to ensure national consistency and adherence to the PDS model. Other agencies and services which may require a joint working protocol or memorandum of understanding may include:

- Acute hospital services
- Schools
- Other relevant disability services such as respite services

Health and education forums

The function of the local forum is to address issues of common concern to those in the education and health sectors engaged in supporting children with disabilities:

• To facilitate networking, build relationships and develop joint working initiatives and opportunities

• To share general relevant information on the range of education and health services in the area

• To develop mechanisms for local health and education staff to jointly support and co-ordinate key transition stages for children and their families including continuing to facilitate information sharing for parents and relevant stakeholders

See **Framework for Collaborative Working between Education and Health Professionals June 2013**

Record Keeping and Information Management

Refer to:

- Data Protection Acts 1988 -2003

  Link: https://www.dataprotection.ie/en/who-we-are/data-protection-legislation

- Freedom of Information Acts 1997-2003

  Link: https://foi.gov.ie/

- HSE Standards & Recommended Practices for Healthcare Records Management 2011

  Link:

  https://www.hse.ie/eng/about/who/qualityandpatientsafety/safepatientcare/healthrecordsmgt/

- HSE Record Retention Periods.2013

  Link: https://www.hse.ie/eng/gdpr/data-protection-covid-19/record-retention-policy-2013.pdf

- Lead Agency record retention policies