

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

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6th April 2022

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

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 15680/22

To ask the Minister for Health the extent to which children with disabilities can expect to receive adequate care and attention and access to services now and in the future; the degree to which his Department has identified issues of interest in this regard; and if he will make a statement on the matter.

PQ 17282/22

To ask the Minister for Health the extent to which health services for children with special needs are being improved; and if he will make a statement on the matter.

HSE Response

The HSE acknowledges the challenges in meeting the demand for children's disability services and is acutely conscious of how this impacts on children and their families.

Historically, access to many services for children with disabilities was linked to their diagnosis. Consequently, services often had extensive waiting lists for diagnostic assessments which in some areas were accessed via the Assessment of Need process (Disability Act 2005).

The principle and importance of early intervention is recognised by the HSE across its services and in particular in the context of the services and supports it provides to children with disabilities, and their families. Additionally, in developing the national policy for the provision of services to children with disabilities, the focus of the HSE has been to develop a strategy for services that is:

- Reflective of best national and international practice;
- Responsive to the requirements of the UN Convention on the Rights of Persons with Disabilities;
- Family and child centred;
- Providing services as close as possible to the community where children and their families live.



A number of significant initiatives have been implemented which have impacted on access to services for children and young people with disabilities, including additional funding of €7.8m secured through Sláintecare to address AONs that were overdue at 30th June 2020, continued implementation of the National Access Policy and the Progressing Disability Services for Children & Young People (PDS) programme and the establishment of Children's Disability Network Teams (CDNTs).

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 rather than based on diagnosis. 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).

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 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 or where they go to school.

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 Sláintecare 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.

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 with a disability who have support needs can be effectively supported within mainstream 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).

Children's Disability Network Teams (CDNTs)

In 2021, the remainder of ninety-one CDNTs were established to provide services and supports for all children with complex needs within a defined geographic area.

CDNTs are teams of health and social care professionals (e.g., occupational therapists, psychologists, physiotherapists, speech and language therapists, social workers) and others disciplines (e.g., nursing). The reconfiguration into CDNTs and the resultant staffing mix was



influenced by a number of factors including the staff resources of existing services and the expressions of interest process. Hence, some CDNTs may have other disciplines such as nurses, family support workers or early educators.

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.

Since 2019, more than 475 development posts have been allocated to children's disability services across the country. These posts have been assigned based on a number of factors, including the existing ratio of staff to the number of children with disabilities in each area.

The table below provides detail regarding the number of development posts by whole-time equivalent allocated to CDNTs in 2019, 2021 and 2022. The Children's Disability Networks Governance Group at CHO level, decided the allocation of these posts by discipline and team in line with the governance procedures for CDNTs. Please note the allocations to CHO 9. The full allocation for 2022 has not yet been agreed, so only those posts that have been allocated are included here.

| CDNT Development Posts | | | |
|------------------------|------|--------|-------|
| | 2019 | 2021 | 2022 |
| CHO1 | 12 | 15.7 | 11 |
| CHO2 | 3.5 | 15.5 | 5 |
| CHO3 | 12 | 13.4 | 4 |
| CHO4 | 6 | 13.3 | 14.5 |
| CHO5 | 15 | 16 | 26 |
| CHO6 | 3.5 | 32.32 | 4 |
| CHO7 | 13 | 26.6 | 24.5 |
| CHO8 | 19 | 14.95 | 23.5 |
| CHO9 | 16 | 39.55 | 17.5 |
| Specialist Services | | | 18.5 |
| Total | 100 | 187.32 | 148.5 |

Much of the expenditure on Disability Services is on staffing and staffing in disability services (HSE and S38) has increased from over 17,000 weres at the end of 2017 to almost 19,000 at the end of 2020 and 19,662 at the end of January 2022.

Commencement of services in all ninety-one CDNTs in 2021 marked the end of Phase 1 of the reconfiguration of children's disability services.

In parallel, phase 2, the development of the interdisciplinary family centred practice (FCP) model is now in train. This involves a significant mind-set change for all stakeholders, including health professionals, families and referrers.

Health and social care professionals (HSCP) are trained at undergraduate level to provide 'care and treatment' for children and their families typically in 'blocks of therapy' and this is what parents and referrers have come to expect. However, all children develop and learn by taking part in daily life and activities with their family, in their home, in pre-school, in school and their community. The child's family and those who are with them every day are the most important people in their lives.

Internationally, there is widespread change from providing disability services 'to' or 'for' children towards supporting families in their role. Services are moving from being professionally centred, or expert led, to being family centred. When services are family centred the team of professionals and the family are equal partners. The family brings knowledge of their child and the team brings their expertise. Together they agree on goals and how they will be achieved.



The additional posts highlighted above are intended to support the newly established CDNTs to prioritise intervention for children with complex needs. In parallel, the recently published Department of Health Waiting List Action Plan provides for funding to address community waiting lists for children. It is envisaged that a portion of this funding will be allocated towards diagnostic assessments for children with disabilities. While diagnostic assessments are not required to access health supports, a practice has developed in the education sector where they are sought for access to special schools and classes and this represents a significant challenge for children's disability services.

Recruitment is challenging for the HSE at this time due to significant ongoing developments and change, including implementation of the Enhanced Community Care Programme. HSE Disabilities and Lead Agencies are reviewing all options, interim and long-term measures, for filling these posts in addition to team post vacancies to address the staffing shortfall.

The HSE is committed to the delivery of appropriate services for children with disabilities and will work with families and staff to develop services that meet their needs.

Yours sincerely

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