



Children's Disability Services Family Representative Induction Guide

March 2026

Contents

1. Welcome to Your Role as Family Representative	Page 3
2. Next Steps and Key Contacts for New Representatives	Page 3
3. Overview of Children's Disability Service Structures	Page 4
4. Roles and Responsibilities in the Family Forum	Page 6
5. Roles and Responsibilities in the Family Representative Group (FRG)	Page 8
6. Roles and Responsibilities in the FRG/OMG Subgroup	Page 10
7. Roles and Responsibilities in the CDNT Governance Group	Page 11
8. Time Commitments for Family Representatives	Page 11
9. Confidentiality	Page 13
10. Your Wellbeing as a Family Representative	Page 13
11. Expenses	Page 13
12. Further Information	Page 13
13. Appendices	Page 14

1. Welcome to Your Role as Family Representative

Thank you for putting yourself forward as a Family Representative for your Family Forum. Your role is a central part of the Children's Disability Network Teams (CDNT) model of service and will help to shape the further development of (CDNTs) in your area. By taking on the role of Family Representative, you will be speaking on behalf all children and young people who require CDNT services. We hope you find the role rewarding, and we look forward to working with you and making positive changes to our CDNTs that will benefit the children that they support.

The following information has been compiled to help support you in your role as a Family Representative. Please read it in conjunction with the 'Frequently Used Terms', which explains abbreviations and gives short explanations of what each term means.

2. Next Steps and Key Contacts for New Representatives

Actions for Children's Disability Network Manager (CDNM)

- ✔ Provide this induction guide to new Family Representatives
- ✔ Hold post Family Forum (FF) meeting with new and existing Family Representatives, to include the normal post FF meeting and to walk through CDNT/FF/key issues for the new representative, for example:
 - a. Number of children attached to CDNT (waitlist and active)
 - b. Geographic area covered in CDNT
 - c. Key issues in the area (recruitment, waitlists, non-attendance at groups, etc)
 - d. Who's who in CDNT- an overview of the team.
- ✔ Follow up with new Family Representative a week after meeting to see if any further questions

Actions for Family Representative Group (FRG) Chairperson

- ✔ Reach out to the new Family Representative to welcome them to the FRG

- Send out any pertinent information relevant to the new Family Representative including, but not limited to, a list of all the Family Representatives in the area, who's who in the FRG, how FRG meetings are run, key issues for the area and minutes/ notes/ actions from the last FRG meetings
- Add the new Family Representative to any WhatsApp groups or mailing lists within the FRG
- Set up a meeting with the new Family Representative to bring them up to date on what has been happening in the FRG, including areas of co-design that have been undertaken, to ensure that the new representative is able to fully participate at the next FRG meeting
- Follow up with the Family Representative a week after meeting to see if any further questions

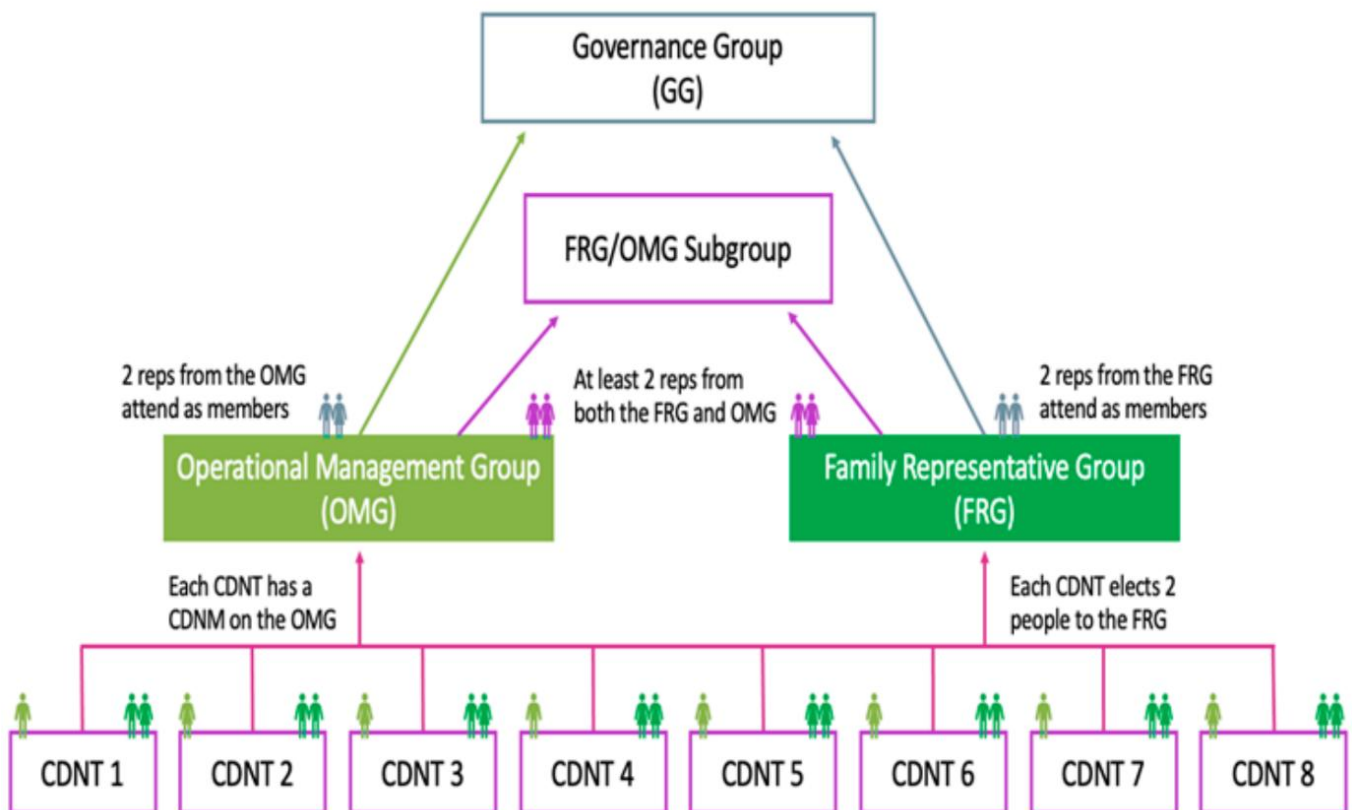
Actions for Existing Representative in the CDNT

- Add the new Family Representative to the WhatsApp group and introduce them to the rest of the FRG
- Follow up separately after new Representative has met CDN and FRG Chair to answer any questions

3. Overview of Children's Disability Service Structures

- There are 93 CDNTs across the country
- Each one is managed by a Lead Agency
- Each CDNT holds a Family Forum for families of all children attending or on the waiting list for a CDNT
- The Family Forum elects two Family Representatives (sometimes there can be more than 2)
- The Family Representative Group is made up of the Family Representatives of each Family Forum (CDNT) in the area or region

- The Children's Disability Network Managers (CDNMs) in an area or region are all on the Operational Management Group (OMG) to allow for idea sharing, discussion of more complex referrals and support
- A small group of OMG and FRG representatives form a subgroup which collects details of projects proposed by Family Forums in the area and prioritises them for progression
- Each area or region has a Children's Disability Network Teams Governance Group
- Two members of the FRG sit on the Governance Group for the area or region



4. Roles and Responsibilities in the Family Forum

Purpose of the Family Forum

- ✔ For the CDN and families to work collaboratively to improve the outcomes for children and families accessing our services and to foster a culture of trust, openness and transparency
- ✔ To give families an opportunity to discuss general issues and ideas for service development and/or enhancement of Children's Disability Services in their local CDNT
- ✔ To elect two Family Representatives who will meet the CDN regarding CDNT issues and ideas raised by the Family Forum, and will join the Family Representative Group at area level
- ✔ To share information on:
 - Service provision, governance and access
 - Community supports
 - Rights of the child and the family
 - Other relevant topics of interest
- ✔ To facilitate Networking and sharing knowledge and experiences amongst families.

Length of Term for a Family Representative

The term for your role is two years. If you would like to stay on as a Family Representative for a further term, you may nominate yourself again and be re-elected.

Role and Responsibilities of Family Representatives at the Family Forum

- ✔ Input to the Family Forum agenda, in collaboration with the CDN
- ✔ Co-Chair the Family Forum with the CDN
- ✔ Provide feedback to the Family Forum from the FRG, FRG/OMG Subgroup and Governance Group
- ✔ To be an advocate for the broad range of families within the Children's Disability Network Team (CDNT)

- ✔ To be comfortable to represent issues within the service relevant to their CDNT, including views that may not be the same as their own
- ✔ To signpost individual concerns or queries to the CDNM
- ✔ If there are any issues or concerns related to the Family Forum, the Family Representatives should work with their CDNM to identify a solution and, if appropriate, ensure families are updated

The following are outside the role of Family Representative:

- ✔ Giving clinical advice to families
- ✔ Representing individuals to the CDNT
- ✔ Being available as emotional support to other families

Family Representative and CDNM Joint Role at the Family Forum

- ✔ Answer questions on the progress of co-design ideas generated previously by the Family Forum and on co-design projects initiated at local and regional level as they arise
- ✔ Encourage participation by all families in the Family Forum
- ✔ Allow opportunity for questions to be asked
- ✔ For more detail regarding the Family Forum meeting see the revised guidance: ***Working Towards Co-Design in Children's Disability Services*** available from your CDNM

Who you will be working with in the Family Forum

- ✔ The other Family Representative for your CDNT
- ✔ The CDNM
- ✔ The Independent Facilitator (where there is one)

CDNT administration

The Independent Facilitator

A facilitator is someone who has experience in leading meetings and managing group dynamics. Independent facilitators were engaged in the early stages of developing Family Forums and Family Representative Groups, to guide and support meetings. While some areas still retain independent facilitators, many have decided they no longer require their support. It is expected that all Family Forums can move to be co-chaired by elected Family Representatives and CDNMs by the end of 2026.

Where they are still retained an independent facilitator will:

- Facilitate in a way that makes it a worthwhile, satisfying, and productive experience for those taking part
- Establish the ground rules for how participants will engage with each other. Part of the role of the independent facilitator is to ensure that the discussions and interactions between parents and CDNT staff are respectful
- Encourage participation from all those attending so that a wide variety of views are heard. This might include encouraging those who are less vocal to participate
- Ensure that the meetings operate within the Terms of Reference

5. Roles and Responsibilities in the Family Representative Group (FRG)

What is the FRG

- This is a group with 2 Family Representatives from each Family Forum
- Where there is an independent facilitator, they will work with the FRG to support them in their aims
- Representatives will raise issues, share concerns, and identify priorities that are emerging in their local Family Forums
- The FRG will nominate 2 people to sit on the CDNT Governance Group as members

- ✔ A minimum of two Representatives of the FRG will meet with a minimum of two members of the Operational Management Group (OMG) as the FRG/OMG subgroup

Who you will be working with in the FRG

- ✔ Family Representatives from all other CDNTs in your area

FRG Meetings

- ✔ The FRG will meet approximately 4 times per year
- ✔ As a group, representatives may decide to meet in person for some meetings and host other meetings online
- ✔ Ideally the FRG will meet before each CDNT Governance Group meeting to ensure that concerns and issues identified by the FRG can be raised at the Governance Group
- ✔ Quorum (number of people who must attend for a meeting to take place) is 50% of the membership

Role and Responsibilities of Family Representatives within the FRG

- ✔ Family Representatives are expected to provide the Chairperson of the FRG with an update on the key issues and areas of codesign at least one week in advance of the FRG Meetings (see template in Appendix 1)
- ✔ Family Representatives are expected to attend FRG meetings on a consistent and regular basis.
- ✔ Family Representatives are expected to actively participate and engage in FRG meetings, representing their Family Forum by expressing the views, concerns and suggestions for improvements based on the collation of ideas and themes from the Family Forum
- ✔ The FRG will agree on the areas of co-design to be brought to the FRG/OMG subgroup for consideration
- ✔ The FRG will agree on the areas of focus to be brought by their Governance Group Representatives to the Governance Group meeting
- ✔ The FRG will agree on the updates to be provided at the forthcoming Family Forums

6. Roles and Responsibilities in the FRG/OMG Subgroup

The purpose of the FRG/OMG Subgroup is to:

- ✔ Decide which proposed co-design projects should be progressed and by whom.
- ✔ Provide updates to the FRG & Governance Group (through the GG Representatives)
- ✔ Ensure effective collaboration and communication between the Family Representative Group (FRG), the Operational Management Group (OMG) and the Governance Group.

Variance in applicability of co-design projects:

- ✔ Some projects may be identified which are limited in objective, applicable only to a particular CDNT or local community. They may be progressed through collaboration between families of children attending the CDNT and the team members.
- ✔ Other proposed projects will be of wider application at Regional Health Area or national level and should be progressed through the following structures and steps.

Who sits on the FRG/OMG Subgroup

- ✔ A minimum of four nominated Family and OMG Representatives (two from each) will form the FRG/OMG Subgroup.
- ✔ The nominations will be for a period of 2 years and will be decided upon as vacancies in nominees arise.
- ✔ Representatives may be re-nominated for subsequent terms, subject to agreement within their respective groups.

FRG/OMG Subgroup meetings

FRG and OMG representatives will meet a minimum of quarterly to consider proposed service improvements.

7. Roles and Responsibilities in the CDNT Governance Group

The purpose of the CDNT Governance Group is:

- ✔ To ensure CDNT services are delivered in line with national policy
- ✔ To provide leadership and direction to the CDNTs
- ✔ To monitor performance of the CDNTs
- ✔ To plan for ongoing delivery of services by CDNTs

A copy of the Governance Policy is available from your CDN.

Who sits on the CDN Governance Group

- ✔ The Governance Group is comprised of CEOs or their nominees from each of the Lead Agencies which has a CDNT in the area, plus the HSE Head of Disability Services or their nominee, and two Family Representatives.
- ✔ The Family Representatives are full members of the Group, involved in the decision-making and representing the “expert by experience” viewpoint for families.

CDNT Governance Group meetings

The CDNT Governance Group will meet a minimum of quarterly.

8. Time Commitments for Family Representatives

The role requires a significant time commitment to prepare for, attend meetings and report on outcomes and actions within their area:

- ✔ All Family Forum meetings for their Children's Disability Network Team (approx. three per year).
- ✔ All Family Representative Group (FRG) meetings (approx. four per year).

- Two nominated Family Representatives from the FRG attend CDNT Governance Group meetings as members (approx. four per year).
- A minimum of two nominated Family Representatives from the FRG attend the FRG/OMG Subgroup on a quarterly basis.
- To maximise effectiveness, meetings, i.e. Family Forum, FRG, OMG/ FRG subgroup and Governance Group, should be scheduled in a coordinated manner in an agreed calendar rotation.

Example below of time commitment – you should discuss with your FRG Chair what yours will be.

Family Forums - Attendance at meetings - Preparation for meetings (to include meeting with your CDNM)	Please allow for three hours for each meeting, as well as three hours for preparation and follow-up review. Total per meeting: six hours
Family Representative Group - Attendance at FRG meetings - Preparation for meetings - Ongoing communications	Please allow for five hours for each meeting, to include attendance at this two-hour meeting, travel and preparation for each meeting*. These meetings tend to occur after a series of Family Forums to give everyone a chance to share their Forum updates and discuss next steps. There is also a quarterly one-hour update meeting for all FRG members after each Governance Group meeting. This meeting is held online. There is an active What's App group for ongoing communications between FRG members. It is one of the principal ways the group stays in touch in-between meetings. Where the FRG has been asked to feedback on documents, these will be circulated to you by email and a deadline for feedback given to you.

9. Confidentiality

The principles of confidentiality, Data Protection and GDPR should be upheld at all times. Further details on Data Protection can be found [here](#) or if you have questions, please ask your CDN.

10. Your Wellbeing as a Family Representative

- The issues raised at Family Forums may understandably be emotive and distressing at times, it is important that you feel supported and safe in your role.
- As explained above, it is not your responsibility as Family Representative to provide emotional support for other families.
- If you encounter any problems at meetings or in individual interactions, or would like some additional support, you can talk in confidence with the Chair of your FRG and your CDN.
- Your fellow Family Representatives who have been in the role longer than you have likely experienced similar situations and may also be able to provide you with guidance and advice.

11. Expenses

Out of pocket expenses and travel expenses can be claimed- please see the HSE policy document [here](#) and the travel expenses claim form in this pack.

12. Further Information

National reports and policy documents relating to Children's Disability Network Teams are available from your CDN.

13. Appendices

Appendix 1: Template for reporting from Family Forums to Family Representative Group. This could be completed in discussion with the CDNM.

1. What were the main issues or areas of concern expressed by families at the Family Forum? Which of these related only to your CDNT and which were wider issues?

2. What were the main ideas/ areas of co-design identified? Which of these are applicable only to your CDNT and which could be addressed at a wider or regional level?

Appendix 2: Typical processes and pathways of communication

