



**Oifig an Stiúrthóir Cúnta Náisiúnta,**  
Foireann Míchumais Náisiúnta,  
An Chéad Urlár - Oifigí 13, 14, 15,  
Áras Phlásóg na Rós, Coimpléasc Gnó na hOllscoile,  
Páirc Náisiúnta Teicneolaíochta,  
Caladh an Treoigh,  
Luimneach.

**Office of the Assistant National Director,**  
National Disability Team,  
First Floor- Offices 13, 14, 15,  
Roselawn House, University Business Complex,  
National Technology Park,  
Castletroy,  
Limerick.

23<sup>rd</sup> July 2024

Deputy Cathal Crowe,  
Dail Eireann,  
Leinster House,  
Kildare Street,  
Dublin 2.  
E-mail: [cathal.crowe@oireachtas.ie](mailto:cathal.crowe@oireachtas.ie)

Dear Deputy Crowe,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary question, which was submitted to this department for response.

**PQ: 29614/24**

*To ask the Minister for Children; Equality; Disability; Integration and Youth the progress made in children's disability services since 27 June 2020; the additional funding provided in successive budgets; his plans for 2024; and if he will make a statement on the matter.*

**HSE Response**

A wide range of disability services are provided to children and adults with physical, sensory, intellectual disability and autism. Disability services focus on supporting and enabling people with disabilities to maximise their full potential, as independently as possible. Current policies are based on the principles of person-centredness to ensure insofar as possible that the supports for a person are based on individual assessed need, will and preference and to support people to remain as close to home and connected to their community as possible.

**The National Access Policy**

The National Policy on Access to Services for Children & Young People with Disability & Developmental Delay ensures that children are directed to the appropriate service based on the complexity of their presenting needs i.e. Primary Care for non-complex functional difficulties and Children's Disability Network Teams for complex functional difficulties

**HSE Joint Protocol Primary Care, Disability and Child and Adolescent Mental Health Services (2017)**

This Protocol underpins the pathway and process for shared assessment and/or shared interventions provided by 2 or more services where it has been identified in the best interest of the child.

Children's Disability Services are provided based on the presenting needs of the child rather than by their diagnosis or the type of disability or service required. Services are provided following assessment according to the child's individual



requirements and support needs. The assessment may be completed by one or more health and social care professionals pending the child's referral information, individual needs and presentation.

### **Children's Disability Network Teams (CDNTs)**

Children's Disability services in Ireland are currently undergoing a major reform process. During 2021, reconfiguration of Children's Disability services, under the Progressing Disability Services model, took place with the establishment of ninety-one Children's Disability Network Teams (CDNTs) to provide equity of access for all children with complex disability to specialised services and supports as close to a child's home as possible.

There are now 93 CDNTs. These teams provide for approximately 5.6% of the total child disability population, i.e. over 70,000 children and their families nationally.

The establishment of CDNTs is intended to facilitate the provision of equitable, child and family centred services for all children with complex needs associated with their disability or developmental delay.

Regardless of the nature of their disability, where they live, or the school they attend, every child with complex needs and their families have access to a range of family centred services and supports of their CDNT according to their individual needs. This includes universal, targeted and specialist supports, such as individual therapeutic intervention and access to specialist consultation and assessment when needed. Supports are provided as is feasible in the child's natural environments - their home, school and community.

The model of service for all CDNTs is family-centred and based on the needs of the child. This includes universal, targeted and specialised 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 are with the child on a daily basis to facilitate the child's developmental needs.

Work is ongoing on mapping specialised services and supports, and paediatric supports available and gap analysis for children with highly complex needs, in order to develop standardised approaches to integrated pathways of support for CDNTs and Primary Care staff.

In 2021, the *National CHO Governance OF Children's Disability Network Services Policy*, agreed by all Lead and Partner Agencies above involved in CDNT services (see link to same below), was implemented across all CHOs to provide a standardised governance for all Children's Disability Network services.

For further information see:

<https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/community-healthcare-organisation-governance-of-children-s-disability-network-service.pdf>

### **Roadmap for Service Improvement 2023 – 2026, Disability Services for Children and Young People**

The HSE's Roadmap for Service Improvement 2023 – 2026, Disability Services for Children and Young People, approved by the HSE Board and launched by the Government and the HSE in October 2023 is a targeted Service Improvement Programme to achieve a quality, accessible, equitable and timely service for all children with complex needs as a result of a disability and their families.

It sets out the overall aim for Children's Disability Services, provided by the HSE and its partner agencies, for every child to have a childhood of inclusive experiences where they can have fun, learn, develop interests and skills, and form positive relationships with others in a range of different settings.

The Roadmap, which is now in its implementation phase, has established four Working Groups which report into a Service Improvement Programme Board every month which in turn reports to the Roadmap Oversight Group chaired by the Minister of State, Ann Rabbitte.

The WGs have wide membership including HSE, Section 38 and 39 front line disabilities staff and management, parent voices, staff reps, Primary Care, CAMHS and Department of Children, Equality, Disability Integration and Youth. The WGs have agreed their Terms of Reference and their Project Charters for the Roadmap Actions within their scope.



These Charters define:

- Key activities to be delivered in order to achieve their Roadmap Actions
- Risks
- Assumptions,
- Interdependencies/dependencies
- Deliveries.

Working Group 1 **Integrated Children's Services** – has responsibility for the implementation of National Access Policy, Equity of Access to Aids and Appliances across all CHOs; and the Review of HSE Tusla Joint Protocol.

Working Group 2: **Service Access and Improvement** – has responsibility for Waitlist Management and Services; Optimising Teams Efficiencies, Effectiveness and Governance; AONs overdue for completion; and the development of a National Capital plan to enable all staff of a CDNT to be co-located.

Working Group 3: **Workforce** – has responsibility for developing a recruitment strategy for all CDNTs regardless of the Lead Agency; Retention of existing CDNT staff; Deployment of Students/Trainees/New Graduates; and Development of Existing Staff.

Working Group 4: **Communication and Engagement** – has responsibility for developing a rolling Communication Plan for the Roadmap and CDNT service, which is a key priority; Staff Engagement, including CHO Roadmap Engagement and Workshop days; and Enhancement of Information for Families (and Staff).

A 5<sup>th</sup> group: will focus on optimising integration between Education and Health and support for special schools. Discussions are ongoing between DCEDIY and Department of Education in regard to its set up and shared leadership.

The Roadmap contains 60 actions of which 12 have been completed and the majority of remaining actions are in train. These include a robust suite of 21 staff retention and recruitment actions.

The HSE is entirely committed to the delivery of the Roadmap actions over the lifetime of the plan.

## Funding

While funding is allocated each year to the CHO areas for the provision of services, the CHOs at local level make the determinations re the allocation of funding for services including children's disability services.

In addition, including the HSE, there are 49 Lead Agencies for the CDNTs. Funding is allocated by the CHO areas to the Lead agencies for the provision of services.

However, we can provide a snapshot in time as of mid year 2021, the pay, pay related and non pay costs related to all staff approved in CDNTs at that time at CHO level. Please see Table 1 below.

**Table 1**

| <b>2021 CDNT Pay, Pay Related and Non Pay Costs confirmed</b> |                             |  |
|---|-----------------------------|--|
| <b>CHO</b>  | <b>Total CDNT WTE Staff</b> | <b>Total CDNT Pay, Pay Related (15%) and Non Pay (12%) costs</b> |
| 1   | 144.57                      | €10,740,771  |
| 2   | 218.64                      | €16,220,210  |
| 3   | 167.8                       | €12,674,396  |
| 4   | 278.49                      | €20,792,116  |
| 5   | 164.47                      | €12,153,629  |
| 6   | 166.6                       | €12,875,832  |
| 7   | 245.17                      | €18,229,017  |



|   |                |                     |
|---|----------------|---------------------|
| 8 | 243.18         | €18,000,596         |
| 9 | 239.52         | €17,734,856         |
|   | <b>1868.44</b> | <b>€139,421,424</b> |

In addition to the CDNTs, supports are provided to children with disabilities across various services including Residential Care, Respite Services, Home Supports, multidisciplinary supports and other community services. Please see the Table below which outlines the increased funding allocated for the provision of services year on year.

It is not possible to extrapolate from overall spend, specific spend on services provided to children.

**Table 2**

| Service area                            | 2018 Funding<br>€000 | 2019 Funding<br>€000 | 2020 Funding<br>€000 | 2021 Funding<br>€000 | 2022 Funding<br>€000 | 2023 Funding<br>€000 |
|---|----------------------|----------------------|----------------------|----------------------|----------------------|----------------------|
| <b>Residential Places</b>               | 1,111,110            | 1,185,355            | 1,254,923            | 1,312,414            | 1,368,021            | 1,461,897            |
| <b>Day Services</b>                     | 389,441              | 433,254              | 477,382              | 543,407              | 580,489              | 620,279              |
| <b>Respite</b>                          | 53,595               | 56,212               | 70,677               | 87,423               | 96,465               | 105,703              |
| <b>PA &amp; Home Support</b>            | 80,957               | 84,909               | 94,885               | 100,613              | 109,809              | 115,191              |
| <b>Multidisciplinary Support (WTE)</b>  | 84,435               | 88,557               | 98,704               | 108,380              | 133,251              | 153,835              |
| <b>Other Community Services &amp; S</b> | 52,762               | 55,338               | 57,929               | 58,664               | 59,346               | 61,648               |
| <b>Total</b>                            | 1,772,300            | 1,903,625            | 2,054,500            | 2,210,900            | 2,347,380            | 2,518,552            |

### **The Children's Disability Services Grant Fund**

The Children's Disability Services Grant Fund was open to organisations, including community groups and service providers, with the aim of supporting children on a waiting list for Children's Disability Network Team services and adding value to existing HSE children's disability services.

There was a huge response from voluntary and community groups and private agencies to our call for submissions for the Grant Fund, with over 500 applications for funding, ranging from proposals for several thousand euro to larger projects seeking up to three million euro over three years. The total funding sought amounted to almost €45 million.

The very high number of applications meant that there was strong competition for finite funds.

A shortlist had to be drawn from the large number of projects and initiatives that we received.

A total of 52 projects throughout the Republic of Ireland were chosen to receive funding under the Children's Disability Services Grant Fund, with a number of the larger projects to be funded over a three year cycle.

Applicants that were not shortlisted to receive funding were informed that their application was not successful on this occasion, but that we would keep their proposal on file in the event that funding for a similar scheme becomes available in the future.

We have also contacted shortlisted applicants to inform them that we are currently in discussions with the Department of Children, Equality, Disability, Integration and Youth (DCEDIY) to agree the final allocation to the grant fund. We hope to have a decision shortly and will then be contacting them again to outline the process of engagement with the HSE around the drawdown of funding to be allocated and the financial and governance requirements in relation to the delivery of projects.

### **Assessment of Need under the Disability Act, 2005**

An Assessment of Need (AON) is a legal entitlement under the Disability Act 2005. Part 2 of the Disability Act (2005) requires the HSE to provide Assessments of Need for persons born on or after 1<sup>st</sup> June 2005 who may have a disability. The Disability Act outlines the statutory timelines under which AON must be completed. In summary, the assessment report must be completed within 6 months of the date the application was received.



The demand for assessments of need (AONs) under the Disability Act, 2005 has increased significantly in recent years, with a 25% increase in the number of applications for AON received in 2023 – from 6,775 in 2022 to 8,472 in 2023. This growth has continued into 2024, with a further 2,603 received in Quarter 1 (569 up on same period last year). The total number of applications ‘overdue for completion’ at end of Quarter 1, 2024, now stands at 9,924 (including 369 applications for which an extended time-frame was negotiated with the parent on the grounds of there being exceptional circumstances as provided for in paragraph 10 of the regulations) – which represents an increase of 115% on the end 2022 figure of 4,613.

Waiting lists are growing as demand outstrips system capacity. We are receiving circa 8,500 applications annually, with around 3,200 – 3,400 AONs completed each year. In this regard, we anticipate that, by the end of 2024, there will be over 20,000 AONs due for completion, comprising: AONs overdue at end 2023; AONs expected during the course of 2024; as well as Preliminary Team Assessments carried out under the previous Standard Operating Procedure (SOP), an approach found by the High Court not to have met the requirements of the Disability Act.

### **Additional funding**

Approximately €10.5m was spent in 2023 to address waiting lists for clinical assessments identified through the Assessment of Need process and in 2024, an additional €5m in one off funding has been allocated. This funding is being utilised to procure diagnostic ASD assessments from the private sector. The HSE at local level is also using time related savings to source AON assessments privately for children in the order as registered on the AOS (AON information management system) in line with the date of receipt of a completed AON application.

### **Targeted Initiative focussed on long waiting families**

A new targeted waiting list initiative is in place and the Government has allocated funding of €6.89 million to facilitate the HSE to procure up to 2,500 additional AONs, with delivery targeted over the next 6 months. This funding is in addition to existing HSE core funding of the €5m mentioned above, allocated for procurement of private assessments.

This waiting list initiative will target those families waiting longest for AONs, with the HSE reimbursing clinicians directly through the procurement of capacity from approved private providers. This provides a more equitable and fair approach rather than reimbursement of parents directly.

Funding has been allocated to each CHO area for the provision of Assessment of Need. The CHO Areas will be in a position to identify the longest waiters

It is envisaged that this initiative will be progressed through the existing framework of providers procured by each CHO Area, while also seeking to expand the list with any new private provision.

### **Other services provided for children with disabilities.**

In addition to ongoing work on the CDNTs, Assessment of Need and addressing waiting lists, other services are available to children with disabilities according to their needs and requirements and within available resources. These include residential, respite services and home support services. As outlined in Table 2 above, there has been year on year increase in funding for these services.

### **National Service Plan 2024**

As per the National Service Plan 2024, the HSE is committed to improving access to services for children and families. As agreed in the National Access Policy, disability services, child and adolescent mental health services and primary care services will work closely to improve co-ordination and integration across all services.

€3m was ring-fenced in the Budget for targeted services for children, allowing projects in relation to the following to be progressed in line with the HSE approval process:

- Chime
- Erb's Palsy
- Central Remedial Clinic
- Dyspraxia / DCD Ireland
- ChildVision
- Debra Ireland
- Crann Centre



- National Rehabilitation Hospital Clinical Lead Programme.

In addition, tenders are being put forward for two research proposals while, separately, a foetal alcohol project will be undertaken using a multi-care health sector approach (primary care, mental health services etc.)

Yours sincerely,

*Bernard O'Regan*

**Bernard O'Regan**  
**Assistant National Director**  
**National Disability Team**

