



**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.

T: 00353 (0) 61 483369  
Suíomh Gréasáin/Website: <http://www.hse.ie>

13<sup>th</sup> April 2023

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 questions, which were submitted to this department for response.

**PQ: 14874/23**

*To ask the Minister for Children; Equality; Disability; Integration and Youth if he will provide details on the number of family forums established as part of Progressing Disability Services; if each children's disability network team has or has not an operational family forum; the number of times family forums meet annually; the process by which the views expressed through each forum impact of policy and service delivery; and if he will make a statement on the matter.*

**PQ: 14875/23**

*To ask the Minister for Children; Equality; Disability; Integration and Youth the obligations of disability service providers for adults to operate family committees and forums for families to share their views on aspects of service provision; and if he will make a statement on the matter.*

**HSE Response**

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.

CDNTs are teams of health and social care professionals, including nursing, occupational therapy, psychology, physiotherapy, speech and language therapy, social work, dietetics and others. The team works closely together in a child and family centred model, focusing on the child's and family's own priorities.

Each CDNT is managed by a lead agency. These agencies include the HSE, S38 organisations and S39 organisations. The detail regarding the lead agencies is provided below.



Lead Agency	No. of CDNTs
HSE	41
Enable Ireland	20
Brothers of Charity	6
Central Remedial Clinic	5
Avista (Daughters of Charity)	4
St Michael's House	4
Cope Foundation	3
St Gabriel's	2
St Joseph's Foundation	2
Stewarts Care	2
CoAction West Cork	1
Kare	1
<b>Total</b>	<b>91</b>

In 2021, the *National CHO Governance OF Children's Disability Network Services Policy*, agreed by all Lead and Partner Agencies above involved in CDNT 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, one 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 participate in. Thus, the membership of each Family Forum will be fluid.

This forum will be independently facilitated and the Children's Disability Network Manager (CDNM) will participate actively with families in the meeting. The purpose of the Forum is to provide an opportunity for families to discuss general issues and ideas about the children's disability services in the network, to network with other families and to work with the CDNM on co-designing service developments and improvements.

Each Family Forum will nominate 2 Family Representatives to join the CHO CDN Family Representatives Group from which 2 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.

As of March 2023, 37 Family Forums have been established and have met at least once. A further 46 are well advanced in setting up their first event by Q2. A training session for CDNMs was delivered in October 2022 and for Independent Facilitators in February this year by the HSE. One CHO has established their CHO CDN Family Representatives Group and others will be established once all Family Forums have commenced.

<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>

### Family Forum Adult Services

The statutory right of persons who avail of Intellectual Disability Services to participate in the organisation of their service is recognised by the HSE.

The document: "*Disability Community Services, Residential Services: Supporting people with an Intellectual Disability, Terms of Reference –Family Forums*" provides information and support to Residential Centres in setting up Family Forums.



The HIQA *National Standards for Children and Adults with Disabilities* (HIQA, 2013) states that people living in residential services should be actively involved in determining the services they receive and are empowered to exercise their rights. Where people have difficulties in communicating their wishes or making informed decisions, there is an obligation on service providers to work in close collaboration with the person's representative who will ascertain the person's wishes and facilitate them in achieving a desired outcome.

Standard 1.3.4 of *The National Standards for Children and Adults with Disabilities (HIQA, 2013)*: Each person exercises choice and control in their daily life in accordance with their preferences.

Residents are encouraged to:

- Contribute ideas to, and participate in, the day-to-day activities of the service;
- Participate in residential committees and fora;
- Are represented in whatever forum is used to discuss and plan the future direction of the service.

An individual's representative can also participate. This representative is the person, preferably nominated by the individual, who acts on their behalf in situations where the individual lacks capacity to make decisions. This person will often be a family member and could also be a friend, advocate or legal advisor. The role of this person is to ascertain, as far as possible, the individual's wishes and to act in every instance in the individual's best interests.

Standard 1.4.3 states that families and friends are welcomed by the service and they participate in and are regularly involved in the person's life, in accordance with the person's wishes.

Standard 1.6.1 states that "*People are consulted about and make decisions about the services and supports they receive and their views are actively and regularly sought by the residential service*".

In order to comply with the above standards, Residential Centres have set up Residents' Committees /Fora which may also contain family/relevant person representatives.

The HSE has supported the provision of Family Forums with *The Social Care Division Intellectual Disability Residential Service, Allocated Service Framework for the Development of a Residents Forum*. This framework which was developed by the National Disability Services, Quality Improvement Team in 2017, outlines the principals and steps that need to be considered when developing a Residents Forum in residential services within an Allocated Service area. This document was widely circulated for use in residential centres.

The Health Information and Quality Authority (HIQA) is the statutory body established under the Health Act 2007 with responsibility for setting standards for health and social care services, and ensuring that the standards are being met. The Authority is responsible for the registration and inspection of 'designated centres' for older people and people with disabilities, as defined in the Health Act 2007 aims to promote progressive improvements in quality and safety of residential services provided to children and adults who use services on either a long-term or short-term basis.

HIQA's Disability inspection teams are legally responsible for the monitoring, inspection and registration of designated centres for adults and children with a disability. All residential centres are inspected against the National Standards and Health Regulations including the centres' provision of residents committee or family forums.

In 2019, residents' groups from 18 different parts of Ireland invited inspectors of residential services for adults and children with disabilities to attend residents' meetings. Inspectors met with 171 residents and peers during these meetings.



HIQA published a Disability Services Residents Forum Meetings Report in December 2022. Using Residents' Forums, HIQA was provided with information regarding what it is like for residents living in Residential Centres. Inspectors gathered feedback from residents about their home, the support they receive and the important areas that inspectors should be looking at when they are on inspection.

For more information please see

<https://www.hiqa.ie/reports-and-publications/key-reports>

Yours sincerely,

*Bernard O'Regan*

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

