

Could you be the voice of families?

We are looking for three Family Representatives to join the National Children's Disability Network Team Steering Group

Expressions of Interest

Background

A total of 91 Children's Disability Network Teams (CDNTs) have been established to provide services for children with complex disability needs. These teams have been established in line with the [Progressing Disability Services for Children and Young People \(PDS\) programme](#).

The teams are supported by a CDNT Steering Group. The voice of families is central to the CDNT model of service and the steering group is looking for three family representatives to join its membership. The terms of reference for the group are available at Appendix 1.

Role of family representatives

Family representatives are essential to the planning and operation of children's disability services as they bring their experience and perspective. While it is not possible for you to represent all families of children with complex needs (approx. 50,000 nationally), you will have a wide view of the varying needs of children and young people with disabilities and their families.

Each Community Healthcare Organisation will have a Family Representative Group for CDNTs. You will link with these groups to find out about current priorities across the country.

Characteristics of a successful family representative

- Is your child accessing or waiting for a children's disability service?
- Are you respectful of others and their perspectives?
- Are you comfortable speaking in a group and interacting with others?
- Are you a good listener?
- Are you able to use your personal experience constructively?
- Can you see beyond your own experience?
- Are you non-judgemental?
- Have you a positive attitude?

- Are you able to work collaboratively with a group?
- Have you an interest in expanding your knowledge and skills?
- Have you a desire to bring about meaningful change?
- Can you maintain confidentiality of service user and organisational information?

How we will support you

Family representatives will receive one-to-one induction on the work of the Steering Group and ongoing support by a named member.

You are not expected to be an expert on the PDS programme, children's disability services or the health service in general. We will support you to become familiar in time with the policies we work within and how the Steering Group works.

Attendance at Meetings

Three family representatives will be selected for the National CDNT Steering Group. This is so that we have two family representatives at each meeting. Family representatives can agree their own schedule for attending meetings and availability for any working groups that may be established.

Meetings of the National Steering Group are held monthly, generally online via MS Teams with occasional face to face meetings in Dublin.

Travel and subsistence expenses will be reimbursed. For details, see HSE policy [here](#).

Term of Family Representatives

Family representatives will join the Steering Group for a two year term.

Family representatives may serve for a maximum of two terms.

Family representatives will step down within six months of their child being discharged from the CDNT.

In the interests of continuity, a maximum of two family representatives will be replaced after the initial two year term.

Selection process

We are looking for expressions of interest from any family members of a child who is attending a Children's Disability Network Team or who is waiting to attend.

We will only use the information on the Expression of Interest form to select the 3 national family representatives. We will not share your information with any other party.

Your Expression of Interest forms will be anonymized.

Once the selection process is finished all expression of interest forms will be shredded and no copies will be retained.

Selection criteria

We endeavour to select family representative to include:

- A geographical spread
- A mix of urban and rural
- A range of ages of children with disabilities
- A range of types of disabilities
- Diversity as feasible e.g. gender, ethnicity

Expression of Interest Form

**Family Representatives National Children's Disability Network Team
Steering Group**

Please return to eileenn.fitzgerald@hse.ie by Friday 30th September 2022

Name:

Address:

Email:

Phone:

Age of your child or children with complex needs:

What in broad terms is the nature of your child's disability?

Which CDNT does your child attend or is waiting to attend?

Please answer the following about your experience and interest in the role using less than 300 words for each question.

1. Have you been involved in advocacy on behalf of others? If so please describe.

2. Tell us about your experience of taking part in groups and committees. Include any local, social, work or professional groups as well as disability services.

3. Tell us about other relevant experience

4. Tell us about your interest in being a member of the National Steering Group

Appendix 1

National CDNT Steering Group Terms of Reference

1. To oversee and monitor implementation of Children's Disability Network Teams under Progressing Disability Services for Children and Young People (PDS) across all CHOs in line with the PDS twelve principles and national policies
2. To oversee the implementation of outcome focused family centred practice in line with the pending *Outcomes Children and their Families Framework Implementation Plan*
3. To establish a nationally standardised CHO governance structure over children's disability services
4. To provide reports to the Head of Operations AND – Disabilities and to the Chief Officer group as required

A meeting quorum is 6 people, including at least one Head of Disability Services.

Decisions will be reached by consensus. Where consensus is not possible, the matter will be raised to the Head of Operations – Disability Services.

Meeting Notes and Actions will be recorded and approved at subsequent meetings.

Meeting agendas and supporting documentation will be circulated by email approximately one week in advance of each meeting.

Membership (see below for explanation of roles)

- Chief Officer, Community Healthcare Organisation (Chair)
- Three family representatives so that two can attend each meeting
- Two Community Healthcare Organisation Heads of Disability Services
- Three National Disability Specialists
- PDS National Programme Coordinator
- Representatives of the CEOs of the Section 38 and Section 39 service providers (e.g. Brothers of Charity, Enable Ireland,)
- Representative of the Department of Health or Department of Children, Equality, Disability, Integration and Youth (as appropriate)

Explanation of terms and roles

Community Healthcare Organisation (CHO)

There are nine Community Health Care Organisations (CHOs). CHOs provide community healthcare services outside of acute hospitals. These include primary care services, services for older people, disability services, mental health and other health and well-being services.

Chief Officer

The Chief Officer is the most senior accountable manager in their CHO.

Head of Disability Services

The Head of Disability Services is responsible for the delivery of disability services in their CHO.

National Disability Specialist

National Disability Specialists are managers who work in the National Community Operations – Disability Team. They support and liaise with Heads of Disability Services with regard to national policy issues.

PDS Programme Co-ordinator

The PDS Programme Co-ordinator works with the National Community Operations – Disability Team and supports Children’s Disability Network Teams in delivering the CDNT model of service.

Section 38 and Section 39 organisations

Disability Services in Ireland are provided by the HSE as well as by organisations that are funded to do so under either Section 38 or Section 39 of the Health Act (2004).

Staff employed in “Section 38” organisations have the same terms and conditions of employment as other public servants including those in the HSE. Organisations funded under Section 39 of the Health Act (2004) receive their funding as a grant from the HSE. Their staff are not public servants.