

Setting up and sustaining the Family Forum - A Guide for CDNMs and Lead Agencies

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1.0 Introduction

Lead Agencies are establishing a Family Forum aligned to each of their Children's Disability Network Teams (CDNTs) per the *CHO Governance of Children's Disability Services National Policy (2021)*¹. The Family Forum is open to family members and carers of children with disabilities² who are attending or waitlisted for CDNT services. This structure and process for families' engagement and participation in service development and improvement is a very important part of the governance of children's disability network services.

*"Effective decision-making is not just about information provision and consultation processes, it is about making sure people with disabilities and their families are involved in the planning, development and review of services that affect their lives"*³.

Whilst recognising the challenges of setting up, running and sustaining a Family Forum, there is no doubt that this is the way to go. Research shows us that where participants are truly engaged as equal partners in reviewing services, and generating service improvements and developments, such a forum will ultimately achieve better outcomes for service users and families, improved satisfaction level for them and for staff, and improved quality of service, value for money and trust by all stakeholders in the local service. CDNTs are leading this positive and innovative development, underpinning the rights of persons accessing their services to have a say in how those services are developed and delivered in line with the UNCRPD.

This Guide is intended to support CDNTs and Lead Agencies in setting up and sustaining their Family Forums and building on their progress made to date in this regard. Some Lead Agencies may have progressed establishment of their Family Forums in a different way to that recommended in the Guide. In this case, the Guide may prove useful as a benchmark. The *CHO Governance of Children's Disability Services National Policy (2021)* is currently undergoing a review and this Guide will be reflected in the reviewed Policy for issue in Q4.

¹ Each Forum will elect two representatives onto the CHO's Family Representatives Group. Two members of the Family Representatives Group will participate in the CHO's CDNT Governance Group meetings.

² CDNTs may from time to time run focus groups for cohorts of children and young people to seek their input/to co-design on service developments and improvements.

³ HSE (2018) *Effective Participation in Decision-Making, Planning for Ordinary Lives in Ordinary Places*, accessed at <https://www.hse.ie/eng/services/publications/effective-participation-in-decision-making-final.pdf>

2.0 Purpose of the Family Forum

The Family Forum Terms of Reference are standardised for all Family Forums in line with the CHO Governance of CDNT Services Policy 2021 as follows:

1. *To involve families in the development of children's disability services in their CDNT through:*
 - *The expression of ideas for future service development and improve existing services*
 - *Identification of issues and ideas for service development and/or enhancement*
2. *To elect two Family Representatives who will meet the CDNM regarding CDNT issues and ideas raised by the Family Forum, and will join the Family Representative Group at area level*
3. *To share information on:*
 - *Service provision, governance and access*
 - *Community supports*
 - *Rights of the child and the family*
 - *Other relevant topics of interest*
4. *To facilitate networking and sharing knowledge and experiences amongst families.*

The purpose of the Family Forum is to promote family engagement, participation, and contribution to and co-design service developments and improvements in their local team and area. It is an opportunity for the CDNM and family members to become a team with a shared purpose and vision. The Forum provides a dedicated space for families to discuss general issues with their Children's Disability Network Manager (CDNM) and to receive CDNM feedback on issues and ideas previously discussed and on service developments at team, CHO and National HSE Disabilities levels. It facilitates relationship building between the CDNM and families, an important component to supporting children and families in achieving their best outcomes possible, and the service making the best use of resources available to it.

The Family Forum is not a place to raise individual child or family issues although it is recognised that families will bring their lived experience of services to the table. These individual issues should be raised one on one with a team member or CDNM, and where a family believes that they do not have a satisfactory resolution, they can log a formal complaint using the Lead Agency's complaints procedure or *HSE's Your Service Your Say*.

3.0 What is “Co-Design”?

“Co-design is an approach to designing with, not for, people...it typically works best where people with lived experience, communities and professionals work together to improve something they all care about...”

Many of our health and social care systems are bursting at the seams through increasing demand and clinical complexity. While this is happening, those systems remain increasingly dependent on professionals to come up with and implement ideas to improve those same organisations and services.

Given our policy gaps, how well is that working for us? Could we tap into the contributions that people with lived experience can make? ...What if instead of asking too much from people with lived experience, we’re asking too little? We don’t need to throw away professional expertise to embrace co-design, but we do need a greater diversity of perspectives and partners. Yes, professionals must share their knowledge, but they must listen, learn and, in some cases, get out of the way.”⁴

Co-design requires sharing power, building trust and authentic participation by service users. Using these principles at service level concurs with family centred practice at the individual level, making for a consistent partnership approach. It will provide additional encouragement to families to recognise their strengths instead of seeing themselves as dependent on professionals.

The invitation for families to the first meeting of the Family Forum will outline the Terms of Reference so they will arrive at the meeting with an understanding of what to expect.

The meeting will put co-design into practice when developing the ground rules together. In response to issues and concerns raised during the meeting, families will be encouraged to voice their ideas for solutions. Initiatives such as improving communication or providing resources for those on waiting lists would benefit immeasurably from input by those who have ‘walked the walk’. Following the principles of co-design therefore at Family Forum meetings, CDNMs and facilitators should:

- Engage in mindful listening
- Encourage expression of positive ideas to solve problems

⁴ McKercher KA. Beyond Sticky Notes: Co-design for real: mindsets, methods and movements.2020.www.beyondstickynotes.com

- Respond carefully and respectfully to all suggestions. If an idea is not feasible or practical, don't dismiss it immediately or spring into defence mode. Ask follow up questions e.g. Can you tell us more about that idea? Make it obvious you are taking a note of it. Say you will make sure consideration is given to the idea.
- Look for opportunities to achieve small wins through local initiatives in partnership with families
- Give timely feedback after the meeting as to what ideas are being followed up and how, and which ideas after consideration were found not possible and why.
Remember the dangers of an information vacuum!
- Consider how power can be shared; the CDNM is not necessarily the lead in this instance but rather a partner with the families in working towards a common goal
- Encourage dialogue between families to share and discuss experience, knowledge and ideas for service improvement and development.

4.0 Preparing for the Family Forum meeting

In recognising the vast and varied experience of CDNMs across the country, National Disabilities with Inclusion Ireland and Disability Federation Ireland are developing a half day training programme for CDNMs to prepare them for their Family Forum. This will include topics such as their role in the Forum, communication including active engagement, active listening, providing timely and comprehensive feedback, dealing with conflict and being open to new and different ideas and to change.

4.1 Family Forum Frequency

The Policy states that the Family Forum should occur at least twice a year. It is recommended that the Forum meets quarterly especially in the first year until it is well established. This will help to build trust and to establish and stabilise a way of working in partnership with families based on the Forum's co-designed Family Forum Agreement. This also acknowledges the significant change being experienced by families and staff, the majority of whom reconfigured to a CDNT in 2021, and the requirement for regular communication with families during this period of stabilisation.

4.2 Family Forum Attendance

A key focus of preparing for the Family Forum meeting will be generating as much interest as possible in families and carers to attend. You will need to identify all possible avenues to advertise the Family Forum to all families in and wait listed for your team's services. It is better that families receive multiple notifications about the upcoming family forum, its purpose and benefit than not receiving the notice at all.

Families will need a tangible, transparent incentive. Communication to families about their Family Forum should clearly articulate the benefits for them and be provided in accessible ways free from jargon and "service—speak". See Appendix 1: *Family Forum Information leaflet* sample that you might customise for your CDNT specifics.

Family Forum attendance may start small and that is ok. As it becomes established and word spreads amongst families of the benefit that participants start to see for them, more may commit to joining and participating in the Forum.

4.3 The CDNM's role in planning Family Forum meetings includes:

4.3.1 Communications:

Reaching your audience:

- ✓ You must strive to ensure that all families attending or waitlisted for your CDNT are informed about the Family Forum, including specific event details, the link to Eventbrite to book their place and any information families should have in advance of each meeting e.g. update on your CDNT service, challenges and plans in action to address them. Informing families of these developments in advance of each meeting will allow the Forum to focus more time on service improvements and developments during the engagement.
- ✓ The HSE has commenced a process for procuring a communication solution for all teams and this will take time. In the interim, you will need to set up whatever communication tool(s) available to you in line with your Lead Agency ICT and Communication Policies for one way communication with families in regards to the Family Forum e.g. text, email, and postal where mobile and/or email addresses are not available. Your Communications department (or if your organisation does not

have one, your CHO's HSE Communications department via the PDS Lead) may be able to advise you on this.

- ✓ Some Lead Agencies will also be able to promote the Family Forum event and a link to documents relevant to the Forum on their webpage and social media platform.
- ✓ Local family support groups may also be able to help you spread the word across their networks. Disability Federation Ireland has offered help to CDNMs in identifying these local groups.
- ✓ Table the Family Forum for 'New Families Introduction to Service' meetings and include it in your presentation to new families on the CDNT service
- ✓ Ask parent members of your former PDS LIG for their input on how to reach and how to motivate the widest possible audience to attend, as relevant to your CDNT.
- ✓ Consider inviting recent CDNT 'graduate' service users for their unique perspective
- ✓ Keep your team fully informed about the Family Forum, when meetings are set, topics in discussion etc. They will help spread the message of the Family Forum and its value for families, and keep you informed of current issues arising for families.

Family Forum Information Pack

- ✓ Put this together in an accessible format and circulate in advance of the first meeting electronically via your chosen communication tool with hard copies to families where electronic communication is not available or consent for same not yet secured. This pack should include as a minimum the following:
 - The Family Forum Information Leaflet (see **Appendix 1 Sample Leaflet**)
 - Your CDNT briefing, including who you provide service for, the number of children attending and waitlisted, who you don't provide service for, and how those services can be accessed. The Forum will then provide an opportunity for you to give any further updates including clarification on pathways of access to services other than the CDNT as required
 - Family Forum Invite (see **Appendix 2 Sample Invite**)
 - Family Forum Agenda
 - Role of the Family Representatives (see **Appendix 4**)

- Family Representative Self Nomination Form (see **Appendix 5 Sample**).
- ✓ Update this Pack in advance of every meeting as required, and recirculate electronically, and hard copy where necessary per above to ensure all participants have the same and current information.

4.3.2 The Family Forum Invite (Appendix 2):

It is suggested that you:

- ✓ Ask your Communications Department to help you design and disseminate the Family Forum invite as widely as possible.
- ✓ Include in the invite:
 - *“ Please go to Eventbrite (link provided) to RSVP, and to confirm any specific requirements, in order to help us prepare for everyone’s needs as much as possible*
 - *It is essential to book on Eventbrite in advance as space is limited and places will be assigned on a first come first served basis”*.

This will help you anticipate the numbers attending but note attendance will likely vary hugely from confirmations on the given night.

- ✓ Consider language requirements of people from diverse backgrounds and people with literacy issues both for electronic and hard copy invites and for the meeting itself. Plain English, free from jargon should be consistently used. Consider video invites as part of the accessibility plan.
- ✓ Set up an account with Eventbrite to promote the meeting, to manage RSVPs and confirmations, and to identify any specific individual requirements. Include a reminder that individual specific requirements should be identified in the RSVP to help the service prepare and plan for everyone’s needs as much as possible.

4.3.3 Access

- ✓ **IPC:** Always confirm with your Infection Prevention and Control department in advance of Family Forum meetings the current restrictions for face-to-face meetings, in light of maximum numbers anticipated to attend and the venue(s) available to you.
- ✓ **Face to face or blended with online participation:** Plan the first meeting face to face, COVID restrictions permitting. Blended meetings pose a challenge to managing large

groups and to developing a shared purpose and co-design element. In the first meeting, raise this challenge with participants and propose that future meetings alternate between in person and online, in order to optimise access to the Family Forum for the greatest number of families possible. Take a vote and include the outcome in the Family Forum Agreement (see 5.3)

- ✓ **Optimal meeting time:** set up the first meeting to run between 10am and 1pm. Plan in the first meeting to propose alternating subsequent meetings between mornings and evenings thereafter to meet the varied needs of families as best as possible. Include the final agreement reached by vote in the Family Forum Agreement
- ✓ **Venue:** Identify local resources available, e.g. family resource centres, community centres, GAA clubs. As far as possible, take into account public transport options to the venue and parking availability including closing times where running an evening event. Although the invite will include a request to RSVP and to identify any specific requirements that a family member may have, you must ensure the venue has basic accessibility requirements, to cater for those who attend without an RSVP e.g.
 - Visual accessibility to and through the facility and also to any material provided during the meeting
 - A wheelchair accessible building, meeting room and bathrooms
- ✓ **Room Set Up:** Plan with your facilitator how best to structure the room to encourage active engagement and exchange e.g. an informal placement of chairs on the level, to generate a sense of ‘we are in this together’, appropriate to co-design and partnership principles and working.
- ✓ **ISL/Foreign Languages:** Will you need interpreters? If so, agree with the facilitator how this will be managed during the meeting
- ✓ Address any other specific requirements identified in RSVPs.

4.3.4 Planning the Agenda

In the spirit of co-design and partnership working, the agenda you circulate in advance of Family Forum meetings should be in draft to allow participants to add topics where there is a consensus at the beginning of the meeting.

It is suggested that you

- ✓ Circulate all relevant updates and information in an accessible format in advance, to maximise time for brainstorming on service improvement and development in the meeting
- ✓ Structure the agenda to include standing items such as Q & A on updates from the last meeting or communication from the CDNM circulated in advance, the Family Representatives update, and themed areas for facilitated discussion. The facilitator should allow flexibility where evolving discussion requires it.
- ✓ Identify key themes for each meeting based on topics raised by families and service areas which the CDNT/Lead Agency/CHO Governance Group is focused on for development and/or improvements. Depending on the individual items, be conscious of the time available for the meeting and service development priorities as agreed with families, in order to get through the agenda.
- ✓ Dedicate time in the first agenda to Q&A on the information you circulated in advance to participants on your CDNT service including who is eligible for it and who is not, types of needs that the team works with, number of children attending and waitlisted, staffing levels, challenges and plans in place to address them. After the first meeting, this information should be updated and circulated in advance of all future meetings to invitees. In the likelihood of different families attending each Family Forum meeting, this will avoid you having to repeat the CDNT Information session in each meeting and risk losing the interest of repeat attendees. Again, this approach can be suggested for inclusion as an action in the Family Forum Agreement
- ✓ **First agenda** should include
 - Introductions: Agree with the facilitator how this will be done for best use of time
 - An icebreaker
 - Family Forum Agreement development including family reps election process
 - Q&A on your CDNT Programme update (circulated in advance)
 - Election of the two Family Representatives
 - Family Forum Meeting Feedback template
- ✓ **Follow on Standard Agenda** should include
 - Review of the Family Forum's Agreement

- Family Representatives update
- Q&A on CDNМ update since last meeting or communication circulated in advance
- Topic(s) for themed discussion

4.3.5 Information sharing

- ✓ Provide your CDNT specific information, including current challenges and initiatives in train to address them, for your facilitator in advance of the first meeting, and any new pertinent information in advance of all future meetings to ensure you both are optimally prepared
- ✓ Ensure you are well informed on national and CHO Governance Group developments e.g. status of recruitment plans, waiting list initiatives, service developments, and other such programmes in train. National Disabilities will provide a regular update to CHOs on national developments to support this.

4.3.6 Decision making and transparency

- ✓ Following discussion with your Lead Agency, and via it, your CHO CDN Governance Group, be clear on what you are accountable to participants in the Forum for i.e. what you can respond on, what you can't and why e.g. proposals or ideas that require exploration with other staff/management, or escalation for decision making.

4.4 The Facilitator's role in planning Family Forum meetings

The facilitator will support the CDNМ in establishing, co-ordinating and managing all aspects of the CDNT Family Forum for an agreed period of time.

Time commitment for the facilitator

- CDNT Family Forums 4 meetings per year of approximately 2 hours each
- Preparation time for each meeting with the CDNМ of approximately 1-2 hours
- Review time after each meeting with the CDNМ of approximately 1-2 hours.

In addition, one of the CHO's facilitators should be contracted to facilitate the Family Representatives Group and the time commitment for this is estimated at

- Family Representatives Meeting x 4 per year of approximately 2 hours
- Preparation in advance and review after the meeting, approximately 1-2 hours hour.

An independent facilitator should be secured from outside of Children's Disability Services to promote independence. A list of potential facilitators who have expressed an interest in this role is available from National Disabilities. It is recommended that where possible, a facilitator is contracted to provide this support for a minimum of 6 – 7 CDNTs, in order to promote consistency and sharing of experience more rapidly across Family Forums.

Whilst facilitators will have competencies in leading meetings and managing group dynamics, they are not required to have experience in Children's Disability Services.

National Disabilities/Inclusion Ireland/DFI are developing a training webinar that will be provided for all facilitators pending Lead Agencies request, to clarify information provided in advance by the CDNМ on the service and programme, current challenges, purpose of the Family Forum as part of the CHO's Governance structure, their role in facilitating the Forum and the CDNМ role as leader of the CDNT and in the Forum, as a partner with parents.

'The facilitator should be the best prepared person in the room'.

In advance of the first meeting:

- ✓ Facilitators will be required to review all CDNT documentation provided by the CDNМ
- ✓ The CDNМ and facilitator should meet to review
 - Your respective roles in the meeting, particularly for the initial events
 - *Setting up and Sustaining Family Forums, a Guide for CDNMs and Lead Agencies*

In advance of subsequent meetings:

- ✓ The CDNМ and facilitator should meet to review agreements made in the last meeting, updates provided in the interim, responses due on issues and ideas that were taken away for review or escalation as required, new developments and ongoing team challenges, and
- ✓ plan the draft agenda and themed area(s) for discussion

This preparation as a minimum will be particularly important in the early stages of development of the Family Forum.

5.0 The Family Forum Meeting in Operation

5.1 The Facilitator's role during the Family Forum meeting

The Facilitator should have

- Knowledge and understanding of group dynamics and experience in facilitating groups
- Demonstrate the ability to empathise with parents and care givers
- Ability to support members of the Forum to understand each other's perspective
- Ability to build trust between family members and the service
- Support discussion and exploration of topics in order to find workable solutions to specific problems.
- Ability to guide Family Forum members in defining the core values and principles in their way of working, to be included in the Agreement. These values include respect, and being respectful of everyone, including towards people with radically different opinions.

In facilitating the Family Forum meetings, the facilitator should

- Set a relaxed, collaborative and open tone
- Conduct meetings so as to enable the free, appropriate and safe expression of views
- Ensure that all voices are heard, and encourage all to participate
- At the outset express the purpose of the Family Forum including the process to elect Family Representatives
- Facilitate the co-design of the Family Forum Agreement in the first meeting and ensure that it is visible for all future meetings should they or participants wish to refer to it.
- Guide the discussion according to the Family Forum Agreement but remain neutral.
- Keep the group focussed.
- Don't let anyone dominate, try to involve everyone.
- Make sure they consider a wide range of views. Ask them to think about the advantages and disadvantages of different ways of looking at an issue or solving a problem.
- Help participants to identify common ground.

- Reserve adequate time for closing the discussion
- At the end of each meeting, recap for all the agreed actions, the lead and where possible, the timeline for completion.

The HSE's Transforming Lives Working Group 3 "*Effective Participation in Decision-Making, Planning for Ordinary Lives in Ordinary Places*" (2018) through consultations, identified a number of key processes to support effective participation in decision making including:

- *Changing and challenging attitudes*
- *Valuing knowledge and experience of participants*
- *Improving communication*
- *Improving accessibility*
- *Making meetings work better*
- *Achieving change*

On making meetings work better, it advises that effective participative outcomes can only be achieved where meetings are purposefully structured and organised. You can help this by

- *Allowing people enough time to get to meetings*
- *Planning for meetings is essential and needs to include all voices*
- *Circulating information to all participants in a timely fashion*
- *Providing facilitated chairing of meetings to ensure equal and effective participation*
- *Creating a positive working environment using introductions, putting people at ease, using ice breaker methods*
- *Giving consideration to the length of meetings including if a break is required*
- *Using media other than PowerPoint*
- *Ensuring supports are available in meeting rooms as required*
- *Using small group discussion formats*
- *Ensuring agendas have been agreed in advance and are clearly understood.*

5.2 The CDNM's role during the Family Forum meeting:

It is important that you as the leader of the CDNT attend and participate in the Family Forum for the full meeting as an equal partner in the process. This is critical to building relationships and trust, working in an open and transparent way with families and optimising communication with them particularly during this period of significant change.

You need to be open to hearing from Family Forum members their experience of engaging with the CDNT. Whilst some feedback may be negative it relates to the service and service capacity. It will be the responsibility of the Facilitator to ensure that feedback is given in a respectful manner. In line with the Family Forum Agreement and with the expertise of a skilled facilitator, the Forum should be a safe place for engaging with Family Forum members.

You need to be prepared to answer questions as they arise in the meeting on your service developments and updates circulated in advance, and make decisions on what is or is not possible there and then, and what you need to explore internally and/or escalate before responding to families. Attendees will start to see the value of attending and this is critical to securing commitment to engagement and sustaining the Family Forum into the future.

CDNMs and facilitators need to consider how to achieve a balance between a structured, purposeful meeting and a degree of informality to encourage all attendees to participate to their full choice and capacity. A structured agenda that participants can feed into, an icebreaker and a co-designed Family Forum Agreement as well as the method and style of meeting facilitation that the facilitator utilizes will help to achieve this in the first meeting. As membership attendance is likely to change significantly from meeting to meeting for a variety of reasons, the CDN and facilitator will also need to consider how to maintain this critical meeting structure/informality balance in future meetings.

5.3 Developing the Family Forum Agreement

The development of a Family Forum Agreement is an important way of setting the tone of the Family Forum meetings. A Family Forum Agreement is a set of principles, behaviours and processes that clearly lay out how the group will work together to achieve its aims. It will also define the purpose of the group or team.

The development of a Family Forum Agreement can help with the following:

1. This will be the first time the facilitator and CDN uses ***principles of co-design*** with the forum. It should be developed in partnership with the families and sends a powerful first message around how the engagement will work.

2. Every team or group needs a clearly **articulated purpose**; this helps the facilitator in keeping the meetings focused and within the agreed parameters of the forum.
3. Ensuring that there is a clearly defined **code of behaviours** which has been agreed by participants, gives the facilitator something to refer to and utilise if there is **conflict**.
4. The Family Forum Agreement can also help to define what is **within the scope of the forum and outside of it** e.g. it can have a statement about what the forum is and what the forum isn't.

You should aim to complete the Family Forum Agreement with families in the first meeting. This exercise will take about 50 minutes.

Proposed process for developing the Family Forum Agreement:

The facilitator can lead the conversation. Family members and CDNMs are equal partners in the development of the Family Forum Agreement. The facilitator describes the importance of having an agreed way of working together and how it will help the group to work in a constructive way. Here are a couple of sample exercises to elicit the information and create the Agreement:

Exercise 1: Team purpose: What are we here to do together? (20 mins)

This is an opportunity for the group to define what their purpose is and to start to develop the sense of team and shared vision.

The facilitator can ask the question of the room:

- *What do we all collectively hope for as a result of working together?*

It is important that the CDNMs communicate their hopes for the forum alongside the family members.

Once some feedback has been elicited, the facilitator can suggest a purpose statement.

The purpose statement should be short and snappy and easy to remember e.g.

- *We want to work together to ensure children get a high quality service from their CDNT.*

Once the purpose statement is agreed, it is written up on a flip chart paper and pinned to the wall, visible for everyone.

Exercise 2: Behaviours and Processes (25 mins)

The facilitator draws a line down the centre of a flip chart page and divides the page in two. On one side h/she will write “how we will act” and on the other side, he/she will write “how we will work”. The facilitator asks the group to think about the best group or team they were ever a part of. If they haven’t been a part of a team or group before, they can think about a team they really admire (like a sports team). The facilitator then asks the group to name the characteristics of that team or what they notice about that team. As the forum feed back their observations, the facilitator transcribes them onto the flip chart paper:

- “Behaviours” are transcribed under “how we will act” e.g. respect, openness, honesty etc.
- “Processes” are transcribed under “how we will work” e.g. good communication, decisions made quickly etc.

The facilitator then presents the transcribed information to the room.

A group discussion around what characteristics the Family Forum will adopt can then take place e.g. do we think respect is important for this group? How will we know if we are respectful? Do you think good communication is important? How will we make sure we communicate well? The group then decides which behaviours and processes to adopt. This, alongside the purpose statement, forms the basis of the Family Forum Agreement.

Exercise 3 *How will the Family Forum Agreement be used as part of the Forum* (5 mins)

Group discussion on how the agreement will be used e.g.

- Should it be visible at every meeting?
- If things “go wrong” can the group agree to refer back to it?
- If new members join, how will the group help them to get on board with the agreement?

Close out on the Family Forum Agreement: The facilitator agrees to write up the notes and agreements into the Family Forum Agreement. The purpose of the forum, agreed behaviours and processes, the family representatives election process and timeline for serving (see 5.5) and a guide for how the Family Forum Agreement will be used will all be noted. This Family Forum Agreement is then circulated as part of the Forum notes.

5.4 Role of the Family Representatives

What is it?

Family Representatives are signing up to the principles and values of the CDNT programme and services. The Family Representative role requires a person to be a voice for a broad range of family experiences specific to the Children's Disability Network Team. They must also be able to represent views that may not be the same as their own.

The Family Representative will;

- Represent their Family Forum by expressing their views, concerns and suggestions for improvements based on grouping of general areas and themes from the Forum.
- Represent all issues and ideas raised by families
- Ensure feedback to families about issues and ideas raised and resulting actions

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?

What is involved?

Two Family Representatives will be elected at the Family Forum meeting. They will remain in the role for a period to be decided by the Family Forum.

The role will require a significant time commitment to prepare for and attend;

- All **Family Forum meetings** for your Children's Disability Network Team (approximately four per year)
- All **Family Representative Group** meetings in the area (approx. four per year)

In addition, Family Representatives in the area will nominate two members of the Family Representative Group to attend meetings with the Operational Management Group and Children's Disability Network Governance Group. This will ensure that all meetings will be attended by two Family Representatives.

Terms of Reference for the Family Representatives Group

- For the two elected Family Representatives from each network in the CHO to learn and share feedback from the various different Family Forums
- To co-ordinate attendance of two Family Representative Group members at each CHO Children's Disability Networks Governance Group meeting
- Two Representatives of the Family Representative Group to meet with the CDNMs Operational Management Group no less than four times per year
- To raise issues for discussion and resolution at appropriate levels of the governance structure
- To develop a feedback template for feedback to the family forums

What supports will you have?

The Family Representatives will be supported by an Independent Facilitator at the Family Forum and Family Representative Group meetings. They will have help to prepare and participate in meetings and design a template to feedback to their Family Forum. CDNMs should ensure that Family Representatives are given an information pack with all the relevant documentation as part of their induction to the role, to include for example the Governance Policy, relevant PDS documents and National CDNT Policies.

Family Representatives should be reimbursed travel and subsistence, and vouched receipts in line with HSE Policy <https://www.hse.ie/eng/about/who/qid/person-family-engagement/resourcesqid/policy-for-the-reimbursement-of-service-user-expenses-2017.pdf>

5.5 Electing Family Representatives

The role of the Family Representatives should be circulated to all families as part of the Family Forum Information Pack.

It is really important that Family Representatives are elected as soon as possible, in order to establish the Family Representatives group, to commence their engagement with the Operational Management Group and to participate on the CHO CDNT Governance Group. Therefore, it is recommended that the process for electing family representatives and time that family representatives will serve for be explored and agreed early in the first Family Forum meeting as part of the co-designed Family Forum Agreement. This should also include who will make the selection where more than one bio share the same number of votes in first or second place, and the plan where less than 2 bios are submitted. The election process can then be completed at the end of the first meeting.

The Family Forum might consider the following as one option of electing its Family Representatives

- In the first Family Forum Meeting Invite, all families will be invited to self-nominate by submitting a bio/brief statement on why they believe they would be a good family representative one week in advance of the first meeting (**Appendix 5 Self Nomination Sample Form**)
- All bios received will be circulated to participants within 5 days of the first Family Forum meeting if feasible, and if not, at the beginning of the first meeting.
- All participants will cast their vote for their two preferred candidates during the 1st Family Forum meeting
- Families are informed of the 2 candidates to receive the highest votes on the day if possible or by an agreed date shortly after the first meeting.

5.6 Concluding the Family Forum Meeting

The facilitator will review actions, persons responsible and where possible, timelines for feedback on the actions with all participants for inclusion in the Meeting Notes and Actions.

The facilitator will remind participants to hand in their completed Family Forum Meeting Feedback form, an essential part in helping optimise outcomes of the Forum into the future.

A Meeting Schedule for the year should be confirmed in the first meeting and included in the Meeting Notes and Actions record.

5.7 Family Forum Meeting Notes & Actions

You will need a note taker present to document the salient points raised, actions agreed and timelines for same where possible, and the lead responsible.

You should aim to circulate the meeting notes and actions to all invitees within 2 weeks of the meeting in draft format for sign off in the next meeting. You can also use this communication to provide an update on any progress you have made on your actions agreed in the meeting.

6.0 After the Family Forum Meeting

6.1 Family Forum Meeting Review

You should review with your facilitator how the meeting went, including a review of the Family Forum Meeting Feedback Forms on the same day if possible when it is fresh in your minds, and identify any areas for improvement or actions, and who is responsible for them.

It is recommended that you both consider draft topics for facilitated discussion in the next Forum meeting based on outcome of today's meeting, pending participants input at the beginning of the next meeting and/or service development needs identified in the interim.

6.2 CDN M Feedback and updates

For meaningful participation, it is essential that you close the engagement feedback loop with families participating in the Forum. That is, that you provide clear, concise updates on issues and ideas they proposed and the actions you agreed to take externally for further review and/or escalation as required, in as timely a manner as possible. In addition to optimising the outcome of each Family Forum meeting, this will also demonstrate clearly to families participating that they have been heard, their input is important, valuable and valued by the organisation, and that they have the ability to shape services in a positive way into the future. This in turn will nurture commitment to the Family Forum by families for as long as they need it into the future.

7.0 Conclusion:

With the support of this guide and In line with the CHO Governance of Children's Disability Services National Policy 2021, lead agencies are establishing family forums across the country.

It is absolutely recognised that this is a challenging time in children's disability services. It has never been more important for families and CDNTs to come together to work in partnership on a shared vision for children with disabilities.

The Family Forums provide an important mechanism for establishing trust, building relationships and ultimately supporting the transformation of services towards a family centred model of support.

For the Forums to be effective, their establishment needs to be an authentic step on the road towards the meaningful participation of families in the design and delivery of services. Families who attend will need to feel that their voices are heard and that they understand the bigger picture of the journey towards the family centred model, challenging and all that has been and will be.

"In times of conflict, it is important to remember what we have in common. Both families and the CDNTs ultimately want the highest quality services for children so that they can thrive and flourish. Creating this sense of shared vision is the most important initial step to take. It is time to move beyond "them and us" and into a space where relationships based on trust can be built. The establishment of the Family Forums are a crucial step on that journey. This doesn't mean it will be easy, but nothing meaningful ever is"

Derval McDonagh, CEO of Inclusion Ireland.

References and resources

Policy documents

- CHO Governance of Children's Disability Networks. HSE. 2021
<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>

Service user Participation

- HSE (2018) Effective Participation in Decision-Making, Planning for Ordinary Lives in Ordinary Places, accessed at <https://www.hse.ie/eng/services/publications/effective-participation-in-decision-making-final.pdf>
- The CES Guide to Inclusive Consultations. Centre for Effective Services. 2021
<https://www.effectiveservices.org/insights/the-ces-guide-to-inclusive-consultations>
- Resources to Support Participation by Children and Youth. Tusla.
<https://www.tusla.ie/services/family-community-support/resources-to-support/>

Co-design

- McKercher KA. Beyond Sticky Notes: Co-design for real: mindsets, methods and movements.2020. www.beyondstickynotes.com
- A generative co-design framework for healthcare innovation: development and application of an end-user engagement framework. [M. Bird](#), et al. [*Research Involvement and Engagement*](#) volume 7, Article number: 12 (2021)
- Health Service Co-design: Working with patients to improve health care services. Guide and Tool kit. Hilary Boyd, Stephen McKernon, Andrew Old. Waitemata District Health Board.2010.
https://www.wdwb.org.nz/assets/Uploads/Documents/45f463d911/rttc_health-service-co-design-by-h-boyd.pdf
- Webinar on 'Relationships - the key to successful implementation'. Centre for Effective Services. 2022. <https://www.effectiveservices.org/insights/the-power-of-relationships-in-implementing-services>

Appendix 1: Family Forum Information Leaflet SAMPLE

Additional details:

Family Forum Terms of Reference

1. To involve families in the development of children's disability services in their local Children's Disability Network through:
 - The expression of ideas for future service development and improve existing services
 - Identification of issues and ideas for service development and/or enhancement
2. To elect two Family Representatives who will meet the Children's Disability Network Manager (CDNM) regarding Network issues and ideas raised by the Family Forum, and will join the Family Representative Group at area level
3. To share information on:
 - Service provision, governance and access
 - Community supports
 - Rights of the child and the family
 - Other relevant topics of interest
4. To facilitate networking and sharing knowledge and experiences amongst families.

Family Representative Role

1. Represent their Family Forum by expressing their views, concerns and suggestions for improvements based on collation of general areas and themes from the forum.
2. Represent all issues and ideas raised by families
3. Give feedback to families about issues and ideas raised and resulting actions

Family Representative Group Terms of Reference

1. For the 2 elected Family Representatives from each network in the CHO (Cork and Kerry area) to learn and share feedback from the various different Family Forums
2. To co-ordinate attendance of two Family Representative Group members at each CHO Children's Disability Networks Governance Group meeting
3. Representatives of the Family Representative Group to meet with the CDNMs Operational Management Group no less than four times per year to raise issues for discussion and resolution at appropriate levels of the governance structure
4. To develop a feedback template for feedback to the family forums

Procedure for selection of Family Representatives

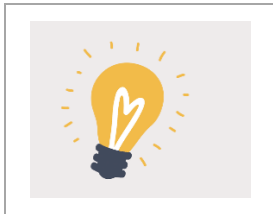
1. Two Family Representatives will be elected every 12 months. Family members can serve more than one term if they choose to nominate themselves again for the role.
2. A nomination form will be sent to all families once a year, together with the invitation to the next Family Forum.
3. Family members who wish to nominate themselves should complete the nomination form and return to the CDNM two weeks before the Family Forum.
4. Two representatives will be elected from those who have been nominated by those in attendance at the family forum. The Election will be conducted by the independent facilitator.

[Name of CDNT] Family Forum



What is the Family Forum?

A place for families to discuss issues and ideas:



The Family Forum is a place for families linked with the team to discuss general issues and ideas about the children's disability services we offer.

How often does the family forum meet and who attends?



The Family Forum meets four times a year. It is open to parents and carers of every family we support. The forum is facilitated by someone who does not work in our Children's Disability Network Team. The Children's Disability Network Manager, [insert name], will also attend each meeting.

How can I get involved?



You will receive an invitation to every Family Forum. You can attend as many as you like to share your thoughts and ideas.

If you would like to become more involved, you can nominate yourself to stand for election as a family representative (see reverse)

What does a Family Representative do?

Two Family Representatives are elected by the Family Forum. They meet with the Children's Disability Network Manager to discuss issues and ideas raised at the Forum, and attends meetings of the larger Family Representative Group in Cork and Kerry (CHO4).

Specific concerns regarding your child:



[insert name].

The Family Forum discusses general issues and ideas for service development only. If you have specific concerns about your child, or wish to make a complaint about the service, you should speak with your key contact in the service or the Children's Disability Network Manager,

Contact us with any questions:



[Street Address]
[City, ST ZIP Code]
Phone: [Telephone]
Email: [Email address]

Appendix 2:

Sample invitation to a Family Forum meeting for all families of children attending or on the waiting list

We invite you to come to a meeting of the (*name of CDNT*) Family Forum

On (*date and time*)

At (*venue*)

The Family Forum is a space for families to meet and talk about general issues concerning the children's disability services we offer. You will also hear from the Children's Disability Network Manager about what is happening locally and nationally.

This is your chance to tell us your ideas on how we could improve services.

The Family Forum is not the right place to talk about individual child issues. You should discuss these with a team member or the Children's Disability Network Manager.

The Family Forum will elect two Family Representatives who will meet the Children's Disability Network Manager regularly and will join the Family Representative Group at area level.

Please register to come to the meeting on Eventbrite and let us know if you have any special requirements to help us plan in advance. (*Eventbrite link*)

As space is limited, places will be given on a first come, first served basis.

Appendix 3: Role of Independent Facilitator:

The Independent Facilitator will support the CDNМ in establishing, co-ordinating and managing all aspects of the CDNT Family Forum for an agreed period of time.

Time commitment for the Independent Facilitator

- CDNT Family Forums 4 meetings per year of approximately 2 hours each
- Preparation time for each meeting with the CDNМ of approximately 1 - 2 hours
- Review time after each meeting with the CDNМ of approximately 1 - 2 hours.

In addition, one of the CHO's Independent Facilitators may be contracted to facilitate the Family Representatives Group and the time commitment for this is estimated at

- Family Representatives Meeting x 4 per year of approximately 2 hours
- Preparation in advance and review after the meeting, approximately 1 - 2 hours.

An independent facilitator should be secured from outside of Children's Disability Services to promote independence. A list of potential facilitators who have expressed an interest in this role is available from National Disabilities. It is recommended that where possible, a facilitator would be contracted to provide this support for a minimum of 6 – 7 CDNTs, in order to promote consistency and sharing of experience more rapidly across Family Forums.

Whilst facilitators will have their own competencies in leading meetings and managing group dynamics, they are not required to have experience in Children's Disability Services. National Disabilities/Inclusion Ireland/DFI are developing a training webinar that will be provided for all facilitators pending Lead Agencies requests, to clarify informant provided by the CDNМ in advance on the CDNT service and programme, current challenges, purpose of the Family Forum as part of the CHO's Governance structure, their role in facilitating the Forum and the CDNМ role as leader of the local CDNT, and in the Forum, as a partner with parents.

'The facilitator should be the best prepared person in the room'.

The Facilitator's role in planning the Family Forum event

In advance of the first meeting:

- ✓ Facilitators will be required to review all CDNT documentation provided by the CDNМ
- ✓ The CDNМ and facilitator should meet to review
 - Your respective roles in the meeting, particularly for the initial events
 - *Setting up and Sustaining Family Forums, a Guide for CDNMs and Lead Agencies*

In advance of subsequent meetings:

- ✓ The CDNM and facilitator should meet to review agreements made in the last meeting, updates provided in the interim, responses due on issues and ideas that were taken away for review or escalation as required, new developments and ongoing team challenges, and
- ✓ plan the draft agenda and themed area(s) for discussion

This preparation as a minimum will be particularly important in the early stages of development of the Family Forum.

The Facilitator's Role during the Family Forum meeting

The Facilitator should have

- Knowledge and understanding of group dynamics and experience in facilitating groups
- Demonstrate the ability to empathise with parents and care givers
- Ability to support members of the forum to understand each other's perspective
- Ability to build trust between family members and the service
- Support discussion and exploration of topics in order to find workable solutions to specific problems.
- Ability to guide Family Forum members in defining the core values and principles in their way of working, to be included in the Agreement. These values include respect, and being respectful of everyone, including towards people with radically different opinions.

In facilitating the Family Forum meetings, the facilitator should

- Set a relaxed, collaborative and open tone
- Conduct meetings so as to enable the free, appropriate and safe expression of views
- Ensure that all voices are heard, and encourage all to participate
- At the outset express the purpose of the Family Forum including the process to elect Family Representatives
- Facilitate the co-design of the Family Forum Agreement in the first meeting and ensure that it is visible for all future meetings should they or participants wish to refer to it.
- Guide the discussion according to the Family Forum Agreement but remain neutral.

- Keep the group focussed.
- Don't let anyone dominate, try to involve everyone.
- Make sure they consider a wide range of views. Ask them to think about the advantages and disadvantages of different ways of looking at an issue or solving a problem.
- Help participants to identify common ground.
- Reserve adequate time for closing the discussion
- Closing each meeting, the facilitator will
 - recap on agreed actions, the lead and where possible, timelines for their completion and feedback for recording in the Meeting Notes
 - remind participants to hand in their Family Forum Meeting Feedback forms, an essential part in helping optimise outcomes of the Forum into the future.

The HSE's Transforming Lives Working Group 3 "*Effective Participation in Decision-Making, Planning for Ordinary Lives in Ordinary Places*" (2018) through consultations, identified a number of key processes to support effective participation in decision making including:

- *Changing and challenging attitudes*
- *Valuing knowledge and experience of participants*
- *Improving communication*
- *Improving accessibility*
- *Making meetings work better*
- *Achieving change*

On making meetings work better, it advises that effective participative outcomes can only be achieved where meetings are purposefully structured and organised. You can help this by

- *Allowing people enough time to get to meetings*
- *Planning for meetings is essential and needs to include all voices*
- *Circulating information to all participants in a timely fashion*
- *Providing facilitated chairing of meetings to ensure equal and effective participation*
- *Creating a positive working environment using introductions, putting people at ease, using ice breaker methods*
- *Giving consideration to the length of meetings including if a break is required*

- *Using media other than PowerPoint*
- *Ensuring supports are available in meeting rooms as required*
- *Using small group discussion formats*
- *Ensuring agendas have been agreed in advance and are clearly understood.*

The Facilitator's Role after each Family Forum meeting

The CDN and facilitator should

- review how the meeting went including a review of the Family Forum Meeting Feedback Forms on the same day if possible, and identify any areas for improvement or actions, and who is responsible for them
- consider draft topics for facilitated discussion in the next Forum meeting based on outcome of today's meeting, pending participants input at the beginning of the next meeting and/or service development needs identified in the interim
- Agree a date and time for planning the subsequent Family Forum meeting.

Appendix 4: Role of Family Representatives

What is it?

Family Representatives are signing up to the principles and values of the CDNT programme and services.

The Family Representative role requires a person to be a voice for a broad range of family experiences specific to the Children's Disability Network Team. They must also be able to represent views that may not be the same as their own.

The Family Representative will;

- Represent their Family Forum by expressing their views, concerns and suggestions for improvements, based on grouping of general areas and themes from the family forum.
- Represent all issues and ideas raised by families
- Ensure there is feedback to families about issues and ideas raised and resulting actions

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?

What is involved?

Two Family Representatives will be elected at the Family Forum meeting. They will remain in the role for a period to be decided by the Family Forum.

The role will require a significant time commitment to prepare for and attend;

- All Family Forum meetings for your Children's Disability Network Team (around 4 per year)
- All Family Representative Group meetings in the area (around 4 per year)

In addition, Family Representatives in the area will nominate two members of the Family Representative Group to attend meetings with the Operational Management Group and Children's Disability Network Governance Group. This will ensure that all meetings will be attended by two Family Representatives.

Family Representatives will raise issues for discussion and resolution at the appropriate levels of the governance structure.

Terms of Reference for the Family Representatives Group

- For the 2 elected Family Representatives from each network in the CHO to learn and share feedback from the various different Family Forums
- To co-ordinate attendance of two Family Representative Group members at each CHO Children's Disability Networks Governance Group meeting
- 2 Representatives of the Family Representative Group to meet with the CDNMs Operational Management Group no less than four times per year
- To raise issues for discussion and resolution at appropriate levels of the governance structure
- To develop a feedback template for feedback to the family forums

What supports will you have?

The Family Representatives will be supported by an Independent Facilitator at the Family Forum and Family Representative Group meetings. They will have help to prepare and participate in meetings and design a template to feedback to their Family Forum. CDNMs should ensure that Family Representatives are given an information pack as part of their induction to the role, to include for example, the Governance Policy, relevant PDS documents and National CDNT Policies. This will have all the relevant documentation to fulfil their role.

Family Representatives should be reimbursed travel and subsistence, and vouched receipts in line with HSE Policy <https://www.hse.ie/eng/about/who/qid/person-family-engagement/resourcesqid/policy-for-the-reimbursement-of-service-user-expenses-2017.pdf>

Appendix 5: Family Representatives Self Nomination Form SAMPLE



Could you be the voice of families? Self-Nomination Form Family Representatives Family Forum for XXXX CDNT

The **XXX Family Forum** will elect two Family Representatives in the upcoming meeting. Please read the attached “**Role of the Family Representative**” and if you are interested in this role, we would welcome your self nomination by __/__/__. All those received will be shared in advance with invitees to the Family Forum and an election process will take place during the Family Forum meeting.

Please return to [\(email and postal address\)](#) by __/__/__

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 four questions 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 Family Representative on your local Family Forum and Regional Family Representatives Group.