



**Oifig an Cheannaire Oibríochtaí,**  
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,  
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Dear Deputy Cullinane,

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 11165/22**

*To ask the Minister for Health the number of family forums established under each Children's Disability Network or under each Children's Disability Services Governance Group; 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.


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 will work closely together in a family centred model, focusing on the child's and family's own priorities. Every child with complex needs will have access to a team, regardless of the nature of their disability, where they live, or the school they attend.

Children and their families will have access to the full range of services and supports of the 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 will be provided as is feasible in the child's natural environments - their home, school and community.

As required under the new model of service a Family Forum must be established for each Children's Disability Network. 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. Two members of the Family Representative Group will be members of the governance group at CHO level. Work to establish these groups is on-going. The progress to date is outlined in the table below.

Status of Family Forum			
CHO	Yes	In train	No
CHO1	0	0	7
CHO2	0	0	9
CHO3	4	3	0
CHO4	1	5	8
CHO5	0	8	4
CHO6	0	7	0
CHO7	0	0	11
CHO8	0	2	10
CHO9	0	12	0
<b>Total</b>	<b>5</b>	<b>37</b>	<b>49</b>

Yours sincerely



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

