National Policy ☒ National Procedure ☐ National Protocol ☐ National Guideline ☐ National Clinical Guideline ☐

National policy on prioritisation of children on a waiting list for a Children's Disability Network Team – revision 1

DOCUMENT GOVERNANCE [1]	
Document Owner (post title):	Assistant National Director – Children's Disability Services
Document Owner name:	Karl Brogan
Document Owner email: (Generic email addresses only accepted)	Children.disability@hse.ie
Document Commissioner(s): (Name and title of post holder):	Bernard O'Regan Assistant National Director – Children's Disability Services
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Document Approved by: (Name and title of post holder)	Karl Brogan Assistant National Director - Children's Disability Services
Document Approver Sign-off: (e-signature)	
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Development Group Name:	National Children's Disability Network Teams Prioritisation Policy Review Group
Development Group Chairperson:	Caroline Cantan
Insert additional rows as required	

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Topic:
Prioritisation of children on a Children's Disability Network Teams (CDNTs) waiting list.
National Group:
HSE Access and Integration – Children's Disability Services
Short summary:
The national policy for all Children's Disability Network Teams on the prioritisation of new referrals to be opened to the team, and of children on a CDNT waiting list whose needs change whilst waiting to be opened.
Description:
Children accepted onto a waiting list for a Children's Disability Network Teams have a very wide range of complex needs arising from a disability. For this reason, their needs cannot be readily compared and ranked in terms of severity or urgency. The development of this policy included a literature review of international prioritisation policy and tools, and consultation with families and staff. The policy states that, in the interests of equity and transparency, children are to be seen in order of date of acceptance of referral and only seen in advance of that order when there is an exceptional need for support.

[3] Records details of the document review or update, even if no changes are made.

[4] Records the document information required for publication on the HSE National Central Repository.

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July 2025

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1.0 Policy Development

This policy was developed by the CDNT Prioritisation Policy Working Group convened by the National CDNT Steering Group. The Prioritisation Policy Working Group comprises nominees from each CHO, Heads of Discipline (HSE, Section 38 and Section 39 organisations), a parent (until July 2024) and a Forsa representative (see list of members Appendix 1). Sub groups to advise on discipline specific priorities (physiotherapy, occupational therapy, speech and language therapy, psychology, social work, dietetics and nursing), comprised nominees from each CHO and were led by members of the Working Group.

The Working Group reviewed the National Policy on Prioritisation of Referrals to CDNTs 2016 and determined that this policy required revision.

Terms of Reference of the Working Group

To advise on the national policy for all Children's Disability Network Teams (CDNTs) on prioritisation of:

- new referrals accepted to the CDNT who are placed on the waiting list
- children who are on the CDNT waiting list and whose needs change whilst awaiting to be opened to the CDNT.

Outside terms of reference:

- Caseload management for children who are open with the CDNT
- Prioritisation for discipline and interdisciplinary team caseloads who are open with the CDNT
- Waitlists for specific interventions for children open with the CDNT.

Evidence gathered to support development of policy

- Survey of CDNMs (Children's Disability Network Managers) on current practice (See Appendix 2)
- Advice on duty of care by the legal advisor to the HSE
- Literature review conducted by National Disability Authority (NDA) (see Appendix 3)
- Advice of discipline specific groups
- Consultation with stakeholders and review of feedback

2.0 Policy Purpose

Children are opened for CDNT services in order of date of receipt of referral once accepted for CDNT. This policy provides for the exception to this. It does not apply to ongoing caseload management and to children open to the CDNT and waiting for a specific assessment or intervention.

3.0 Scope of the Policy

This policy applies to management and staff in all Children's Disability Network Teams.

4.0 Roles and Responsibility

It is the responsibility of each governance group for children's disability services to oversee the implementation of this policy at management and CDNT level, and to monitor its operation.

5.0 Procedure

5.1 Model of Service

The model of service for all CDNTs is family-centred and based on the needs of the child. This includes universal, targeted and individual supports and interventions, as appropriate to the individual child and family. It is based on the objectives of empowering and supporting parents and others who interact with the child daily.

The CDNT is an interdisciplinary team of health and social care professionals who have specific expertise to support children with complex needs arising from a disability and their families. Members of the CDNT support parents and others by building capacity and resilience within the child's immediate network of support, thus enabling children and young people reach their individual potential.

5.2 Referral

5.2.1 Each Regional Health Area must have a protocol for the management of CDNT referrals including providing clear information for parents, referrers and the CDNT members.

5.2.2 The appropriate service for each child (Primary Care or CDNT) is decided according to the complexity of the child's needs in line with the National Policy on Access to Services for Children with Disability or Developmental Delay:

> *2.2.3 The Children's Disability Network Teams are the main providers of support for children and young people with complex needs arising from a disability who require services and supports from an interdisciplinary disability team.*

Access to Children's Disability Network Teams is determined by the range and extent of functional difficulties and the level of interdisciplinary supports required.[5]

Therefore, this policy on prioritisation applies to children whose needs have already been determined as complex, based on the information available at the time of the original referral, and who are accepted for access to the CDNT. Some children may receive joint care in line with the Joint Working Protocol Primary Care, CAMHS and Disability Services.[6]

5.2.3 CDNTs are not an emergency service. Emergencies and urgent issues must be directed to the appropriate service, such as a hospital emergency department, the Gardai, Tusla, a general practitioner or appropriate community resources.

5.2.4 In areas where there are specialised support services, such as palliative care teams, these services may be accessed as appropriate to meet presenting needs.

5.2.5 The National Children's Services Referral Form and Additional Information Forms include questions which will assist in identifying needs. Consent to the CDNT service by parents, and the young person if they are aged over 16 years, must be given in line with the HSE National Consent Policy[7] before a referral can be considered.

5.2.6 CDNTs can only make decisions based on the information they have. Referrers have a duty of care to ensure accurate, detailed and relevant information is provided. It is the responsibility of referrers and parents of children on the waiting list to let the team know of any changes in the child's needs over time.

[5] **National Policy on Access to Health Services for Children with Disability or Developmental Delay 2019** .
[6] **HSE Joint Working Protocol between Primary Care, Disability and child and Adolescent Mental Health Services September 2017**
[7] National Consent Policy. HSE.2022

5.2.7 The CDNM will take the lead in processing referrals with CDNT members and, where relevant, request further information and clarification, or alternatively assign this role to an appropriate member of the service.

5.2.8 From the time of receipt of a referral, the service has a duty to act in a fair, open and transparent manner in processing referrals. If the child's name is placed on a waiting list for services, their family must be given information about how the waiting list is managed.

5.3 Prioritisation of children on a waiting list for the CDNT

Children accepted onto the waiting list for a CDNT have a very wide range of complex needs arising from a disability. For this reason their needs cannot be readily compared and ranked in terms of severity or urgency. After extensive enquiry (See Appendix 3 NDA research) no existing appropriate tool has been sourced and it is not feasible to develop a comprehensive and robust prioritisation tool which could capture this wide range of needs and would be fair to all children. In the interests of equity and transparency, children are therefore seen in order of date of receipt of referral and only seen in advance of that order when there is an exceptional need for expedited support.

Concerns identified within the referral information or which come to the attention of the team while the child is on the CDNT waiting list, may require a member of the team to look for further information from the referrer or the child's family. Sufficient information to make a decision may be obtained by a follow up contact. The response to seeing a child in advance of date order of receipt of referral may be by one or more disciplines for a specific intervention, as appropriate to address the exceptional need. A specific intervention does not mean the child is automatically open to the whole team.

Individual decisions on prioritisation for exceptional need are documented in the child's file with clear reasoning for the decision. Scope of the clinical discussion to include but not limited to:

- Identifying exceptional needs

- Is further information required and who actions this?
- What supports are required based on exceptional needs
    - from the CDNT
    - from community and voluntary services
- Communications with parents

Please see Appendix 4 for a sample form to document the clinical discussion

Appendix 1 Members of CDNT Prioritisation Policy working Group

Caroline Cantan National Programme Co-ordinator HSE National Disabilities (Lead)

CHO Representatives
CHO 1 Faye Read CDNM (until January 2024)
CHO 2 Ajay Kumar CDNM
CHO 3 Nicola McMahon CDNM
CHO 4 Gillian Darrer Director of Services Enable Ireland
CHO 5 Therese Healy CDNM
CHO 6 Anna Meegan General Manager HSE
CHO 7 Mary Feely CDNM
CHO 8 Margaret Barrett CDNM
CHO 9 Sinead English CDNM

Parent representative
Rebecca O'Riordan (until July 2024)

Discipline Managers
HSE: Roisin Egan Principal Psychologist Manager Children Disability Services CHO 5
Section 38 organisations: Denise McCarthy Dietitian Manager St Michael's House
Section 39 organisations: Claire Mortell Speech and Language Therapy Manager St Joseph's Foundation

Forsa staff representative
Catherine Rafter Principal Social Worker St Michael's House

Appendix 2: Summary Results Survey of CDNMs 28.4.24

24 Responses (26% of CDNMs)

Q.1 Is the Interim Revised National Policy on Prioritisation of Referrals to CDNTs November 2023 sufficient to meet your needs for guidance on prioritising referrals?
No 82% Yes 17%

Q2. If you answered No to Q1, what additional guidance is needed?

- Original 2016 policy preferable x 4
- National urgent response protocol x 2
- National protocol on managing referrals
- More specific criteria x 3
- Examples x 2
- Tiered prioritisation dependent on resources
- Information for parents about prioritisation
- Definition of urgent
- Definition of waiting list – does it include children transferred on reconfiguration who are still not open to CDNT?
- Guidance where CDNT is not only service child requires e.g. also needs CAMHS
- 'Urgent' is too subjective
- Prioritisation tools do not work
- Different priorities for each discipline
- Need for consistency across the country

Q3 Please outline the procedure you use for prioritising referrals (responses included combinations of below)

- Review of information received
- Team intake meeting
- Screening appointment
- Individual discipline prioritisation criteria
- Team member calls family to verify information and f ind out priorities
- Prioritisation by individual disciplines
- Ref errals score sheet
- Process map of procedure - CDNM review of information, log of previous decisions to ensure consistency, individual discipline input where CDNM not of that discipline
- Prioritisation form
- Gather additional information e.g. family, school, creche

Q4 What prioritisation tools do you use?

- 2016 policy
- Individual discipline tools
- Specific needs prioritisation e.g. aids and appliances matrix
- Clinical experience
- Risk assessment
- National Access Policy
- CORU standards
- Regulatory body guidance of best practice
- No tools - prioritise groups of children according to specific need e.g. school starters at particular time of year
- Hardiker model
- No tools – base on information from family, school etc.

Appendix 3 NDA Literature Review

Literature Review

The National Disability Authority carried out a review of relevant national and international literature to inform the development of this policy. Their report concludes:

'The literature has shown that professional disagreement on what constitutes urgency remains an issue, even when structured priority criteria are followed…. This report did not find any models within the literature (*on prioritisation*) that referred to interdisciplinary teams.'

Full report available on request

Appendix 4 Sample form when considering exceptional circumstances for seeing children in advance of date order of referral

- Child's name:
- Date of birth:
- Date of acceptance of referral by CDNT:
- Summary of child's exceptional needs according to available information:
- Further information required:
- Action to gather information- by whom and by what date? (e.g. phone call to parent, online or in-person appointment):
- Decision re supports required based on exceptional needs for:
  - the services of a CDNT and clinical rationale for same
  - from other community and voluntary services
- Clinical rationale for above decisions
- Communication to parents, by whom and by what date:
- Team members involved in decision (Print name and discipline):

Signatures of team members

Date:

Appendix 4: Signature Sheet

I have read, understand and agree to adhere to this Policy.

Document Title: National policy on prioritisation of children on a waiting list for a Children's Disability Network Teams

Print Name	Signature	Job Title	Date