

Oifig an Stiúrthóir Cúnta Náisiúnta,

Foireann Míchumais Náisiúnta, An Chéad Urlár - Oifigí 13, 14, 15, Àras 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.

10th May 2024

Deputy Cian O'Callaghan, Dail Eireann, Leinster House, Kildare Street, Dublin 2.

E-mail: cian.ocallaghan@oireachtas.ie

Dear Deputy O'Callaghan,

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: 11716/24

To ask the Minister for Children; Equality; Disability; Integration and Youth if he is aware that many parents feel as though the care and support provided to their disabled children has decreased under the community disability network teams, specifically in relation to children with Down syndrome being provided more generalised care as opposed to specialised services that existed under the CRC; his advice for parents with these concerns; and if he will make a statement on the matter.

HSE Response

Progressing Disability Services for Children & Young People (PDS)

The implementation of the Progressing Disability Services for Children & Young People (PDS) programme is agreed Government and HSE policy. This policy supports the reconfiguration of children's disability services to provide equitable, child and family centred services based on need rather than diagnosis. This aligns with the UN Convention on the Rights of People with Disabilities.

The PDS programme will ensure that services are provided for children with complex needs regardless of where they live or where they go to school. Each Community Healthcare Organisation works with key stakeholders in their area including parents and education services to ensure that appropriate arrangements are put in place to facilitate in-reach services to special school settings as appropriate.

The Progressing Disability Services for Children and Young People (PDS) model addresses the previous inequity in service provision whereby there may have been an excellent service for some children and little or no service for others. This variance may have been linked to diagnosis, age group or geography. Under the PDS programme children's



disability services are changing from diagnosis based to needs based, so that all children with a disability or developmental delay have access to the right service based on their needs no matter where they live.

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 rather than based on diagnosis. Many children and adults with a disability who have support needs can be effectively supported within mainstream child and adult health services. This policy provides a single point of entry, signposting parents and referrers to the most appropriate service (Primary Care for non-complex functional difficulties and Children's Disability Network Teams for complex functional difficulties).

The HSE is committed to the full implementation of the Progressing Disability Services for Children and Young People Programme (PDS). PDS is a significant change programme for the provision of services and supports for children from birth to 18 years of age, in line with Slaintecare and the Programme for Government, in order to:

- Provide a clear pathway and fairer access to services for all children with a disability
- Make the best use of available resources for the benefit of all children and their families
- Ensure effective teams are working in partnership with families and with education staff to support children with a disability to reach their full potential.

PDS aligns with two clear objectives of The Sláintecare Report to:

- Provide the majority of care at or as close to home as possible
- Create an integrated system of care with healthcare professionals working closely together.

Childrens' Disability Services

91 Children's Disability Network Teams (CDNTs) are aligned to 96 Community Healthcare Networks (CHNs) across the country and are providing services and supports for children aged from birth to 18 years of age.

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.

The CDNTs are currently providing services and supports for 45,741 children and strategies and supports for urgent cases on the waitlist where staffing resources allow. However, there are significant challenges for CDNTs including:

- Significant staffing vacancies
- Growth in numbers of children with complex need
- Growth in demand for Assessment of Need, diverting further resources away from interventions

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 was approved by the HSE Board on July 28th and launched by the Government and the HSE on Tuesday 24th October 2023.

The Roadmap 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.

Based on the CDNT Staffing Census (Oct 2022), there are over 700 vacant whole time equivalent posts in CDNTs. The HSE continues to explore a range of options to enhance the retention and recruitment 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.

The Roadmap actions includes a robust suite of 60 actions, including 21 on CDNT Retention and Recruitment targets, and many of which are now in train.

Due to the recent Forsa Industrial Action, work on the CDNT Staffing Census 2023 was delayed. This will be available in due course.

An Independent Review of the CDNT Service Model by the NDA will include a review of competencies and skill mix required and staffing to child population ratios across teams, to optimally support children and families. It will evaluate the experience of children and families in CDNT services, service providers and staff providing children's disability services including CDNTs, Primary Care, CAMHS and Disability Act Office.

Yours Sincerely,
Bernard O'Regan

Bernard O'Regan

Assistant National Director National Disability Team

