



Oifig an Cheannaire Oibríochtaí,
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,
31-33 Sráid Chaitríona, Luimneach.

Office of the Head of Operations,
Disability Services/Social Care Division,
31-33 Catherine Street, Limerick.

T: 00353 (0) 61 483369
Suíomh Gréasáin/Website: <http://www.hse.ie>

17th April 2023

Deputy Bernard Durkan,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: bernard.durkan@oireachtas.ie

Dear Deputy Durkan,

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: 15899/23

To ask the Minister for Children; Equality; Disability; Integration and Youth the extent to which health services for children with special needs are being improved; his plans for the future in this regard; 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. 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 the full 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.

CDNTs are teams of health and social care professionals, including nursing, occupational therapy, psychology, physiotherapy, speech and language therapy, social work and others. The team works closely together in a child and family centred model, focusing on the child's and family's own priorities.

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. This includes the establishment of Family Forums, one per Children's Disability Network Team (CDNT), to which family members and carers of all children attending or waitlisted for CDNTs will be invited to participate in. Thus, the membership of each Family Forum will be fluid.

This forum will be independently facilitated and the Children's Disability Network Manager (CDNM) will participate actively with families in the meeting. The purpose of the Forum is to provide an opportunity for families to discuss general issues and ideas about the children's disability services in the network, to network with other families and to work with the CDNM on co-designing service developments and improvements.

Each Family Forum will nominate 2 Family Representatives to join the CHO CDN Family Representatives Group from which 2 Family Representatives will be nominated to participate on the CHO's CDN Governance Group. Work to establish these groups is on-going and is a priority.

As of March 2023, 37 Family Forums have been established and have met at least once. A further 46 are well advanced in setting up their first event by Q2. A training session for CDNMs was delivered in October 2022 and for Independent Facilitators in February this year by the HSE. One CHO has established their CHO CDN Family Representatives Group and others will be established once all Family Forums have commenced.

<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>

Since 2019, more than 610 development posts have been allocated to children's disability services across the country. These posts have been assigned to teams based on a number of factors, including the existing ratio of staff to the number of children with disabilities in each area. This figure includes 190 posts provided in 2022 as well as an additional 136.3 WTEs to restore pre-existing services in 104 special schools.



The HSE continues to explore a range of options to enhance the recruitment and retention of essential staff across all aspects of the health services. The HSE is operating in a very competitive global market for healthcare talent as there are significant shortages of qualified healthcare professionals across the globe. The HSE Community Operations Disability Services is working collaboratively with the CDNT lead agencies at CHO level to promote CDNTs as a workplace of choice in a competitive employment market. Each lead agency is responsible for recruitment of staff on their CDNTs and is using a variety of approaches to fill funded vacancies.

In accessing services, parents may refer their children directly to Primary Care or to Children's Disability Network Teams (CDNT) by completing the relevant referral forms. Parents do not need to provide any professional reports to access health services. When families have reports available from health, social care or education professionals, these will be considered by the services. This will include where appropriate, consideration of the outcome of the assessment, the assessment tools used and the professionals involved in the assessment.

Assessment of Need under the Disability Act, 2005

The Disability Act (2005) provides for an Assessment of Need (AON) that outlines the health and education needs for people born on or after 1st June 2002 who are suspected of having a disability.

The numbers of applications for AON under the Act have risen steadily since its implementation in June 2007. 6,755 applications for AON were received in 2022. This was the highest number of applications received in any year since Part 2 of the Act was commenced in June 2007.

The HSE has endeavoured to meet its legislative obligations under the Act. However, as a consequence of a High Court ruling of December 2009, the effect of which was to open eligibility to all children born after 1st June 2002, the number of children aged five and over, and in addition of school-going age, has risen steadily as a percentage of all applications received. At the end of 2011, the figure stood at 26%, while throughout 2022, this figure averaged 55%. This is a reflection that the AON process is an accumulative process in terms of numbers of children seeking access.

The judgement of Ms Justice S Phelan in the case of CTM & JA v the HSE on 11th March 2022 found that the Preliminary Team Assessment approach described in the HSE's Standard Operating Procedure for Assessment of Need does not meet the requirements of the Disability Act. This judgement in effect requires the HSE to deliver diagnostic assessments where necessary and appropriate as part of the Assessment of Need process. This ruling has a significant impact operationally and has resulted in a growth in the numbers of overdue Assessments of Need. The requirement for services to prioritise the statutory Assessment of Need process will also impact significantly on their capacity to provide necessary intervention / treatment for children with disabilities.

The HSE is continuing to review the files of all children who received a preliminary team assessment and engaging directly with families to establish what additional assessments will be required to meet the requirements of the Act.

The HSE's National Clinical Programme for People with Disability (NCPPD) has led the process of developing Interim Clinical Guidance to replace the Preliminary Team Assessment. This new Interim Clinical Guidance has now been clinically approved and will be implemented following engagement with colleagues in the Department of Children, Equality, Disability, Integration and Youth.

Approximately €11m has been allocated to address waiting lists for clinical assessments identified through the Assessment of Need process. This funding will be utilised to procure diagnostic ASD assessments from the private sector. A successful procurement process will facilitate the Children's Disability Network Teams to focus on the provision of intervention for children on their caseloads.

The capacity of the domestic market to provide the necessary skilled clinicians for direct employment or the procurement of private assessments is extremely limited. As a result, the HSE is exploring the potential to progress a large scale international procurement process to secure significant numbers of diagnostic ASD assessment.



Additional 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 the needs and requirements and within available resources. These include respite services and home support services.

Respite Services

The HSE and its funded Agencies provide respite care to children and adults with disabilities, which can occur in a variety of settings for various lengths of time, depending on the needs of the individual service user and their family or carer, and according to available resources. Respite is not always centre-based and can be provided in a number of ways, e.g. Centre based; In-Home; Home-to-Home; Family Support, etc. As a vital part of the continuum of services for families, respite potentially helps prevent out-of-home full-time residential placements, preserves the family unit, and supports family stability.

Children's Disability Services routinely provide a range of alternative respite activities, particularly during the summer holiday period. This includes Summer Camps, after-school respite services, Saturday Clubs and other community based respite support activities that are designed to meet the needs of children and families, particularly over the Summer Months. This also includes family support and in-home respite support.

The HSE is very much aware of the importance of respite service provision for the families of both children and adults with disabilities and the impact the absence of respite service provision can have on other services being delivered. In this regard, the HSE was allocated funding for additional respite services in 2021 and 2022. This is being used to develop additional centre-based respite services, along with a range of alternative respite projects including Saturday clubs, breakaway schemes, and summer schemes.

Home Support Services

The HSE provides a range of assisted living services including Home Support Services to support individuals to maximise their capacity to live full and independent lives.

Home Support Services are provided either directly by the HSE or through a range of voluntary service providers. The majority of specialised disability provision (80%) is delivered through non-statutory sector service providers.

Services are accessed through an application process or through referrals from public health nurses or other community based staff. Individuals' needs are evaluated against the criteria for prioritisation for the particular services and then decisions are made in relation to the allocation of resources. Resource allocation is determined by the needs of the individual, compliance with prioritisation criteria, and the level of resources available. As with every service there is not a limitless resource available for the provision of home support services and while the resources available are substantial they are finite. In this context, services are discretionary and the number of hours granted is determined by other support services already provided to the person/family.

National Service Plan 2023

In the National Service Plan 2023, the HSE will seek to provide improved access to children's disability services and improved compliance with the statutory Assessment of Need process.

The HSE is committed to the following:

- Progress the recruitment of 136 senior clinicians to facilitate children's disability network teams (CDNTs) to restore on-site health and social care supports to 104 special schools, as required by Government. This initiative will be in addition to recruiting the balance of the 2021 allocation of therapists to special schools as well as the continued recruitment of the 2022 allocated posts.
- Implement the range of actions in the draft Roadmap for Progressing Children's Disability Services, through the CDNTs, with a specific focus to:
 - Progress a range of initiatives to recruit and retain staff on CDNTs to maximise the supports available to children and families requiring these services

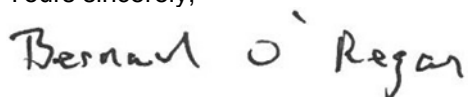


- Recruit two consultant paediatricians, in conjunction with the Paediatric programme, to provide essential paediatric medical supports and interventions.
 - Improve communication with all stakeholders, especially families
 - Implement an initiative for all children currently awaiting CDNT first or follow up service
 - Improve governance of the service
 - Develop integrated service pathways to ensure children and families can access the right service at the right time.
- Progress a capacity-building initiative in two CHOs to demonstrate an all-team approach to supporting children with complex behaviours.
 - Review and implement the (i) National Access Policy and (ii) the HSE's primary care, disabilities and CAMHS Joint Protocol with Tusla, in conjunction with primary care and mental health services.
 - Establish 91 family forums and nine family representative groups in order to co-design CDNT service improvements and developments with families.
 - Deliver a public-facing communications / media plan to highlight the work of the CDNTs.

In addition, with regard to Respite and Residential services, the HSE commits to:

- Provide 23 residential care packages to young people ageing out of Tusla services in line with the Joint Protocol.
- Provide 27 additional in-home respite packages to children and young adults in a full year.

Yours sincerely,



**Mr Bernard O'Regan,
Head of Operations - Disability Services,
Community Operations**

