



Oifig an Cheannaire Oibríochtaí,
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,
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5th May 2022

Deputy David Cullinane,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: david.cullinane@oireachtas.ie

Dear Deputy Cullinane,

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

PQ 19296/22

To ask the Minister for Health the number of open cases by CDNT; the number of individual family service plans issued to open cases by CDNT; the number of key contacts assigned by CDNT and the number of open cases without a key contact assigned in tabular form; and if he will make a statement on the matter.

PQ 19297/22

To ask the Minister for Health the number of family forums established by CDNT in tabular form; and if he will make a statement on the matter.

HSE Response

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.

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)

Children with complex needs associated with their disabilities access services from a Children's Disability Network Team (CDNT). Ninety-one CDNTs are now in place across the country. These 91 Children's Disability Networks (CDN) are aligned to 96 Community Healthcare Networks (CHNs) across the country and each Children's Disability Network has one CDNT providing services and supports for children aged from birth to 18 years of age

Services and supports provided are based on children's needs rather than diagnosis and regardless of where they live or which schools they attend. This aligns with the UN Convention on the Rights of People with Disabilities and with the objectives of Sláintecare and the Programme for Government.

The team will work closely together with the child and family to identify the child's and family's own priorities and agree a plan to address those goals. Children and their families will have access to a range of services and supports of the CDNT according to their individual needs and within available resources. This includes universal interventions such as information sessions, talks and programmes for families on particular topics, targeted interventions for groups of children and/or parents with identified similar needs, e.g. PECS training, Lámh training, Hanen, Incredible Years, and direct interventions for a child and family to address a significant identified need that cannot be met by a universal or targeted intervention.

In 2021, the *National CHO Governance OF Children's Disability Network 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, 1 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 attend. Thus, the membership of each Family Forum will be fluid. This forum will be independently facilitated with the Children's Disability Network Manager invited to attend a part of the meeting. These fora will provide an opportunity for families to discuss general issues and ideas about the children's disability services in the network. Representatives of each family forum will form a Family Representative Group in each of the nine Community Healthcare Organisations. Each Family Forum will nominate 2 Family Representatives to join the CHO CDN Family Representatives Group from which 3 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. The progress to date is outlined in the table below.

Currently there are 15 family Fora in place with a further 39 in the process of being set up.

<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>



National Information Management System for the CDNTs (CDNTIMS)

With regard to the number of open cases by CDNT, the number of individual family service plans issued to open cases by CDNT; the number of key contacts assigned by CDNT and the number of open cases without a key contact, all service users will be assigned a link worker when they are accepted onto each CDNT. The HSE is currently developing a plan to improve service contact and communication with families.

A National Management Information System for all 91 CDNTs (CDNTIMS) is in development and when implemented, will provide contemporaneous activity data for all CDNTs. This will include collation of data on IFSPs and whether a key contact has been assigned to the service users. It is expected that this system will be rolled out in 2023.

Yours sincerely



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