



Progressing  
Disability  
Services  
for Children  
& Young People

# **CHO Governance of Children's Disability Network Services**



**Version 1: January 15th 2021**

## Table of Content

1.0	Introduction	3
2.0	Purpose	4
3.0	Scope	4
4.0	Glossary and Abbreviations	4
5.0	Relevant Legislation, Policies and Governance related documents	5
6.0	Governance	5
6.1	Family Participation in Governance	6
6.2	Clinical Governance	7
7.0	Structure for governance of Children’s Disability Networks	9
7.1	CHO Children’s Disability Networks Governance Group	10
7.1.1	Terms of Reference	10
7.1.2	Membership	11
7.1.3	Standing Orders	11
7.1.4	Roles	11
7.2	CDNM Operational Management Group	12
7.2.1	Terms of Reference	12
7.2.2	Membership	12
7.2.3	Standing Orders	13
7.2.4	Roles	13
7.3	CHO CDN’s Clinical Advisory Group	14
7.3.1	Terms of Reference	14
7.3.2	Membership	14
7.3.3	Standing Orders	14
7.3.4	Roles	14
7.4	Children’s Disability Network Manager	15
7.5	Family Forum (one per network)	15
7.5.1	Terms of Reference	15
7.5.2	Membership	15
7.5.3	Standing Orders	16
7.5.4	Roles	16
7.6	Family Representatives Group (one per CHO)	16
7.6.1	Terms of Reference	16
7.6.2	Membership	17
7.6.3	Standing Orders	17
7.6.4	Roles	17
8.0	Implementation	18
9.0	Evaluation and Review	18

# CHO Governance of Children's Disability Network Services

## 1. Introduction

Under the *Progressing Disability Services for Children and Young People Programme* (PDS), the purpose of Children's Disability Networks (CDNs) is to:

- Provide a clear pathway and fairer access to services for each child with a disability and their family based on their need, not on 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, with education staff and with other services such as Primary Care, CAMHS and community groups etc to support children with a disability to reach their full potential.

The PDS Programme provides for Children's Disability Networks with teams of health and social care professionals under a lead agency approach within each of the CHOs, therefore offering greater utilisation of service provision and equity of access to vital services and supports for children and young people with a disability. The role of the Lead Agencies across Section 38, 39 and the HSE is critical in the reconfiguration of children's services into a fully functioning model and in the future provision of children's services.

Each CDN, comprising one Children's Disability Network Team (CDNT), operates within the legislative context for health services in Ireland and follows the direction of national strategy and policy. CDNs are delivered and managed by a range of service providers including the HSE, Section 38 and Section 39 agencies. Each CDN operates under a Lead Agency model where the Lead Agency has responsibility for the service provision in an assigned area in line with the National Policy on the Lead Agency Model.

The foundation for the CDNT model of service is the following twelve principles.

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

See the PDS Policy Framework <https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/> for a short explanation of each principle. Putting

these principles into operation on a sustained and consistent basis requires a robust governance system of CDNTs for every CHO.

There are 91 Children's Disability Networks (CDN) aligned to 96 Community Healthcare Networks (CHNs) across the country and there will be one CDNT per Children's Disability Network. On full reconfiguration of children's disability services into CDNTs, every child across the country with complex needs arising from their disability will have access to a Children's Disability Network Team. All CDNTs will provide services and supports for children aged from birth to 18 years of age. Early Intervention Teams and School Age Teams already in place are reconfiguring into 0-18 CDNTs.

A standardised CHO Governance structure and processes are critical to ensure consistency and quality of services across all CDNs in line with the National PDS Programme, policy and guidance. This document outlines the standardised approach for immediate implementation across CHOs, and includes a review process to be led nationally in partnership with CHOs.

## 2. Purpose

To provide a nationally standardized governance structure for children's disability network services across the CHOs.

## 3. Scope

All Children's Disability Network services in the CHO.

## 4. Glossary and abbreviations

CDN: Children's Disability Network: Ninety one CDNs provide services for children with complex needs and their families across the country. In most cases the CDN is coterminous with the Community Health Network.

CDNT: Children's Disability Network Team: An interdisciplinary team of health and social care professionals which provides services for all children with complex needs from birth to 18 years of age in the CDN.

CDNM: Children's Disability Network Manager: The accountable and responsible person for ensuring the delivery of high quality, safe, integrated children's disability services to the population of the CDN(s) on behalf of the Lead Agency.

CHO: Community Healthcare Organisation: Nine CHOs responsible for the delivery of primary and community-based services.

CHN: Community Healthcare Network: Ninety six CHNs with an average population of 50,000 that deliver Primary Health Care Services across Ireland.

CHO Children's Disability Network Governance Group: is responsible for ensuring the delivery of CDN services in the CHO in line with national policy, providing leadership and direction, and monitoring performance.

CDNM Operational Management Group: is responsible for ensuring consistency in management and operation of all CDNTs across the CHO in line with the PDS model.

Family Representative Group: comprises two representatives from each Family Forum in the CHO, to share feedback and learning, and to provide for representation on the Children's Disability Network Governance Group.

Family Forum: provides an opportunity for families to discuss general issues and ideas about the children's disability services in the Children's Disability Network level.

GDPR: General Data Protection Regulation: The legal framework that sets guidelines for the collection and processing of personal information from individuals who live in the European Union.

Lead Agency: has the responsibility for the provision of services for children aged from birth to 18 with complex disability in the CDN(s) assigned to that agency. The lead agency may be a HSE funded non-statutory organisation or a CHO.

## 5. Relevant Legislation, Policies and Governance related documents

(in alphabetical order)

Child Care Act 1991

Children's Disability Network Manager Job Description

Children First Act 2015

Children First: National Guidance for the Protection and Welfare of Children (2017)

Disability Act 2005

General Data Protection Regulation

Health Act 2004

Health Act 2007

HSE Governance Arrangements for funding Non-Statutory Agencies ([here](#))

HSE Risk Management Policy

HSE Your Service Your Say

Joint Protocol for Interagency Collaboration between the HSE and Tusla to promote the best interests of children and families V2 (2020).

National Policy on the Lead Agency Model

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

## 6.0 Governance

Governance can be defined as the framework of rules, practices and policies by which an organisation can ensure accountability, fairness and transparency in an organisation's relationship with its stakeholders. In the health context, the stakeholders of the HSE include service users, their families, employees, the Minister and Department of Health, other Government Departments, service providers and the general public. See *HSE Code of Governance* [here](#) .

In line with the Lead Agency Policy and mediated agreement regarding the Children’s Disability Network Manager, the Lead Agency holds governance responsibility and accountability for the Children’s Disability Network and team(s) within that network as agreed between the HSE, Lead Agencies and partner organisations in each CHO. This includes resource and performance accountability under the service arrangement. Each Lead Agency has the responsibility for the provision of services for children aged from birth to 18 with complex disability in their assigned Children’s Disability Network(s). The Lead Agency may be a HSE funded non-statutory organisation (Section 38 or Section 39) or a HSE Community Healthcare Organisation. See *National Policy on the Lead Agency Model 2019* ([here](#)).

The Service Arrangement which is the governance framework between the HSE and Non-statutory Agencies under the Health Act 2004 will be utilised to manage the overall service provision by the Lead Agency (where it is not the HSE) in line with formal specification of services to be provided in return for funding, and to agree clearly defined service levels, outcomes and performance indicators thus enabling effective monitoring of performance.

The Chief Officer of the CHO has ultimate responsibility and accountability for the provision of services in line with the National HSE Operational Plan. Therefore, Children’s Disability Network services in each CHO must have a governance structure for oversight and accountability with clear roles, responsibilities, reporting relationships and decision making processes.

## 6.1 Family Participation in Governance

*“Experts by Experience are people who have personal experience of using, or caring for someone who uses health, mental health and/or social care services.”<sup>1</sup>*

Each CHO’s Children’s Disability Networks Governance Group will be inclusive of all key stakeholders. In accordance with the *Guidelines for Local Implementation Groups on Developing a Governance Structure and Policies for Children’s Disability Services (2011)*, the Children’s Disability Networks Governance Group should have a minimum of two family representative members. Further to this, the *Report of the Review of Network Disability Teams Kildare West Wicklow* recommended formal family representation on the governance group.<sup>2</sup>

Participation by families should be facilitated through responsiveness to their diverse circumstances and needs, and by supporting inclusion.

Family participation will be promoted through Family Forums at Children’s Disability Network level, and Family Representatives from each Family Forum will form a Family Representative Group at CHO Level. Two members of the Family Representative Group will be members of the CHO Children’s Disability Network Governance Group. The inclusion of family representatives on CHO Children’s Disability Networks Governance Group adds significant value by:

- Ensuring there is a focus at all times on the needs of children and their families

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<sup>1</sup> Effective Participation in Decision-Making for People with Disabilities and Families. Planning for Ordinary Lives in Ordinary Places A Step by Step Guide to Implementation for HSE Managers and Social Care Staff <https://www.hse.ie/eng/services/publications/effective-participation-in-decision-making-implementation-for-hse-staff.pdf>

<sup>2</sup> Report of the Review of Network Disability Team Service in Kildare West Wicklow. Dermot Rush – the Performance Partnership. 2017 <https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/review-of-kildare-ndts/report-of-the-kildare-west-wicklow-review.pdf>

- Bringing the view from the family perspective on all issues discussed
- Bringing a wide range of competencies and experience
- Bringing lived experience and themes expressed via Family Forums.

## 6.2 Clinical Governance

- Clinical governance is described as the system through which healthcare teams are accountable for the quality, safety and satisfaction of service users in the care they have delivered. For healthcare staff, this means specifying the clinical standards you are going to deliver and showing everyone the measurements you have made to demonstrate that you have done what you have set out to do. *Ref: HSE (2012) Quality & Safety prompts for multidisciplinary teams*
- Clinical governance is built on a model of senior managers working in partnership with senior clinicians. *Ref: HIQA (2012) National Standards for Safer Better Healthcare (Chapter 7, P. 94)*
- A key characteristic of clinical governance is a culture and commitment to agreed service levels and quality of care to be provided. *Ref: HSE (2012) Quality & Safety prompts for multidisciplinary teams*
- The Lead Agency through the CDN is responsible for the governance of all specialist services and associated pathways assigned to it within the CDN and will engage with all relevant internal and external stakeholders as required with the requisite experience in children's disability services to ensure appropriate governance, supervision and oversight.

### Principles

- CDNTs will adhere to all National Policies and Guidance in regards to PDS principles and model of service.
- CDNTs will work within the overall governance document agreed by the CHO while ensuring compliance with all relevant national regulations and standards including HIQA, EPSEN, and Disability Act.
- CDNTs will adhere to best practice and to standards set out by CORU and Professional Bodies. Team members will take individual responsibility for Continuous Professional Development.
- There must be structures in place to support children disability network managers and staff and to respond to governance issues in a timely manner. This is to ensure safe processes and a safe working environment for all levels of staff.
- It is recognised that clinical governance is everyone's responsibility. There must be clear lines of accountability including clinical accountability and a performance management structure for all members within the CDNT.
- The CDN will work within the governance and management structures of the Lead Agency including financial reporting with oversight by the Director of Finance and Executive Team of the Lead Agency

## HSE Guiding Principles for Quality and Safety

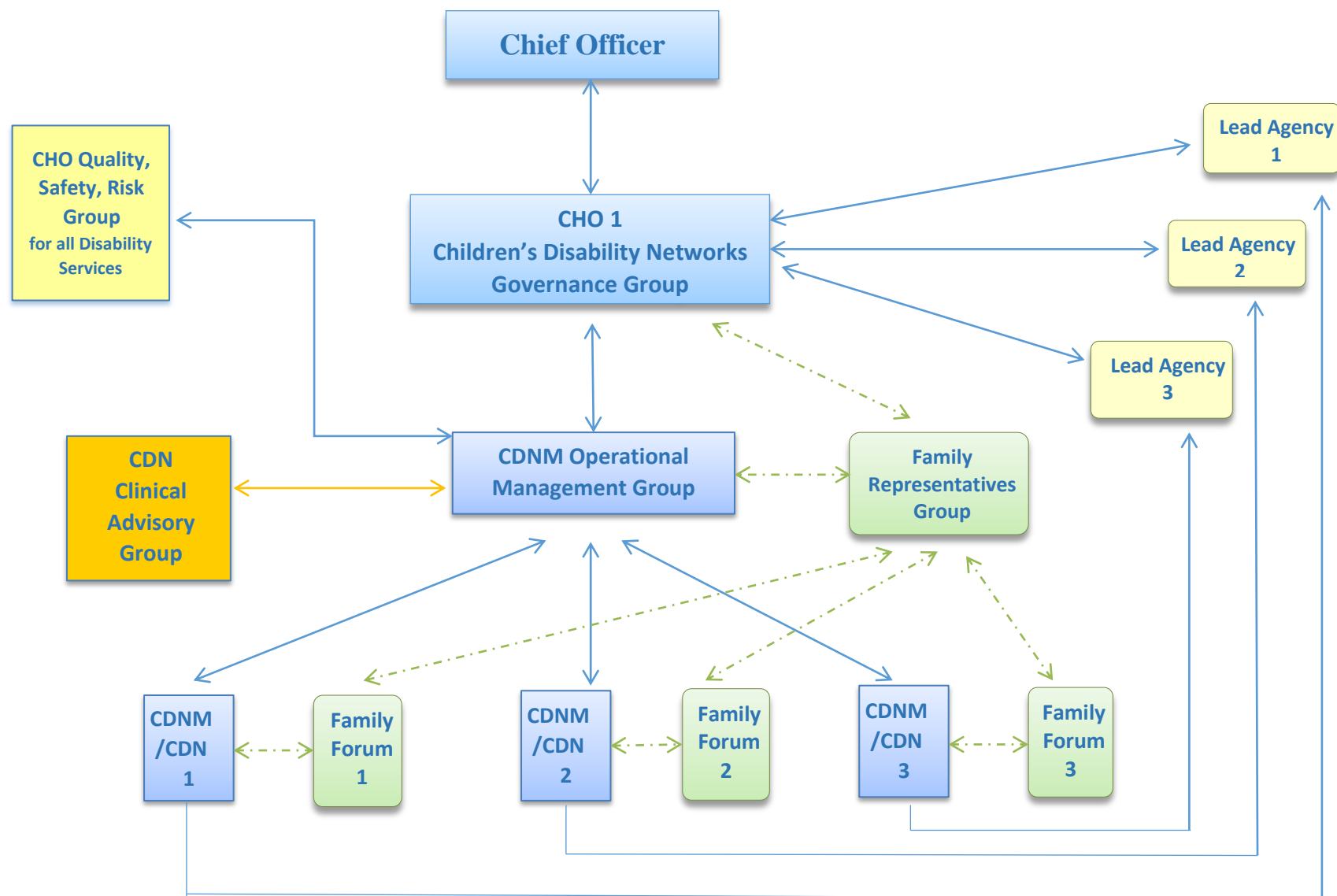


Clinical governance is an integral component of governance arrangements, where:

- 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*



## 7.0 Structures for governance of Children’s Disability Networks



**Organogram Key:**

- ◄- - - - -> = Family partnership and participation
- ◄- - - - -> = CHO Operational relationships as described in sections 7.1 – 7.5.

## 7.1 CHO Children's Disability Networks (CDN) Governance Group

### 7.1.1 Terms of Reference

#### To ensure CDNT services are delivered in line with national policy

- To ensure on-going strategic direction for CDNTs in line with PDS principles, national policy and standards, and National Service Plans
- To agree annual and longer term objectives in line with PDS principles and agree plans to achieve them, and ensure alignment with the Lead Agency's Service Arrangement with the HSE
- To act within statutory, financial and other constraints
- To ensure consistency of models of service and supports in line with PDS principles across all Lead Agency CDNs in the CHO through regular review of evidence
- To provide reports to HSE National Disabilities Operations as required
- To ensure in all Governance Group engagements that no named individual, child, family or staff member is discussed in line with GDPR.

#### To provide leadership and direction to the CDNTs

- To ensure clear and effective standards of governance in the delivery of services across all CDNTs in the CHO
- To ensure that the agreed principles for the CDNTs are evidenced in the continued operation of the services
- To ensure the service is responsive to the needs of children/young people and their families
- To provide robust and regular communication with all stakeholders, in particular an active two way communication channel with the CDN Operational Management and Family Representative Groups.

#### To monitor performance of the CDNTs

- To monitor performance in line with national metrics and data and any additional metrics developed by CHOs to address CHO specific challenges and service areas. KPIs will be monitored to ensure that there is measurable demonstration of the effectiveness of CDNTs in achieving key objectives, targets and outcomes for children and their families and value for money for the resources allocated to the service providers.
- To establish performance and quality targets against agreed annual and longer term objectives that maintain the effective use of resources and provide value for money
- To oversee the delivery of planned results by monitoring performance against objectives and ensuring corrective action is taken when necessary
- To monitor quality, safety and risk of service provision.

#### To plan for ongoing delivery of services by CDNTs

- To oversee the development, ratification and application of CHO and local policies
- To support the essential training and development needs for teams
- To escalate and make recommendations on emerging issues/risks, and identify gaps in the CDNTs to the Chief Officer
- To provide an annual report to the Chief Officer and the Head of Disabilities of the service's activities, challenges, developments and plans
- To establish and maintain the CHO CDN services risk register, ensuring that risks are systematically identified, reported, managed and analysed in accordance with agreed HSE policy
- To specify requirements for service and financial planning succinctly, efficiently and in good time to ensure the Governance Group can fulfil its responsibilities.

### 7.1.2 Membership

- Head of Disabilities, Chair of this group
- CEOs or Directors of agencies (inclusive of Lead and Partner Agencies)
- Head of Primary Care
- Head of Mental Health
- Two representatives of the CHO Family Representative Group
- Two representatives of the CDNM Operational Management Group, including that group's Chairperson and one CDNM. The CDNM Operations Management Group Chair will maintain a rotational schedule for the CDNM representation on this group.

Other representatives such as Finance, HR, Quality, Safety and Risk from Lead/Partner Agencies may be invited from time to time as required.

### 7.1.3 Standing orders

- Frequency of meetings: monthly until CDNTs are established and quarterly thereafter.
- Quorum: The Chairperson, and fifty percent plus one, including at least 1 Family Representative Group rep and 1 CDNM
- Substitutes: Nominees may deputize on behalf of each of the Governance Group members where required. In the unforeseen event that the Head of Disabilities is not available to chair the group, his or her nominee deputized to chair the meeting will be authorized to fulfill all aspects of the role detailed below
- Decision Making: Decisions made by the group should be determined by way of consensus with all members of the group. In the rare event that a consensus view cannot be reached regarding matters encapsulated within the terms of reference, as chair of the group, the Head of Disabilities is required to escalate such matters to the Chief Officer. The Chief Officer of the Community Healthcare Organisation (CHO) will make the final decision as they have overall governance and accountability for the CDNTs and are the accounting officer for the CHO.

### 7.1.4 Roles

#### Chairperson: the CHO Head of Disabilities

- to lead the review of evidence of all Lead Agency CDNTs working in line with PDS principles and model of services
- to provide leadership and direction on achievement of the CHO Children's Disability Networks Governance Group's objectives
- to facilitate and build consensus for decision making, ensuring all voices are heard
- to agree on communication of such decisions as appropriate to relevant stakeholders, including the CDNM Operational Management Group and Family Representatives Group
- to organise regular meetings and circulate meeting minutes and agenda
- to report to the Chief Officer on progress, issues, risks and mitigation, and items in which consensus was not reached within the group which requires the Chief Officer's final decision
- to provide reports to the Head of Operations – Disabilities as required
- To make arrangements for accounting on HSE performance as a Lead Agency.

## CEO or Director of Lead and Partner Agencies/CDNM Operational Group/Family Representatives Group reps:

- to work in partnership with and empowerment of all members to achieve priorities in line with PDS principles and national policies
- Lead Agency CEOs/Directors provide ongoing evidence that they are implementing the Lead Agency Policy and CDN services in line with PDS model

## 7.2 CDNM Operational Management Group

### 7.2.1 Terms of reference

- To ensure consistency in management and operation of all CDNTs across the CHO in line with the PDS model
- To carry out risk assessment and management measures using the HSE Risk Management Framework
- To establish and maintain the CHO CDN services risk register ensuring that risks are systematically identified, reported, managed and analysed in accordance with the HSE Risk Management Policy and emerging issues/risks escalated where not possible to mitigate locally to the CHO Children's Disability Networks Governance Group
- To ensure that an evidence based clinical governance structure is in place across the CHO that includes performance management, supervision and support for all CDNT staff
- To ensure that the delivery of services reflects best practice with performance being measured against agreed objectives
- To identify, analyse, prioritise and support essential training and development needs of teams and where necessary, identify gaps to the CHO Children's Disability Network Governance Group
- To lead and promote continuous quality improvement in line with evidence based practice across all children's disability networks
- To work in partnership and hold regular scheduled meetings with representatives of the Family Representative Group, not less than four times per year.
- To establish and co-chair joint Education and Health Local Forums (see *Framework for Collaborative Working between Education and Healthcare Professionals*)
- To provide an annual report to the CHO Children's Disability Network Governance Group of the service's activities, challenges, developments, plans, including financial planning and service review in line with agreed plans
- To provide peer support and shared learning/CPD, for example, Action Learning Sets, focused on management and leadership.

### 7.2.2 Membership

- Chairperson
- All CDNMs

### 7.2.3 Standing orders:

- Frequency of meetings: twice a month initially and review in due course
- Quorum: The Chairperson and fifty percent plus one of the CDNMs
- Substitutes: each member may nominate a deputy to attend on their behalf
- Voting rights: all core members will have voting rights. In the rare event where consensus cannot be reached on a topic under the above terms of reference, the group may be

required to vote. In the unexpected situation where a majority vote is not possible, the topic should be escalated to the CHO Children's Disability Network Governance Group.

#### 7.2.4 Roles

##### Chairperson:

- to facilitate and build consensus for decision making, ensuring all voices are heard
- to coordinate the evidence that all Lead Agency CDNs are working in line with PDS principles and model of services
- to provide leadership and direction on achievement of the CDN Operational Group objectives in an equitable and consistent manner
- to agree on communication of decisions as appropriate and escalating to the CHO Governance Group
- to organise regular meetings and circulate meeting minutes and agenda
- to report to the Head of Disability Services and CHO Children's Disability Networks Governance Group on progress, issues, risks and mitigation
- to provide reports to the Head of Disability Services as required
- to maintain a schedule of CDNs rotating onto the CHO Children's Disability Networks Governance Group with the Chair
- To be a member on the CHO's Quality Safety Risk Group.

##### Appointment of the Chair:

The Chairperson will be appointed by the Head of Disabilities.

##### CDNs:

- To participate on the CDN Operational Management Group forum
- To agree an annual work plan for the group with clear and measurable outcomes in line with the CHO Children's Disability Network Governance Group Annual Plan
- To make recommendations to the CHO Children's Disability Network Governance Group on the strategic direction of CDNs
- To ensure and provide evidence that all CDNs' practices are in line with PDS principles and model of service, and direction of the CHO Children's Disability Network Governance Group
- To develop an evidence based quality assurance system to ensure sound clinical governance across all CDNs. This will include a system of evaluation and review of the service, its policies, and findings of the CDN Self-Audit Tool and clinical audit, against national standards and national PDS Policy Suite across all CDNs
- To identify risks and gaps, for example in service provision or team competencies required to achieve the core deliverables of a CDN in line with the PDS model, and to develop innovative quality improvement initiatives to address same, or escalate to the CHO Children's Disability Networks Governance Group where this is not possible.
- To identify quality, risk and safety programme priorities, based on the findings of internal and external audits of Incident Investigation Reports, Risk Management, Health and Safety, Infection Prevention and Control, recommendations arising from complaints investigations and other clinical audits
- To establish and maintain a CHO Children's Disability Network's Clinical Advisory Group comprising staff experienced in children's disability services from which the CDN group will draw relevant expertise for specific topics as required, to support a robust quality assurance system

- To establish and implement a process for identifying, developing, implementing and reviewing local PPPGs as required
- To establish and maintain effective clinical supervision structures and practice across all CDNTs
- To identify a prioritised training plan in line with nationally standardised Strengths Needs Analysis template across the CHO
- To meet with 2 Family Representatives Group reps a minimum of 3 monthly for initial 2 year, in order to seek input on service experiences and service development opportunities and agree action plans and timelines for same.

## **7.3 CHO CDNs Clinical Advisory Group**

### **7.3.1 Terms of Reference**

- To support the CDNM Operational Group in the development, implementation and sustainability of a robust quality, risk and safety programme across all CDNTs in the CHO
- To provide advice and guidance for the implementation of clinical governance in collaboration with existing and future processes for assessment, implementation and monitoring of compliance against national and regulatory standards and legislation including the Disability Act, HIQA, CORU etc
- To promote and advance the importance and value of quality, safety and risk management

### **7.3.2 Membership**

- Rotating CDNM Chair
- Health and social care professionals experienced in children's disability services.

### **7.3.3 Standing Orders**

- Frequency of meetings: initially monthly in order to set objectives, targets and membership for individual work strands
- Quorum: the Chairperson, 50 % of the membership plus one
- Substitutes: like for like, ensuring that substitutes also have the required experience in children's disability services.

### **7.3.4 Roles**

#### **The CDNM Operational Management Group**

- To establish and maintain the CDN Clinical Advisory Group
- To set clear objectives and timelines for achievement for the Clinical Advisory Group annually and more often, as required
- To appoint an annually rotating CDNM Chair.

#### **The Chair:**

- to provide leadership on achievement of the Clinical Advisory Group's objectives
- to organise regular meetings and circulate meeting minutes and agenda
- to ensure an appropriate communication flow between the CDN Clinical Advisory Group and the CDNM Operational Management Group.

#### **All CDN Clinical Advisory Group members**

- To advise and support the CDNM Operational Management Group through the Chair on

- the establishment and on-going review of the CHO CDN quality assurance system
- quality, risk and safety programme priorities, based on the findings of internal and external audits of Incident Investigation Reports, Risk Management, Health and Safety, Infection Prevention and Control, recommendations arising from complaints investigations and other clinical audits
- a process to ensure appropriate PPPGs are in place, implemented and reviewed across all CDNTs.

## **7.4 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 Network services and line management of the CDNT within a designated area in line with National Policy. 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(s). This will be provided in accordance with legislative and service delivery frameworks and requirements within the resources allocated.

## **7.5 Family Forum (*one per Network*)**

The Family Forum provides an opportunity for families to discuss general issues and ideas about the children’s disability services in the Network. If a family has an issue or complaint about their own child’s service, they should raise this with the team or with the CDNM. If a family issue cannot be resolved by the team and CDNM, then the family can log a formal complaint using the local complaints procedure or *HSE’s Your Service Your Say*.

The Family Forum will be set up in each Network within six months of the issue date of this policy in the case of existing CDNTs or where not yet established at this date, within six months of reconfiguration into CDNTs.

### **7.5.1 Terms of Reference**

1. To involve families in the development of children’s disability services in their local CDN through:
  - The expression of ideas for future service development and improve existing services
  - Identification of issues and ideas for service development and/or enhancement
2. To elect two Family Representatives who will meet the CDNM regarding Network issues and ideas raised by the Family Forum, and will join the Family Representative Group at area level
3. To share information on:
  - Service provision, governance and access
  - Community supports
  - Rights of the child and the family
  - Other relevant topics of interest
4. To facilitate networking and sharing knowledge and experiences amongst families.

### **7.5.2 Membership**

Family members and carers of children and young people attending a Children’s Disability Network Team (CDNT) in the Network are invited to join the Family Forum.

### 7.5.3 Standing Orders

- Frequency: The family forum has a minimum of two meetings per year
- Consideration should be given to alternative methods of hosting meeting such as video-conferencing
- Quorum: There is no set quorum for the family forums as they are fluid
- Nomination of family representatives is by post/email for the whole cohort of families from the CDN
- Elections are managed by the Family Forum
- In order to have representatives from the Family Forum selected for the Family Representative Group, nominations should be sought prior to the first meeting of the Network Family Forum. The election can then take place at the Family Forum meeting, whether in person or online.
- Confidentiality, Data Protection and GDPR to be upheld at all levels
- Regular feedback is provided for families on issues and ideas raised at the Family Forum and resulting actions.
- Full information on the role of the Network Family Forum and the Family Representative Group will be sent to all families including:
  - The Network Family Forum's Terms of Reference
  - The Family Representative Group's TOR
  - Roles and responsibilities of Family Representatives
  - Procedure for selection and nomination form for Family Representatives.

### 7.5.4 Roles

**The CDN** will manage and coordinate the logistics of the Family Forum, to include:

- Circulating all families with a child attending the service about meetings and arranging a room for the meetings. In the initial stage of forming the forum, they may include families of young people who have recently attained the age of 18 and ceased to attend the CDNT, in order to provide continuity and experience.
- Attending part of the meetings to build relationships and answer general queries.

**Family Representatives** from the Children's Disability Network Family Forum will

- Meet with the CDN to relay issues and ideas raised at the Forum
- Provide feedback to the Forum via a Feedback template
- Attend meetings of the Family Representative Group at CHO level

**A Facilitator** for Family Forum meetings will be identified by the CHO Head of Disabilities. The role of the Facilitator requires skills and experience in facilitation. They will

- establish ground rules
- conduct the meetings so as to enable the free, appropriate and safe expression of views.

## 7.6 Family Representative Group (*one per CHO*)

### 7.6.1 Terms of Reference

- For the 2 elected Family Representatives from each network in the CHO to learn and share feedback from the various different Family Forums
- To co-ordinate attendance of two Family Representative Group members at each CHO Children's Disability Networks Governance Group meeting



- 2 Representatives of the Family Representative Group to meet with the CDNMs Operational Management Group no less than four times per year
- To raise issues for discussion and resolution at appropriate levels of the governance structure
- To develop a feedback template for feedback to the family forums

### 7.6.2 Membership

Two representatives from each of the Family Forums elected as in 7.4 above

### 7.6.3 Standing Orders

- Frequency of meetings: The Family Representative Group will meet prior to each Children's Disability Networks' Governance Group meeting.
- Quorum: A facilitator plus fifty percent of the membership
- Consideration should be given to alternative methods of hosting meeting such as video-conferencing
- Confidentiality, Data Protection and GDPR will be upheld at all levels

### 7.6.4 Roles

#### Family Representatives:

- Represent their Family Forum by expressing their views, concerns and suggestions for improvements based on collation of general areas and themes from the family forum.
- Represent all issues and ideas raised by families
- Ensure there is feedback to families about issues and ideas raised and resulting actions

**The CDNMs** in the CHO will manage and co-ordinate the logistics of the Family Representative Group, including:

- Contacting each representative nominated from the Family Forums in the CHO
- Provide these contact details to the facilitator, conforming with GDPR requirements
- Arranging a venue for meetings
- Dissemination of minutes
- Arrange for expenses to be covered for Family Representatives attending CDNMs Operational Management Group meetings and Children's Disability Networks Governance Group meetings.
- Arranging for induction and capacity building for family representatives

**A Facilitator** for Family Representative Group meetings will be identified by the CHO Head of Disabilities. The role of the Facilitator requires skills and experience in facilitation. They will

- establish ground rules and Terms of Reference
- will conduct the meeting so as to enable the free, appropriate and safe expression of views
- will help the representatives to do the following:
  - Ensure they have clarity on their role and responsibilities
  - Provide support and resources to build their knowledge and capacity
  - Collate issues/ideas/themes from the Family Forum
  - Develop the issues/ideas/themes for a feedback template to the Family Forum
  - Support the rotation and succession planning of the representatives on the CHO Children's Disability Networks Governance Group.

## **8.0 Implementation**

This policy will be implemented by each CHO immediately.

Where governance structures and operations for Children's Disability Networks are already in place, those CHOs will review their current practice and amend accordingly in line with this policy. During this transition phase, existing governance/steering groups may need to co-exist for an agreed time limited period until this policy is fully implemented.

## **9.0 Evaluation and Review**

This policy and its implementation will be reviewed by the CHO Children's Disability Networks Governance Group after one year and feed into a national review to be developed and implemented by HSE Community Operations – Office of Head of Disabilities, supported by the National PDS Steering Group.