



**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.

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21<sup>st</sup> April 2022

Deputy Holly Cairns,  
Dail Eireann,  
Leinster House,  
Kildare Street,  
Dublin 2.  
E-mail: [holly.cairns@oireachtas.ie](mailto:holly.cairns@oireachtas.ie)

Dear Deputy Cairns,

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: 18119/22**

*To ask the Minister for Health the number of family forums that are planned to be established as part of progressing disability services in each CHO; the number of family forums which have been established in each CHO; the number of persons on each of the established family forums; the means by which persons can join family forums; 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)**

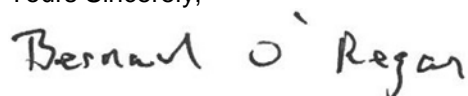
In 2021, the remainder of ninety one Children’s Disability Network Teams (CDNTs) were established to provide services and supports for all children with complex needs within a defined geographic area. These 91 Children’s Disability Networks (CDN) are aligned to 96 Community Healthcare Networks (CHNs) 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.

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.

| <b>Status of Family Forum</b> |            |                 |           |
|-------------------------------|------------|-----------------|-----------|
| <b>CHO</b>                    | <b>Yes</b> | <b>In train</b> | <b>No</b> |
| <b>CHO1</b>                   | 0          | 7               | 0         |
| <b>CHO2</b>                   | 9          | 0               | 0         |
| <b>CHO3</b>                   | 5          | 2               | 0         |
| <b>CHO4</b>                   | 1          | 5               | 8         |
| <b>CHO5</b>                   | 0          | 5               | 7         |
| <b>CHO6</b>                   | 0          | 7               | 0         |
| <b>CHO7</b>                   | 0          | 0               | 11        |
| <b>CHO8</b>                   | 0          | 1               | 11        |
| <b>CHO9</b>                   | 0          | 12              | 0         |
| <b>Total</b>                  | <b>15</b>  | <b>41</b>       | <b>35</b> |

<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>

Yours Sincerely,



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

