



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



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CHO Governance of Children's Disability Network Team Services

1. Introduction

Under the *Progressing Disability Services for Children and Young People Programme* (PDS), the purpose of Children's Disability Network Teams (CDNT) 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 to support children with a disability to reach their full potential.

There are ninety one Children's Disability Network Teams (CDNTs), aligned to 96 Community Healthcare Networks (CHNs) across the country, each CDNT covering a defined geographical area within a CHO. The CDNTs comprise health and social care professionals and administrative support who provide interdisciplinary, child and family centred services and supports for children from birth to 18 with complex needs arising from their disability, in line with the PDS principles and service model. .

Each CDNT operates within the legislative context for health services in Ireland and follows the direction of national strategy and policy. CDNTs are delivered and managed by a range of service providers including the HSE, Section 38 and Section 39 agencies. Each CDNT 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 role of the HSE, Section 38 and 39 Agencies is critical in the development and sustainability of CDNT services in line with the PDS 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 Policy Framework for Service Delivery of CDNTs

<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.

A standardised CHO Governance structure and processes are critical to ensure consistency and quality of services across all CDNTs 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, Lead and Partner Agencies.

2. Purpose of this Policy

To provide a nationally standardized governance structure for CDNT services across the CHOs.

3. Scope of this Policy

This policy applies to

- All Children's Disability Network Team staff in the CHO
- Lead and Partner Agencies CEOs and Senior Management
- HSE Chief Officers and Heads of Service Disabilities.

4. Glossary and abbreviations

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 CDNT.

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 their Lead Agency.

CHO: Community Healthcare Organisation: Nine CHOs responsible for the delivery of primary and community-based services across the country, each with a defined geographical remit.

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 Team (CDNT) 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.

Operational Management Group (OMG): is responsible for ensuring consistency in management and operation of all CDNTs across the CHO in line with the PDS principles and CDNT model of services and supports.

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

Family Forum: provides an opportunity for families to discuss general issues and ideas about the children's disability services and engage in service co design and development with the CDNM at CDNT 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 CDNT(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

Assisted Decision Making (Capacity) Act (2015)

Child Care Act 1991

Children's Disability Network Manager Job Description ([here](#))

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 Consent Policy (2022)

HSE and Lead Agencies respective Child Protection and Welfare Policies

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

HSE Integrated Risk Management Policy ([here](#))

HSE Incident Management Framework (2021) ([here](#))

HSE Interim Guidance on Clinical and Professional Supervision for CDNTs (2021)

HSE Your Service Your Say ([here](#))

Interagency Agreement (2021)

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

National Policy on the Lead Agency Model (2019) ([here](#))

Policy Framework for Service Delivery of Children's Disability Network Teams ([here](#))

United National Convention on the Rights of Persons with Disabilities.

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/CDNT context, the stakeholders of the HSE and Lead Agencies include service users, their families, employees, partner agencies, the Minister and Department of Children, Equality, Disability, Integration and Youth, , 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 CDNT(s) as agreed between the HSE, Lead Agencies and partner organisations in each CHO. This includes resource and performance accountability under the Lead Agency's 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 CDNT(s). The Lead Agency may be a HSE funded non-statutory organisation (Section 38 or Section 39) or a HSE Community Healthcare Organisation (CHO). 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 is utilised to manage the overall service provision by the Lead Agency (where it is not the HSE) in line with HSE Code of Governance and 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 Service Plan and Operational Plan, and CHO Operational Plan. Therefore, CDNT 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."*¹

Each CHO's CDNT 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 CHO CDNT 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.²

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

¹ 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>

² 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>

Family participation will be promoted through Family Forums at CDNT level. Two Family Representatives will be elected from each Family Forum to form a Family Representatives Group at CHO Level. Two members of the Family Representative Group will be members of the CHO CDNT Governance Group. This ensures that the voices of families and their children are heard at all levels of operations within the CHO, and informs CDNT service developments and improvements, to ensure we are best meeting the needs of children and their families within resources available. The inclusion of family representatives on the CHO CDNT Governance Group adds significant value by:

- Ensuring there is a focus at all times on the needs of children and their families
- 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 CDNM is responsible for the governance of all CDNT specialised services and associated specialised pathways assigned to it within the defined geographical area of the CDNT 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 structure and processes as agreed by the CHO CDNT Governance Group in line with this policy 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, where relevant 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 CDNM 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

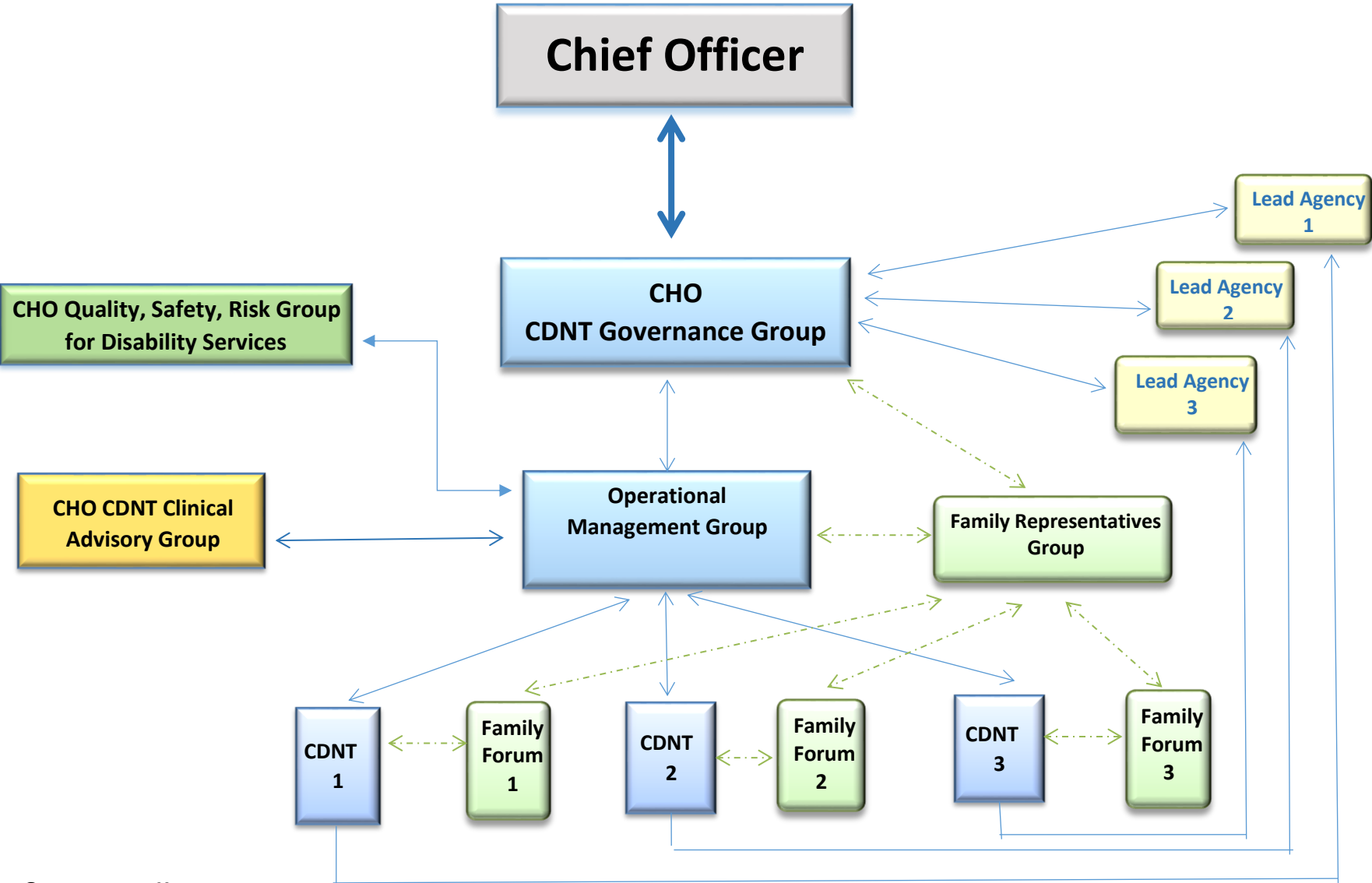
HSE Guiding Principles for Quality and Safety



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 Network Teams (CDNT) Governance Group

7.1.1 Terms of Reference

Working in partnership, the CHO CDNT Governance Group will:

1. Provide strategic leadership and direction for the CHO's CDNTs on service development and delivery now and into the future in line with national policy and the UNCRPD by:

- Taking a strategic focus in developing annual and longer term objectives , statement of strategic priorities and a collaborative, annual work plan to achieve them, ensuring alignment with the HSE National Service and Operational Plans, CHO's Operational Plan, Lead Agency' Service Arrangement with the HSE and their own Corporate Plans
- Ensuring CDNT services are delivered in line with national policy and standards, and National Service Plans so that services are responsive to the needs of children/young people and their families
- To ensure consistency of models of service and supports in line with PDS principles across all Lead Agency CDNTs in the CHO through regular review of evidence
- Acting within statutory, financial and other constraints
- Ensuring clear and effective standards of governance in the delivery of services across all CDNTs in the CHO
- Interrogating CHO CDNT data e.g. CDNT Tracker, BIU returns, CDNTIMS Metrics, to identify key issues and challenges, and to agree the response to addressing them
- Creating a culture of partnership, openness and transparency
- Defining targets for the Operational Management Group (OMG) annually, aligned to the Governance Group's statement of strategic priorities and work plan, in order to inform the OMG work plan, and monitor the OMG's progress against those targets
- Ensuring agreed robust and regular communication with all stakeholders, in particular an active two way communication channel with the Operational Management Group and Family Representative Groups
- Overseeing the development, ratification and application of CHO and local policies
- Providing and ratifying the CHO CDNT Annual Report to the Chief Officer on all CDNTs' service activities, challenges, developments, and strategic (Governance Group) and operational (OMG) plans
- Establishing and maintaining the CHO CDNT services Risk Register in line with the governance structures of each CHO, ensuring that risks are systematically identified, reported, managed and analysed in accordance with agreed HSE policy
- Ensuring evidence based data from the OMG is available to inform specific requirements for service and financial planning succinctly, efficiently and in good time to ensure the Governance Group can fulfil its responsibilities.

2. Drive optimal management and development of resources by

- Ensuring an equitable spread of resources across CDNTs for optimal risk management through evidence informed, workforce planning and allocation of development posts
- Ensuring the essential training and development needs for all teams, as identified by the OMG, are resourced and delivered
- Informing and making recommendations on emerging issues/risks in the CDNTs to the Chief Officer.

3. Monitor performance of the CDNTs by

- Monitoring performance across the CHO's CDNTs in line with national CDNT metrics 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 CDNTs effectiveness in achieving key objectives, targets and outcomes for children and families and value for money for resources allocated, and corrective actions taken when necessary.
- Establishing performance and quality targets against agreed annual and longer term objectives for all teams that optimise use of resources and value for money
- Monitoring quality, safety and risk of service provision, and informing the Chief Officer, with recommendations for actions, where required, to address gaps.
- Providing reports to HSE National CDNT Steering Group as required.

7.1.2 Membership of the Governance Group:

- Head of Disabilities (Chair)
- CEOs or their delegated persons, including Lead and Partner Agencies
- Two representatives of the CHO Family Representative Group
- Two representatives of the Operational Management Group, including that group's Chairperson and one CDN. The Operations Management Group Chair will maintain a rotational schedule for the CDN representation on this group
- HSE CHO Service Improvement Lead for Children's Disability Services

Note: where there are less than 3 Lead Agencies, consideration must be given to balancing representation of Lead Agencies in Governance Group meetings.

Others 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: quarterly at a minimum.
- Quorum: The Chairperson, and fifty percent plus one, including at least 1 representative each of Family Representatives Group and Lead Agencies, and one CDN
- Substitutes: Named persons may deputize on behalf of the each of the Governance Group members where required. Consistency of the named person must be maintained to support the functioning and achievements of the group. In the unforeseen event that the Head of Disabilities is not available to chair the group, their deputy chairing 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, reflecting the agreed Partnership Principles, Addendum to the Interagency Agreement. 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 CHO will make the final decision as they have overall governance and accountability for CDNTs and are the accounting officer for the CHO.

7.1.4 Roles

Chairperson: CHO's Head of Disability Services will

- Create a culture of partnership, openness and transparency
- Lead the review of evidence of all Lead Agency CDNTs working in line with PDS principles and model of services
- Provide leadership and direction on achievement of the CHO CDNT Governance Group's objectives
- Facilitate and build consensus for decision making, ensuring all voices are heard
- Agree on communication of such decisions as appropriate to relevant stakeholders, including the Operational Management Group and Family Representatives Group
- Organise regular meetings and circulate meeting minutes and agenda
- 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
- Provide reports to the Head of Operations – Disabilities as required
- Make arrangements for accounting on HSE performance as a Lead Agency.

CEOs or their delegated persons/CHO Service Improvement Lead for Children's Disability Services /Operational Management Group/Family Representatives Group representatives will:

- Work in partnership, openness and transparency and empower all members to achieve priorities in line with PDS principles and national policies
- Lead Agency CEOs/CHO will provide ongoing evidence that they are implementing the Lead Agency Policy and CDNT services in line with PDS model.

7.2 Operational Management Group (OMG)

7.2.1 Terms of reference

The Operational Management Group will

- Develop an annual OMG work plan based on targets set by the CHO CDNT Governance Group, and aligned to the Governance Group's statement of strategic priorities and work plan
- Amend the OMG work plan in year as required in agreement with the Governance Group, and provide regular reports to the Governance Group on progress against agreed targets
- Ensure consistency in management and operations of all CDNTs, and in development and management of interdisciplinary, child and family services across the CHO in line with the PDS model, and supported by regular review of evidence
- Identify and carry out risk assessment and mitigation measures for risks applicable to more than 1 CDNT in the CHO using the HSE Risk Management Framework. Where risks and gaps relate, for example, to service provision or team competencies required to achieve the core deliverables of a CDNT in line with the PDS model, the OMG will develop innovative quality improvement initiatives to address same, or escalate to the CHO CDNT Governance Group where this is not possible.
- 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 Establish and implement a process for identifying, developing,

implementing and reviewing local PPPGs as required/requested for sign off by the CHO CDNT Governance Group

- Ensure that an evidence informed quality assurance system underpinning sound clinical governance structure is in place across the CHO that includes minimum standards for performance management, supervision³ and support, for all CDNT staff, and aligned to Lead Agencies' policies. This will include a system of evaluation and review of the service, its policies, and findings of the CDNT Self-Audit Tool and clinical audit against national standards and policies across all CDNTs
- Establish and maintain effective clinical supervision structures and practice across all CDNTs in line with existing lead agencies policies Establish and maintain a CHO CDNTs' Clinical Advisory Group comprising staff experienced in children's disability services from which the OMG will draw relevant expertise for specific topics as required, in order to develop, implement and sustain the quality assurance system for all CDNTs
- Set clear objectives, targets and timelines for achievement for the Clinical Advisory Group as informed by the OMG and the Governance Group work plans annually and more often, as required
- Appoint an annually rotating Chair for the Clinical Advisory Group.
- Ensure the delivery of services reflects best practice and continuous quality improvement with performance being measured against agreed objectives, aligned to the CHO CDNT Governance Group statement of strategic priorities and work plan
- Identify, analyse, prioritise and support essential training and development needs of teams in line with nationally standardized Strengths Needs Analysis template and where necessary, identify gaps to the CHO CDNT Governance Group
- Work in partnership and hold scheduled meetings with representatives of the Family Representative Group as indicated by the CHO CDNT Governance Group In order to seek input on service experience and service development opportunities, and to agree action plans and timelines for their delivery
- Establish and co-chair joint Education and Health Local Forums (see *Framework for Collaborative Working between Education and Healthcare Professionals*)
- Provide peer support and shared learning/CPD for CDNT members of the group, e.g. Action Learning Sets focused on management and leadership.

7.2.2 Membership of the OMG

- Chairperson: will rotate between Lead Agency Representatives in the spirit of partnership working (Partnership Principles – Addendum to the Interagency Agreement)
- All CDNTs
- CHO Service Improvement Lead for Children's Disability Services
- 1 Children's Services Manager (or equivalent role) as representative for each Lead Agency.
- Where the HSE may not be a Lead Agency in a CHO, an appropriate HSE Manager will also be a member and rotating Chair of this group.

7.2.3 Standing orders:

- Frequency of meetings: to be determined by the OMG based on their annual work plan with a minimum of once a month.

³ HSE Interim Guidance on Clinical and Professional Supervision for CDNTs (2021)

- Quorum: The Chairperson and fifty percent plus one of the membership to include at least one representative from each Lead Agency in a decision making capacity.
- Substitutes: It is vital that all members aim to attend each OMG.
- Decision Making: 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 CDNT Governance Group. Decisions made at the OMG will be binding with the decision making authority of the OMG.

7.2.4 Roles

The Chairperson will:

- Create a culture of partnership, openness and transparency
- To agree an annual work plan with the OMG including clear and measureable outcomes in line with the CHO CDNT Governance Group statement of strategic priorities and work plan and targets it sets for the OMG.
- Facilitate and build consensus for decision making, ensuring all voices are heard
- Facilitate coordination of the evidence that all Lead Agency CDNTs are working in line with PDS principles and model of services
- Provide leadership and direction on achievement of the Operational Management Group objectives in an equitable and consistent manner
- Ensure agreed robust and regular communication, including of decisions as appropriate, in particular an active two way communication channel with the CHO CDNT Governance Group and with the Family Representative Group
- Organise regular meetings and circulate meeting minutes and agenda
- Provide reports to the CHO CDNT Governance Group via the Head of Disability Services as Chair, as required, on progress against the OMG Work Plan, issues, risks and mitigation
- Maintain a schedule of CDNMs rotating onto the CHO CDNT Governance Group and CAG Chair role with the Governance Group Chair.

Appointment of the Chair:

The Chairperson will be appointed by the Head of Disabilities, on a rotational annual basis as a minimum term.

The CDNMs will:

- Assist in creating a culture of partnership, openness and transparency
- Participate on the OMG each representing their respective CDNT and Lead Agency's approach and risks, and providing two way communication between their Lead Agency, their CDNT and the OMG
- Ensure that all actions are implemented consistently across their respective CDNTs
- Ensure that decisions made and actions required to be taken by the OMG are aligned to the Governance Group's statement of strategic priorities and work plan, and Lead Agencies' strategic plans.

The CHO Service Improvement Lead for Children's Disability Services will

- Gather, collate and provide analysis on CDNT data to submit, as appropriate, to the OMG and Governance Group, supporting their respective operational and strategic roles.
- To be a member on the CHO's Quality Safety Risk Group, providing a two way communication between it and the OMG, and providing insight, data and information in regards to CDNTs service quality , safety and risk.

The Lead Agency Representatives will:

- Participate in the OMG forum, each representing their respective lead agency's to enable timely decision making aligned to their overall strategic objectives, provide two way communication between their Lead Agency, their team(s) and the OMG.
- Assist in creating a culture of partnership, openness and transparency
- Ensure that decisions made and actions required to be taken at the OMG are aligned to each Lead Agency's individual strategic plan
- Ensure that the appropriate decision maker is present so that actions can be developed, agreed, and/ or implemented.
- Ensure that all actions are implemented consistently across their respective Lead Agencies

7.3 CHO CDNTs Clinical Advisory Group (CAG)

7.3.1 Terms of Reference

- The CAG will support the CDNMM Operational Management Group in the development, implementation and sustainability of a clinical governance structure and processes, including a robust quality, risk and safety programme across all CDNTs in the CHO in line with Lead Agency and National policies and guidance

A Clinical Governance Framework will include, for example,

- A robust clinical supervision programme for all team members
- Development of clinical pathways
- Development and implementation of clinical audit programme to ensure compliance with legislation, national policy etc.

7.3.2 Membership of the CAG

- Rotating CDNMM Chair
- Core base of health and social care professionals experienced in children's disability services who will support competency development of CDNT staff and development of clinical pathways. This may include discipline managers, clinical specialists and experienced CDNT members.
- Additional members with the required knowledge, competencies and experience may be invited from time to time to participate for specific agreed work developments.

7.3.3 Standing Orders

- Frequency of meetings: as determined by the OMG work plan with a minimum of quarterly in order to set the annual CAG work plan including objectives, targets and membership for individual work strands
- Quorum: the Chairperson, 50 % of the membership plus one

- **Named Substitutes:** ensuring that substitutes also have the required knowledge, competencies and experience in children’s disability services.

7.3.4 Roles

The Chair (CNDM) will:

- Provide leadership on achievement of the Clinical Advisory Group’s objectives
- Organise regular meetings and circulate meeting minutes and agenda
- Ensure an appropriate communication flow between the CDNT Clinical Advisory Group and the Operational Management Group.
- Track and coordinate information flow and progress against targets of various working groups under the CAG and the CAG
- Provide an annual report to the OMG.

All CDNT Clinical Advisory Group members

- To bring their discipline specific knowledge, competency and experience to the group to support development of CDNT staff, the team, interdisciplinary pathways and the service.

7.4 Children’s Disability Network Manager

The Children’s Disability Network Manager (CDNM) is responsible to the Lead Agency for the development of CDNT 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 CDNT(s) on behalf of the Lead Agency. This will be provided in accordance with legislative and service delivery frameworks and requirements within the resources allocated.

7.5 Family Forum

A Family Forum will be set up for each CDNT.

7.5.1 Purpose of the Family Forum

1. For the CDNM and families to work collaboratively to improve the outcomes for children and families accessing our services and to foster a culture of trust, openness and transparency
2. To give families an opportunity to discuss general issues and ideas for service development and/or enhancement of children’s disability services in their local CDNT
3. To elect two Family Representatives who will meet the CDNM regarding CDNT issues and ideas raised by the Family Forum, and will join the Family Representative Group at area level
4. To share information on:
 - Service provision, governance and access
 - Community supports
 - Rights of the child and the family
 - Other relevant topics of interest
5. To facilitate networking and sharing knowledge and experiences amongst families.

7.5.2 Who can attend Family Forum Meetings?

Family members and carers of children and young people attending and waitlisted for the CDNT are invited to join the Family Forum.

7.5.3 How will the Family Forum work?

- The Family Forum is recommended to have four 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, including those of children in service and waitlisted for the CDNT
- Elections are managed by the Family Forum
- The principles of confidentiality, Data Protection and GDPR should be upheld at all times
- Regular feedback is provided for families on issues and ideas raised at the Family Forum and resulting actions.
- If a family has an issue or complaint about their own child's service, they should raise this with the team or the CDNM. If a family issue cannot be resolved by the team and CDNM, then the family can log a complaint using the local complaints procedure or HSE's Your Service Your Say.

See also *Setting Up and Sustaining the Family Forum - a Guide for CDNMs and Lead Agencies September 2022*

7.5.4 Roles

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

- Circulating information to all families with a child attending the service about meetings and arranging a room for the meetings.
- Attend and provide updates for the meetings to build relationships, answer general queries, share information, seek families input on service developments
- Provide feedback to families on previous proposals/ideas raised.

Family Representatives will

- Attend meetings of the Family Representative Group at CHO level
- 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 issues and ideas raised by families
- Provide feedback between the Family Representative Group and the Family Forum
- The Family Representative's official interface with the family members should be solely at the Family Forums. There is a pathway for families with queries relating to individual children and it is not appropriate to get engaged in issues related to individual children. Family Representatives should direct the family member to the CDNM or tell them to contact the CDNT via phone, email or post.

A Facilitator for Family Forum meetings will be identified by the CHO CDNT Governance Group. 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

- Facilitate development of an Agreement/Guiding Principles on how members will work together.

7.6 Family Representative Group (one per CHO)

7.6.1 Terms of Reference

- For the two elected Family Representatives from each Family Forum in the CHO to learn and share feedback from the various different Family Forums
- To select two Family Representative Group members to attend each CHO CDNT Governance Group meeting
- To select two Representatives of the Family Representative Group to meet with the Operational Management Group as indicated by the CHO CDNT Governance Group, in order to seek input on service experiences and service development opportunities and agree action plans and timelines for same.
- To raise and collate issues, and suggestions/ideas for their resolution at appropriate levels of the governance structure
- To develop a feedback template to support timely feedback to the family forums

7.6.2 Membership

Two representatives from each of the Family Forums in the CHO elected as in 7.5.3 above

7.6.3 Standing Orders

- Frequency of meetings: The Family Representative Group will meet prior to each CHO CDNT 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
- The principles of confidentiality, Data Protection and GDPR will be upheld at all times.

7.6.4 Roles

Family Representatives:

- Attend meetings of the Family Representative Group
- 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 issues and ideas raised by families
- Provide feedback between Family Representatives Group and the Family Forum including on issues and ideas raised and resulting actions
- To participate if required in other forums as may be requested from time to time by the CHO CDNT Governance Group

The CHO Service Improvement Lead for Children’s Disability Services 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
- Provide support and resources to build their knowledge and capacity

- Arrange for expenses to be covered for Family Representatives attending Family Representatives Groups meetings, Operational Management Group meetings and CHO CDNT 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 CDNT Governance Group. 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
 - Collate issues/ideas/themes from the Family Forum
 - Develop the issues/ideas/themes for feedback to the Family Forum
 - Support the rotation and succession planning of the representatives on the CHO CDNTs Governance Group.

8.0 Implementation

This policy, issued for immediate implementation in 2021 to CHOs, and reviewed and revised in 2023, will be adhered to consistently under the direction, guidance and oversight of the CHO CDNT Governance Group.

9.0 Evaluation and Review

This policy and its overall implementation will be reviewed on a 3 annual basis, or sooner where required, led by National HSE Community Operations – Office of Head of Disabilities, supported by the National CDNT Steering Group.